Neighbourhood nursing:

connection, place and meaning in the
everyday experience of dementia

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Neighbourhood nursing: connection, place and meaning in the everyday experience of dementia

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Za moje roditelje, brata i familje Odzaković, Kadrispahić, Karišik i Avdić

To understand is to experience harmony between what we aim at and what is given, between the intention and the performance – and the body is our anchorage in the world. (Merleau-Ponty)

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ABSTRACT

Background: Recent policy is marked by a shift towards enabling people with dementia to remain at home and in their neighbourhoods, yet little is known about the wider perspective of neighbourhood as an everyday place of connection, practice and meaning in the lives of people with experience of dementia.

Aims: The aim of this thesis is twofold. The first aim is to explore the neighbourhood as an everyday place for people with experiences of dementia. The second aim is to explore neighbourhood as a place for practice.

Methods and Designs: Five studies are included in the thesis with both quantitative and qualitative designs. Study I had a cross-sectional exploratory and descriptive design. A total cohort of 17, 405 people with a dementia diagnosis were identified and matched with data about home care services and housing, and were then associated with socio-demographic factors in three county councils: Östergötland, Stockholm and Västerbotten. Study II had a phenomenological design; 14 community-dwelling people diagnosed with dementia in the County of Östergötland participated using walking interviews. Study III had an inductive and exploratory qualitative design including 14 community-dwelling people living alone with dementia in England, Scotland and Sweden involving multiple data collection methods. Study IV had an inductive and explorative qualitative design that included 22 people with the lived, personal and professional experiences of dementia and used semi-structured individual and group interviews. Study V had an inductive and explorative qualitative design where the perspectives of 18 participants (registered and specialist nurses) were included using shadowing as the main method for data collection.

Findings: In study I, 72% of the cohort was living in ordinary housing and 28% in special housing of the total of 17, 405 people with a dementia diagnosis. Overall, 52% of 17, 405 people with dementia in three county councils (Östergötland, Stockholm and Västerbotten) were living alone. Study II revealed that walking in the neighbourhood was an integral part of their day-to-day activities that helped them to manage life with dementia. Connection to nature by being outdoors was a restorative practice for people living with dementia. Neighbourhood was often described as a social context, although some participants living alone revealed that their social contacts were mainly staff working in municipal home care. In study III, participants across all three field sites channelled their efforts to stay connected to the neighbourhood into creating new ways of maintaining social networks and relationships. By participating in several activities (provided in the United Kingdom by the third-sector and charitable groups, and in Sweden, by the municipalities), bonds of friendship were created. However, the impact

of stigma surrounding dementia was highlighted by the participants, which caused experiences of involuntary solitude or loneliness. Despite the impact of stigma, participants took control over their lives by searching for new daily social connections in the neighbourhood and were by no means passive in the face of the challenges in everyday life. In study IV, the participants discussed how dementia was stigmatized in the community. People living with dementia were often not being respected as active citizens with their own resources in the community. Being socially active in a group or in public spaces were strategies to maintain a social role in the community. Participants with different experiences of dementia wanted the day care centres and teams to be more centrally involved in person-centred care and health-promoting improvements. Finally, in study V, participants struggled with the commonly held view of their role and their workplace within the health care system, interpreting it as being invisible, as if placed in a black box. The tasks and responsibilities of the participants were shifting to assistant nurses, neighbours and family members according to the socio-economic level of the municipality. Nonetheless, the participants were clearly part of the neighbourhood. The findings of this thesis have been integrated into a combined thematic analysis based on the five studies to reach an overall representation of people's experiences of neighbourhood as an everyday place and a place for practice in the context of dementia. Five main themes (and three sub-themes) emerged from the analysis: (1) walkable attachment to the lived neighbourhood; (2) daily activities promote health and well-being; (3) opportunities for social connections; (4) just treat us as active citizens; (5) neighbourhood: a place for practice. The analysis suggested the neighbourhood was not only described as a walkable, social and citizenship arena in the context of dementia; it was also a place where practice was ongoing around the clock (studies II, III, IV and V) because most of the people with dementia are living in ordinary housing (study I).

Conclusion: The thesis presents a new foundation and knowledge to understand neighbourhood as a place for everyday life and practice by applying a new lens for understanding. The neighbourhood can be understood as a place linked by connections that people actively searched out, and where the meaning of place emerges via movement of the body through the world. It is also a site where practices support everyday life for people with dementia, especially for those living alone with dementia. This points to the need to re-think nursing practice, where "neighbourhood nursing" as a formal model with a lifeworld perspective has to be established in dialogue with citizens.

Keywords: dementia; living alone, neighbourhood; neighbourhood nursing; social connections

POPULÄRVETENSKAP SAMMANFATTNING

Bakgrund: Den senaste samhällsutvecklingen och de politiska ambitionerna har utgått alltmer från att göra det möjligt för personer med demenssjukdom att bo kvar allt längre i sina hem och grannskap. Trots denna utveckling finns det lite kunskap utifrån det bredare perspektivet om grannskapet som en vardaglig plats för relationer, omvårdnad samt vilken mening det har för personer som har erfarenhet av demens.

Syfte: Syftet med avhandlingen var för det första att undersöka grannskapet som en plats i vardagen för personer som har erfarenheter av demens, och för det andra, att undersöka grannskapet som en plats för omvårdnad.

Design och metod: Avhandlingen inkluderar fem delstudier med både kvalitativ och kvantitativ design. Studie I hade en explorativ och beskrivande tvärsnittsdesign. Totalt ingick det 17 405 personer med en demensdiagnos som identifierades och samkördes med information av hemtjänstinsatser och boende. Denna informationen förenades sedan med de socio-demografiska faktorerna i de tre regionerna Östergötland, Stockholm och Västerbotten. Studie II hade en fenomenologisk design som inkluderade 14 personer som bodde i ett eget boende med en demensdiagnos i Östergötlands län och som deltog i 'promenad intervjuer'. Studie III hade en induktiv och beskrivande kvalitativ design vilket inkluderade 14 personer som bodde ensamma i ett eget boende med en demensdiagnos i England, Skottland och Sverige. De 14 personer som bodde i ett eget boende med en demensdiagnos i Studie III deltog i flera datainsamlingsmetoder. Studie IV hade en induktiv och beskrivande kvalitativ design som inkluderade 22 personer med levda, personliga och professionella erfarenheter av demens som deltog i semi-strukturerade individuella och gruppintervjuer. Slutligen, Studie V hade också en induktiv och beskrivande kvalitativ design där 18 deltagare (legitimerade sjuksköterskor och specialistsjuksköterskor) inkluderades skuggning som är den huvudsakliga metoden för datainsamlingen.

Resultat: I Studie I fann vi att 72 % av den totala befolkningen av 17 405 personer med en demensdiagnos bodde i ordinärt boende och 28 % i särskilt boende. Sammantaget bodde 52 % av de 17 405 personerna med demens i singelhushåll i de tre regionerna Östergötland, Stockholm och Västerbotten.

Studie II påvisade att promenader i grannskapet var en betydelsefull del av deras dagliga aktiviteter som hjälpte personer med en demensdiagnos att hantera ett liv med demens. Att vara utomhus i naturen medförde att personer med demens knöt an till naturen och genom det återhämtade sig. Grannskapet beskrivs ofta som ett socialt

sammanhang, även om vissa deltagare som bodde ensamma berättade att deras sociala kontakter främst var med personalen som arbetade i den kommunala hemsjukvården (och hemtjänsten).

I studie III beskrev personer med demens i England, Skottland och Sverige hur de ansträngde sig för att hålla kvar kontakten med grannskapet men också hur de skapade nya sätt att upprätthålla och hitta nya sociala nätverk och kontakter. Dessa vänskapsband skapades genom att delta i olika aktiviteter (som tillhandahålls i England av tredje sektorn och välgörenhetsgrupper, och i Sverige, av kommunerna). Även effekterna av stigmatiseringen kring att leva med demens betonades av deltagarna, de beskrev detta som en orsak till ofrivillig ensamhet. Trots påverkan av stigmatiseringen tog personerna med demens, kontroll över sina liv, genom att finna nya dagliga sociala kontakter i grannskapet. Personer med demens är intresserade av att anta nya utmaningarna i vardagen.

I studie IV diskuterade personerna med olika erfarenheter av demens hur demenssjukdomen som ett stigmatiserat tillstånd i samhället påverkade dem. De ansåg att deltagarna som lever med en demensdiagnos ofta inte respekterades som aktiva medborgare med sina egna resurser i samhället. Personerna med olika erfarenhet av demens framhöll också att vara socialt aktiv i en grupp eller i offentliga rum var strategier för att upprätthålla en social roll i samhället. Förutom betydelsen av det sociala livet påpekade personerna med olika erfarenheter av demens att de skulle önska att dagverksamheterna och demensteamerna skulle utgå mer utifrån person-centrerad vård och hälsofrämjande förhållningssätt.

Slutligen, i studie V observerades det hur legitimerade sjuksköterskor och specialistsjuksköterskor kämpade med den vanligt förekommande synen på deras profession och arbetsplatsen inom hälso- och sjukvården som gav sig uttryck som osynlig. Deras uppgifter och ansvar hade även förändrats och allt mer hade överlåtits till undersköterskor, grannar och familjemedlemmar och kommunernas socioekonomiska status hade betydelse. Legitimerade sjuksköterskor och specialistsjuksköterskorna var en självklar del av grannskapet.

Resultaten av denna avhandling har integrerats i en sammansatt tematisk analys baserad på de fem studierna för att nå en övergripande representation av människors upplevelser av grannskapet som en plats för det dagliga livet och omvårdnad med utgångspunkt utifrån erfarenheter av demens. Analysen resulterade i fem huvudteman (och tre underteman): (1) anknytning till det existerande grannskapet via promenader (2) dagliga aktiviteter främjar hälsa och välbefinnande; (3) möjligheter för sociala kontakter; (4) behandla oss som aktiva medborgare; (5) grannskapet som en plats för omvårdnad. Grannskapet beskrivs inte bara som en framkomlig, social medborgarskapsarena i relation till demens, utan var även en plats där sjuksköterskepraxis pågick dygnet runt (studierna II, III, IV och V) eftersom de flesta personer som lever med demens bor i ordinarie boende (studie I).

Konklusion: Avhandlingen presenterar ett nytt underlag och ny kunskap för att förstå grannskapet som en plats för dagligt liv och omvårdnad genom att använda ett nytt

perspektiv för att få förståelse. Grannskapet kan förstås som en plats förenad genom förbindelser som människor aktivt söker efter och där betydelsen av grannskapet inträder genom kroppens rörelse ut mot världen. Det är också en plats där omvårdnad sker som i sin tur stödjer vardagslivet för personer med demens, särskilt för dem som lever ensamma med demens. Detta visar på behovet av att tänka om i praktiken vad det gäller omvårdnaden, där ”omvårdnad i grannskapet” som en modell med ett livsvärldsperspektiv behövs i dialog med medborgarna.

Nyckelord: demens; ensamboende; grannskap; omvårdnad i grannskapet; sociala kontakter

SAŽETAK

Pozadina: Nedavni trend demencije ogleda se u ovome da osobe koje žive sa demencijom ostanu u kući ili u susjedstvu, ali još uvijek nije poznato mnogo u široj perspektivi koju nude ta susjedstva kao svakodnevno mjesto povezivanja, medicinske njege, te samog značaja u životu onih koji žive sa demencijom.

Ciljevi: Cilj je istražiti susjedstvo kao svakodnevno mjesto boravka za ljude koji žive od demencije, te kao drugo istražiti susjedstva kao mjesta gdje bi se pružala medicinska njega.

Metode i dizajni: Ukupno pet studija uključeno je u rad sa kvantitativnim i kvalitativnim dizajnom. Studija I imala je istraživački i opisni dizajn. Populacija od 17. 405 ljudi sa dijagnozom demencije bila je identifikovana, te usklađena sa podacima o kućnoj njezi i mjestu prebivališta, a zatim povezana sa tri općine: Östergötland, Štokholm i Vasterboten. Studija II imala je fenomenološki dizajn gdje je 14 osoba koje žive sa demencijom u porodičnoj kuci učestovalo u Östergötlandu u intervju pri šetnji. Studija III imala je induktivni i istraživački kvalitativni dizajn koji je uključivao 14 ljudi iz porodičnog domaćinstva koji žive sami sa demencijom u Engleskoj, Škotskoj i Švedskoj, uključujući više metoda prikupljanja podataka. Studija IV imala je induktivni i istraživački kvalitativni dizajn koji je obuhvatio 22 osobe koje žive, ili imaju lično i profesionalno iskustvo sa demencijom, gdje su se koristili pojedinačni i grupni intervju. Studija V imala je induktivni i istraživački kvalitativni dizajn gdje je uključeno ukupno 18 medicinskih sestara, a kao glavna metoda za prikupljanje podataka korištena je metoda praćenja i posmatranja.

Završni rezultati: U studiji I, 72% od 17. 405 ljudi koji su imali demenciju živjeli su porodičnim kućama a 28% u starački domovima. Ukupno 52% od 17. 405 ljudi koji žive sa demencijom u tri općine su Östergötland, Štokholm i Vasterboten žive sami. Studija II otkrila je kako svakodnevna šetanja je sastavni dio njihovih aktivnosti koje su im pomogle u životu sa demencijom. Može se reći da je boravak na otvorenom, te povezivanje sa prirodom je vrlo praktično za ljude koji žive sa demencijom. Susjedstvo je često opisano kao socijalni kontekst, iako su neki učesnici u istraživanju koji žive sami otkrili kako je njihov jedini društveni kontakt bio sa uposlenicima kućne njege. U studiji III učesnici ispitivanja u Engleskoj, Škotskoj i Švedskoj su sve svoje napore da ostanu povezani sa susjedstvom kako bi stvorili nove načine koji bi pomogli stvaranje novih veza i odnosa. Učestvovanjem u nekoliko aktivnosti (koje su u Velikoj Britaniji omogućile dobrotvorne i slobodne organizacije, a u Švedskoj općine) stvorene su veze i prijateljstva. Međutim, utjecaj predrasuda povezanih s demencijom, što su i naglašavali sudionici, vodilo je kao iskustvu samoće i usamljenosti. Uprkos utjecaju predrasuda, učesnici su preuzeli kontrolu

nađ svojim životima, te su tražili nove svakodnevne društvene veze u susjedstvu, ne pokazujući tako pasivnost prema svakodnevnim izazovima s kojima se susreću. U studiji IV učesnici su razgovarali o predrasudama o demenciji u zajednici. Ljudi koji žive sa demencijom često nisu uvaženi kao aktivni članovi koji mogu doprinijeti zajednici. Kako bi održali svoje uloge u zajednici vrlo je bitno da ostanu društveno aktivni. Učesnici sa različitim iskustvom demencije izrazili su želju da se centri za svakodnevnu njegu i timovi više baziraju kao unapređenju njega i zdravlja, kao i da se akcenat stavi na osobu za demencijom. Na kraju, u studiji V medicinske sestre su se borile sa općeprihvaćenim stavom o njima i njihovoj ulozi, te njihovom radnom mjestu u sistemu zdravstvene zaštite, opisujući to kao nevidljivo. Zadaci i odgovornosti medicinskih sestara prebacivali su se na pomoćne sestre, komšije i članove porodica prema društveno-ekonomskom nivou opštine. Unatoč tome, medicinske sestre su očito bile dio susjedstva. Iskustva, odnosno pronalasci u ovoj tezi integrisani su u kombinovanu analizu prema pet tematski obrađenih studija, kako bi se dostigao sveobuhvatan prikaz iskustava u susjedstvu kao svakodnevnom mjestu, te mjestu zdravstvene podrške u kontekstu demencije. Iz ove analize pojavilo se pet glavnih tema (kao i tri podteme): (1) povezanost sa susjedstvom; (2) svakodnevne aktivnosti promovišu zdravlje i dobrobit; (3) mogućnosti za socijalne veze; (4) tretiranje kao aktivne građane; (5) susjedstvo je mjesto za medicinske prakse neprekidno traju. Analize pokazuju kako se susjedstvo ne opisuje samo kao prohodno, socijalno i građansko polje u kontekstu demencije, već kao i mjesto gdje medicinske prakse neprekidno traju (studije II, III, IV i V), jer većina ljudi s demencijom žive u običnom domaćinstvu (studija I).

Zaključak: Teza predstavlja nove temelje i znanja, kako bi se lakše razumio pojam susjedstva kao svakodnevnog mjesta za život, kao i njega kroz nove objektivne razumijevanja. Susjedstvo bi se moglo shvatiti kao mjesto spojeno vezama koje ljudi aktivno potražuju gdje se značenje mjesta spaja sa kretanjem tijela kroz svijet. To je također mjesto gdje je svakodnevno obezbjeđena njega za ljude koji žive sa demencijom, posebno za one koji žive sami. Ovo ukazuje na potrebu da se preispita medicinska praksa, gdje se "njega u susjedstvima" kao formalni model sa životnom perspektivom treba uspostaviti u dijalogu sa građanima.

Ključne riječi: demencija; društvene veze; njega u susjedstvu; susjedstvo; živjeti sam

ORIGINAL PAPERS

The framework of this thesis is comprised of five studies presented here and through whole thesis by their Roman numerals (I-V).

- I. Odzakovic, E., Hydén, L. C, Festin, K., & Kullberg, A. (2019). People diagnosed with dementia in Sweden: What type of home care services and housing are they granted? A cross-sectional study. *Scandinavian Journal of Public Health*, 47(2), 229-239. doi: 10.1177/1403494818755600.
- II. Odzakovic, E., Hellström, I., Ward, R., & Kullberg, A. (2018). 'Overjoyed that I can go outside' : Using walking interviews to learn about the lived experience and meaning of neighbourhood for people living with dementia. *Dementia*. doi :10.1177/1471301218817453.
- III. Odzakovic, E., Kullberg, A., Hellström, I., Clark, A., Campbell, S., Manji, K., Rummery, K., Keady, J., & Ward, R. (2019). 'It's our pleasure, we count cars here' : an exploration of the 'neighbourhood—based connections' for people living alone with dementia. *Ageing & Society*. doi: 10.1017/S0144686X19001259.
- IV. Odzakovic, E., Hellström, I., Nedlund, A-C., & Kullberg, A. “*Just treat us for the person we are, not for the disease*”: a dementia friendly initiative for an inclusive local community from a health promoting perspective. Re-submitted.
- V. Odzakovic, E., Kullberg, A., Bielsten, T., Marcusson, J., & Hellström, I. Task shifting in municipal homecare from the perspectives of registered and specialist nurses in Sweden: a qualitative study using shadowing. Submitted.

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PREFACE

In this first chapter, I present my journey towards my doctoral studies. Why did I start my doctoral studies? I began as a registered nurse in a neurological care department, became a newly graduated district nurse and then began a new research path towards neighbourhood and dementia. This decision came as a surprise to many of my colleagues at the neurological care department, because I had to learn to go at a slow pace, and I would probably miss the emergency events. As one patient that I cared for expressed: “here comes the running nurse” when I entered his room. His careful perception of me as a person behind the nurse’s uniform was correct. I run to new unknown arenas as I need new challenges. Hence, my interest in research began when I was writing my master’s thesis, which involved people with intellectual disability where aspects of environment and person-centred care were found to be important to enhance good care for these individuals. This spurred my interest in research and it was a personal challenge to learn more and develop my skills as a district nurse. From that moment, I decided that I wanted a career as a researcher. After some months as a research assistant, teaching nursing students and working part time at the hospital, I started my doctoral studies in the international research programme, Neighbourhood and Dementia.

That said, I am a district nurse and had limited pre-understanding of the meaning of the “neighbourhood” or “dementia” from any perspective other than the biomedical model. The concept of neighbourhood in relation to ageing in place was unknown to me as a district nurse. While interviewing people with dementia and shadowing registered and specialist nurses in the neighbourhood, I have learned the value of the neighbourhood and of attachment to the local environments. Neighbourhoods are arenas of opportunity for social interaction, life, movement, temporality and, of course, for practice. These aspects were new to me. I hope that with this thesis, I can encourage professionals and students in social and health care disciplines to open their eyes and see beyond the hospital environment and primary care centre out to the neighbourhood, and what it holds for people with experience of dementia and in the work of municipal home care. This thesis highlights the value of neighbourhood nursing where all citizens, irrespective of condition, have a contribution to make towards an inclusive local community. We have to change our focus to acknowledge that the neighbourhood is a place where nursing takes place and should be considered in particular patient groups such as, for example, people living with dementia. People with dementia are active agents, able to promote their own health and well-being.

1.INTRODUCTION

Recent policy is marked by a shift towards enabling people with dementia to remain at home and in their communities (Menec, Means, Keating, Parkhurst, & Eales, 2011; Rosenwohl-Mack, Schumacher, Fang, & Fukuoka, 2018; Schön, Lagergren, & Kåreholt, 2016). This development has been shaped by an increasing ageing population worldwide because age is a risk factor for a dementia diagnosis (Qiu, Bäckman, Winblad, Agüero-Torres, & Fratiglioni, 2001; Sundström, Westerlund, & Kotyrlö, 2016; Winblad et al., 2016). In 2017, an estimated 50 million people were living with a dementia diagnosis worldwide, and by 2050, it is estimated that over 152 million people will be living with dementia (Alzheimer's Disease International, 2018). In Sweden, around 158,000 (113,000–169,000) people are living with dementia and this figure is expected to double over the next 20 years (National Board of Health and Welfare, 2014). Given the correlation between dementia and ageing, the ageing population living in single households is also predicted to increase across European countries, which inevitably includes an increasing proportion of those with dementia (Gaymu & Springer, 2010; Prescop, Dodge, Morycz, Schulz, & Ganguli, 1999; Prince, Wimo, Guerchet, Ali, Wu, & Prina, 2015). An ageing population presents social and economic challenges for the health care system (Huber, Rodrigues, Hoffmann, Gasior, & Marin, 2009; National Board of Health and Welfare, 2014) such as for home care and the registered nurses working in these organizations (Genet et al., 2011; Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013; Palesy, Jakimowicz, Saunders, & Lewis, 2018).

Conditions in Sweden are in line with other European countries, where it has been observed that older people are staying in “ordinary housing” for longer (Blomgren, Martikainen, Martelin, & Koskinen, 2008; Huber et al., 2009; Rostgaard & Szebehely, 2012). Over 60% of persons with dementia are living at home worldwide (Kerpershoek et al., 2016). In Sweden, for example, in 2012 it was estimated that 58% of people with dementia were living in their home. Over the past decades, there has been a decrease in the number of beds available in special housing in Sweden (from 120,000 in 2000 to 90,500 flats in 2012) (National Board of Health and Welfare, 2014). However, these estimates do not necessarily correspond to the actual number of people diagnosed with dementia. A large number of people with symptoms of cognitive impairment may never be diagnosed with dementia, especially older people living with multi-morbidity in ordinary housing (Ekdahl, Odzakovic, & Hellström, 2016).

Nonetheless, despite policy innovations with regard to practice, there is still widespread failure in acknowledging people living with dementia as agents over their lifeworld in the community. The perspectives and meaning of a life with dementia in the neighbourhood is rarely discussed, as Kitwood (1997) stated: “Whatever happens to dementia can no longer remain a minor parochial matter, confined within the boundaries of geriatrics. There will, of necessity, be profound repercussions in society at large” (p.

144). Today, Swedish policy documents are mainly structured according to dementia stages to provide the basis for practice; the focus is on moving those with dementia into a nursing home (National Board of Health and Welfare, 2019a).

Woods (1989, p. 7) argued early on that dementia was a brain disease caused by different losses in the brain that led to destruction of memory. In recent years, other researchers have changed their views on/of dementia from those presented in the 1980s.

However, this thesis is from the standpoint of personhood and a lifeworld perspective based on the experiences of people living with dementia. This thesis aims first to explore the neighbourhood as an everyday place for people with experiences of dementia and second to explore the neighbourhood as a place for practice.

The author of this thesis invites readers to consider the following questions: Is the classification of dementia according to Woods (1989) still relevant? How can we work together with people living with dementia to develop inclusive local communities where their voices are heard and citizenship is considered essential? How can we increase awareness about dementia in our neighbourhoods? How can we as registered nurses create a new practice paradigm towards neighbourhood nursing together with the citizens?

2.BACKGROUND

This chapter summarizes the context of neighbourhood in relation to the theory of place attachment to better understand neighbourhood as a place. Beyond the neighbourhood, the concept of neighbourhood nursing is presented as a new model in a Swedish context. The definition of neighbourhood nursing relies on knowledge of the neighbourhoods in which practice is provided to the citizens in the community. The development of different perspectives on dementia studies, beginning with the biomedical perspective and moving on to personhood and citizenship models within dementia studies, is outlined here. The models of personhood and citizenship capture the theoretical standpoint of this thesis. Finally, the focus is on dementia in relation to environmental considerations; the research carried out from 2018 to 2019 on public spaces, inclusive environments, and dementia-friendly communities is reviewed. In this thesis, the main standpoint is the perspectives of people living with dementia in a neighbourhood context.

2.1. Neighbourhood

In many countries, the concept of neighbourhood is defined as a significant unit of analysis with social and subjective connotations (Bernard, Charafeddine, Frolich, Daniel, Kestens, & Potvin, 2007) where ageing in place can be established (Wiles, Leibing, Guberman, Reeve, & Allen, 2012). Access to the immediate outdoor and social environment surrounding the home in later life supports the quality of life and well-being (Bowling, 2008; Day, 2008; Wiles et al., 2012). Familiarity and safety are important to achieve a sense of control and belonging to the neighbourhood (Möttus, Gale, Starr, & Deary, 2012; Van Dijk, Cramm, & Nieboer, 2013). In addition, green spaces in the neighbourhood have a positive impact on promoting physical activity, health, well-being and social relationships (Alidoust, Bosman, & Holden, 2018; Bengtsson & Carlsson, 2013; Mitchell & Burton, 2010; Rappe & Topo, 2007; Solnit, 2001; Van Hoof, Kort, van Waarde, & Blom, 2010).

The neighbourhood has been defined for many different purposes, depending on the discipline. In most cases, the neighbourhood is understood as a geographic area with immediate connection to the built environment, such as housing, sidewalks or symbolic boundaries (Galster, 2001). Some describe the neighbourhood as starting indoors, that is, the view through the window (Tang & Brown, 2006), and others as the area 5–10 minutes' walk from home (Galster, 2001; Kearns & Parkinson, 2001). The neighbourhood is an integrated system of a “walkable zone of experiences”, based on a person’s walking patterns from the home into the neighbourhood (Blackman, 2006, p. 107). Walking plays an essential part in gaining knowledge through the body and our lived experience in relation to the rest of the world (Merleau-Ponty, 1962). It is through walking in the

neighbourhood that the connection between space and time becomes a reality (Solnit, 2001).

In addition, the concept of neighbourhood changes seasonally and gradually over the life course (Milton et al., 2015). Social relationships and connections with family and friends become more important (Blackman, 2006; Bowling, 2005). To understand the connection between neighbourhood and people, it is useful to explore people's attachment to their neighbourhood. Attachment to neighbourhood relates to the emotional connection with both the physical and social environments (Woolever, 1992). Bowling (2005) argues that personal attachment and social networks develop over time in the neighbourhood due to the extent of social capital that neighbourhoods hold for people. Blackman (2006) contends that neighbourhoods are closely linked to identity, a sense of self and maintaining control of our lives: "neighbourhoods are where we feel more or less in control of the surroundings in which we live, and more or less buoyed by the status of where we live" (p. 69). The neighbourhood represents a unit of analysis in this thesis whereby the importance of walkability, social networks and attachment to places becomes essential during a life time. Place attachment needs to be closely examined to understand what meaning the neighbourhood holds for people with dementia.

2.2. Place attachment

This section describes the theory of place attachment and the concept of place identity. An understanding of neighbourhood as a place of attachment is dependent on the experiences of people, both citizens with dementia and registered nurses in municipal home care. Therefore, it is necessary to consider the theory of place attachment to understand the relationships between people with experiences of dementia, registered nurses and neighbourhood.

The theory of attachment was developed during the 1960s in the work of John Bowlby (1969) and Mary Ainsworth (1967) focusing on person-to-person bonding at the heart of attachments and relationships to children, including cross-cultural aspects. According to Bowlby's (1969) interpersonal theory, children need the attachment of their parents for comfort and support otherwise they will develop psychological problems as adults. Ainsworth (1968) added cross-cultural validation to Bowlby's theory. In the early 1970s, the story of place-people bonding was acknowledged by geographers and sociologists, and concepts of territoriality (Altman, 1975) and place identity (Proshansky, 1978) became of interest in research. Since then, the concept of place attachment has been revised to a more multi-dimensional level to apply in practice (Altman & Low, 1992). Scannell and Gifford (2010) structured a three-dimensional framework of place attachment defined as a person-process-place (PPI) framework. This framework integrates the bond between these three levels to understand attachment from a psychological process (Scannell & Gifford, 2010), and in their latest work, the benefits of place attachment (Scannell & Gifford, 2017) are described as developed from the initial models of place attachment.

The integrated concept of place attachment involves different aspects aiming to understand how people interact towards places (Altman & Low, 1992; Altman & Low, 2018, p. 4–6). These aspects constitute attachment to actors of place (people, groups and cultures), social relationships, temporal aspects and places (of various scales, specifically and physically) that are dependent on cognition and practice (Altman & Low, 2018, p. 8). Attachment, as a concept, describes “affect”, and the world of “place” highlights the environmental surroundings to which people have a connection emotionally and culturally (Altman & Low, 2018, p. 5). Kearns and Moon (2002, p. 609), on the other hand, argue that place is “an operational ‘living’ construct”. Nonetheless, definable places could be a community, neighbourhood and even a nation (Altman & Low, 2018). Different disciplines of cultural and social geography, environmental psychology (Altman & Low, 2018) and phenomenological philosophy (Manzo, 2005) have expanded the theoretical perspective on place over the years.

The phenomenological philosophy (Manzo, 2005) goes beyond the definition of place, focusing instead on the lived world developed by Husserl (1970). The lifeworld consists of four dimensions: lived space (spatiality), lived time (temporality), lived body (embodiment) and lived other (inter-subjectivity), which give meaning and are actively lived through a life course (Husserl, 1970). However, the lifeworld is not a “free” world without any interpretations; therefore, social, historical and cultural aspects have to be considered to understand the everyday life of people (Moustakas, 1994). This lifeworld theory has been developed further by Merleau-Ponty (1962) who emphasizes the notion of the “mind-body-world system” where lived, situated experiences of everyday life are central in relation to consciousness (mind), and by the movement of the lived body. The lived experience of the explored phenomena occurs by our consciousness through movement of the lived body in the world (place) (Merleau-Ponty, 1962).

Places are therefore much more than a physical character; instead, they include environments of community, cultural and interpersonal relationships that people are attached to during a life time (Rowles & Watkins 2003; Rubinstein & Parmerlee, 1992). This classification of place attachment was used in this thesis when designing the studies and during the data analysis to capture the experiences of neighbourhood as an everyday place for connections in dialogue with people with experiences of dementia.

2.2.1. Place attachment in gerontology research

As emphasized by Rubinstein and Parmerlee (1992) and Rowles and Watkins (2003), the attachment to place consists of experiences over a lifetime. The concepts of place attachment, place identity and ageing have a long history in gerontological research, especially by scholars in environmental gerontology such as Lawton and Nahemow (1973), Lawton (1977, 2001) and Rowles (1978, 1983, 2008). They have developed theories and have had an impact on policy and practice, especially with regard to institutional design and aspects around the home environment. With regard to the institutional environment and attachment, Lawton and Nahemow (1973) developed the Ecological Theory of Aging, where they argue that personal competence and

characteristics in the environment have an impact on older people's level of functioning to remain independent. Wahl and Oswald (2010) have found that the "process of agency" is essential to maintain control of the physical environment in which one lives and to create and sustain places.

On the other hand, Rowles (1978) argues how people attach to their environment from a qualitative and geographical ethnographical perspective. In the framework offered by Rowles (1978, 1983), place attachment is defined as a creation through people's "sense of places" as social and physical insidedness. The notion of social insidedness is described by Rowles as a social exchange over a long period of time, which leads to integration in a social structure and a central connection with a venue. Whereas physical insidedness is connected to the dialogue between person and place that develops over the life course, familiarity and routine are a result of this insidedness (Rowles, 1983). So, in the gerontological literature, place attachment has been defined as exposure to places over long periods that have given a meaning to the spaces older people have used and inhabited. When discussing or defining place attachment in the context of older people, place identity is a central concept related to the incorporation of place: an extended concept of self (Proshansky, Fabian, & Kaminoff, 1983). Place identity is defined by Proshansky et al. (1983) as a "potpourri of memories, conceptions, interpretations, ideas, and related feelings about specific physical settings, as well as types of settings".

To pay attention to place identity and place attachment, the "landscapes of memories" have to be recognized; they are our recollections of past events, childhood places and artefacts, together with personality and autobiography (Rowles, 1983). Artefacts become important in the process of making and remaking place, because they consist of our personal history and help us create our autobiography even if a move in later life becomes a reality for many. Rowles (2008) suggests that refined place-making skills become a reality through our psychological preparation and expectation; here, we transfer our meaning of place in space and time. The definition of place attachment includes different aspects that develop during a life course, and how long an individual becomes attached to place depends on our "trajectory of change" (Golant, 2011). It is the individual capability developed over a life course that decides how well we can attach to a place (Golant, 2011; Rowles, 1983). In addition, place attachment is a connection involving both cognitive and emotional bonding, which we redefine in the process of engaging with place (Rowles & Bernard, 2013, p. 129–152).

2.3. Neighbourhood nursing

The intention behind the concept of "neighbourhood nursing" was first proposed in 1986 by Julia Cumberlege in a report titled "Neighbourhood nursing: a focus of care". In this report, Cumberlege (1986) presented strategies for future community care, where she argued that the best care for patients is provided in their own communities in a primary care setting. The idea of neighbourhood nursing can only be understood within a network consisting of primary health care teams and the local community working together in the

provision of health. Further, this partnership requires that professionals in primary health care allow local people in the community to participate (Christopher, Reinhard, McConnell, & Mason, 1993). To accomplish neighbourhood nursing, it is essential for the professionals, for example, nurses, to have knowledge about the neighbourhood (Cumberlege, 1986).

Cumberlege (1986) put forward that specific skills and more training are needed on the importance of neighbourhood. These recommendations have been developed by Reinhard and colleagues, who also suggest that there has to be a connection between the neighbourhood and the care setting across the life span (Reinhard, Christopher, Mason, McConnell, Rusca, & Toughill, 1996). Further, neighbourhood nursing embraces continuity of care and integrates the person, family and community together as one unit (Reinhard et al., 1996). Hence, a clear definition of the neighbourhood concept is needed in the nursing literature (Milbrath & DeGuzman, 2015). This development of neighbourhood nursing requires a chain of practice interventions and a paradigm shift of thinking in nursing practice, which this thesis seeks to provide, offering new knowledge on the nursing field of research and practice.

Despite an extensive literature search, no research studies or nursing theories have been found in this context of neighbourhood nursing in general. Today, the focus is on the care provided in hospitals or mobile teams going out from hospitals and primary health centres despite 30 years having passed since the first report about neighbourhood nursing (Cumberlege, 1986) was published. Only one thesis in architecture was found mostly because of the title “A neighbourhood nursing care facility for the elderly” by Chung (1995); this provides a picture of how care facilities should be situated in neighbourhoods and suggests that placement of a nurse’s office in care facilities has an impact on their work.

The care provided in the homes or communities where people spend much of their time during their lives is still neglected in the nursing literature. Although Florence Nightingale, one of the pioneers of nursing, proposed that “The connection between health and the dwellings of the population is one of the most important that exists” (Lowry, 1991). Yet, we have a long way to go to achieve a re-thinking in practice and in research to establish neighbourhood nursing along with a policy of ageing in place. This knowledge in this thesis provides a good place to start with this work.

2.4. Home care

This section starts with an introduction to the definition of home for the purposes of municipal home care and informal and formal practice. Municipal home care is a focus here to explore the essence of the thesis, given that all participants living with dementia in the five studies were living in their own home (ordinary housing), not in institutional care. The meaning of home as define by Bonnefoy (2007) is a central place for human life and includes a sense of belonging and privacy and supports well-being and social integration. A place to call home has a deeper meaning than just a roof over one’s head;

it is an essential part of a person during their lifetime (Bonney, 2007; Oswald, Hieber, Wahl, & Mollenkopf, 2005, p. 21–46; Oswald, Jopp, Rott, & Wahl, 2011). A home acquires meaning through a process of habitation in which space is part of the identity that comes to life (Rowles & Bernard, 2013, p. 11). The support of home care becomes essential for many older people to allow them to live at home for a longer period.

Tarricone and Tsouros (2008, p. 1) define home care as “to satisfy people’s health and social needs in their homes by providing appropriate and high-quality home-based health care and social services, by formal and informal caregivers, with the use of technology when appropriate, within a balanced and affordable continuum of care”. Thomé, Dykes and Hallberg (2003) found that the concept of home care is complex because of different welfare structures globally; they concluded that the definition of home care has to be seen as care in practice, provided by professionals to people living in their own homes.

In the last two decades, the shift towards home care from institutional care has increased, with emphasis on people’s home and communities, but also as a future workplace for registered nurses (Genet et al., 2011; Harris-Kojetin et al., 2013; Palesy et al., 2018; Tarricone & Tsouros, 2008). This is a result of an ageing population (≥ 65 years) which will increase in the coming years (Banerjee, 2015) as a result of increasing life expectancy and better lifestyles in many middle- to high-income countries (United Nations, 2015; World Health Organization, 2019a). The consumption of home care will increase among frail older people, who often have multiple medical diagnoses, related to ageing (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013; Collard, Boter, Schoevers, & Oude Voshaar, 2012). The organization of home care for older people in European countries varies when it comes to policy, regulations and insurance coverage (Genet, Kroneman, & Boerma, 2013; Van Eenoo et al., 2016). In addition, the political movement of care has turned towards private services and informal care instead of public provision (Bettio & Verashchagina, 2012). Formal home care has increased in Nordic countries such as Sweden but also in the United Kingdom (Huber et al., 2009; Rodrigues, Huber, & Lamura, 2012; Szebehely & Meagher, 2017), in contrast to Spain and Portugal where informal care provided by the family is still more common and preferred (Huber et al., 2009). Alongside this expected development of an ageing population and need for home care, a lack of qualified health and social care staff worldwide is also anticipated. To meet this change in the health and social care, low-skilled staff are needed to meet some of the needs of this population of older people outside the hospitals (Genet, Boerma, Kroneman, Hutchinson, & Saltman, 2012), in their homes and communities.

2.4.1. Municipal home care

In Sweden, restructuring of care for older people (≥ 65 years) took place in 1992, named the Ädelreformen and regulated by the Social Services Act (SFS-Svensk författningssamling, 2001). The main aim of this reform was to allow older people to continue to live at home as long as they wanted. The responsibility for home care was transferred from county councils to municipalities (National Board of Health and

Welfare, 1996). This shift also led to a regulation for providing care for older people structured at three levels: national, regional and local (SFS-Svensk författningssamling, 2017). At the national level, the government are in charge of legislation, policy declarations and state subsidies. At the regional level, the 21 county councils oversee hospitals and primary health care. At the local level, the 290 municipalities are legally assigned to provide home care and social services for older people living in ordinary housing and health care up to the level of responsibility for registered nurses (SFS-Svensk författningssamling, 2017; Swedish Association of Local Authorities, 2019). During 2018, municipal home care consisted of 25% of all care provided in Sweden (National Board of Health and Welfare, 2019b).

This challenge of policy shifting towards home care entailed a new work place for registered nurses and changed their professional role and tasks (Kapborg & Svensson, 1999; Lundström & Ehnfors, 2001). Registered and specialist nurses also had to adopt new ways of working because they worked independently from the home care service team, becoming coordinators for several care providers. This transfer of elderly care in 1992 led to a new policy in 2014, defined as Hemsjukvårdsreformen and regulated by both the Social Services Act (SFS-Svensk författningssamling, 2001) and the Health and Medical Services Act (2017:30) (SFS-Svensk författningssamling, 2017), which led to home care and home visits from primary health care workers being governed by the municipalities. In this reformation, eligibility thresholds were developed to determine which patients could be granted municipal home care. These criteria stipulated that patients who could not travel to primary health care facilities on their own and/or needed longer treatment time for home care could be granted municipal home care (National Board of Health and Welfare, 1996).

Older people in Sweden, as in other Scandinavian countries, can be granted home care services based on an assessment of their needs, according to the Scandinavian welfare model based on equality and universality (Szebehely & Trydegård, 2012). This means that application for home care services is not judged by income but on the need for care of the individual (Mukadam, Cooper, & Livingston, 2011; Szebehely & Trydegård, 2012). However, an income-graded fee for the care applies; those on a low income (about one-third) do not pay any fee, but this differs between the municipalities (Blomgren et al., 2008; Rostgaard & Szebehely, 2012). In Sweden, care managers assess applications for home care services and special housing (Szebehely & Trydegård, 2012). Some home care services that can be granted under this system include home help coupled with assistance with personal care, or meals on wheels, or day care centre referral. Day care centre places can be granted to people living with dementia, or others with disabilities, and includes daily participation in meaningful activities (Måvall & Malmberg, 2007). Beyond home care services, older people can apply for special housing, where all home care services are included (National Board of Health and Welfare, 2012). In 2012, it was estimated that 42% of all individuals with dementia were living in special housing (National Board of Health and Welfare, 2014).

The amount of home care services, especially formal care, granted to people living with dementia increases once they receive a formal diagnosis. Existing research has

focused on informal care provided by family but far less on formal care by the health care system. In a Swedish context, it is estimated that people living with dementia receive from four to eight times more formal home care services than informal care (Wimo, Sjölund, Sköldunger, Johansson, Nordberg, & von Strauss, 2011). However, there is a lack of research into the type of home care services and housing granted to people with dementia in Sweden; much of the registered data on home care services are for older people in general and not those with a dementia diagnosis, which this thesis addresses.

2.5. Dementia

2.5.1. Conceptualizing dementia beyond the biomedical model

Dementia is a clinical condition whereby the capacity to live independently is affected by progressive deterioration in cognitive function as a result of neurodegeneration (American Psychiatric Association, 2013). According to the DSM-5 criteria, dementia is a general term defined as a neurocognitive disorder categorized as major and minor dementia. In these types of dementia, six different areas are often affected and presented in the process of diagnosing an individual with dementia: difficulties with attention, working memory, learning, communication (language), perceptual cognition and social cognition. One of the most common forms of dementia is Alzheimer disease (50%–60% of all cases) followed by vascular dementia (10%–50% of all cases) and mixed dementia (with both neurodegenerative and vascular factors), which is the most common type diagnosed in primary care and memory clinics in Sweden (Garre-Olmo, Garcia-Ptacek, Calvó-Perxas, Turró-Garriga, López-Pousa, & Eriksdotter, 2016).

Beyond these diagnoses, dementia is an overall concept that is often divided into three stages according to a medical model of the condition: mild (can manage daily tasks independently), moderate (some help is needed in daily life) and severe (constant help is needed) (American Psychiatric Association, 2013). All three stages of dementia can lead to several difficulties that can affect day-to-day life as a result of the six domains of cognition mentioned earlier and presented in the biomedical model of dementia (Innes & Manthorpe, 2013).

Other factors that affect the development of dementia include age (Blennow, de Leon, & Zetterberg, 2006; Qiu et al., 2001; Sundström et al., 2016; Winblad et al., 2016), a low level of education, physical inactivity and cardiovascular diseases (Kivipelto, Mangialasche, & Ngandu, 2018; Najar et al., 2019; World Health Organization, 2019b). It is important to consider the current biomedical model to understand the development of dementia as a concept (Innes & Manthorpe, 2013; Lyman, 1989). The framework of research, policy and practice is still influenced by this model of thinking when decisions on dementia are made in different disciplines (Cotrell & Schulz, 1993; Downs, 1997; Wilkinson, 2002). For example, the development of a standardized procedure for care plans for health and social care in Sweden is still built on the dementia stages model and

frames decision-making when it comes to the care provided for people living with dementia (National Board of Health and Welfare, 2019a).

The connection to a person's selfhood via their cognitive capability is largely neglected in the biomedical model (Millet, 2011). However, it has been acknowledged by biomedicine that the impact of support and care is important for people living with dementia (Dupuis et al., 2011; McGettrick, 2015). It is important to recognize that the timeline of conceptualizing dementia began with the biomedical model, where dementia was described as "a reduced capacity for self-care and self-direction" (Woods, 1989). From this perspective, the focus has changed to see the person behind the condition. Tom Kitwood (Kitwood, 1997) was one of the first pioneers to describe a personhood model in which the personhood and experiences of people living with dementia are presented. In this thesis presents a paradigm shift in thinking, whereby the person with dementia is presented as an ambassador of their own life and their interests and experiences should be given priority in every decision that is made with them as citizens and agents in neighbourhoods.

2.5.2. Personhood and dementia

Tom Kitwood (1997) was one of the first to coin the term person-centred care in relation to dementia. Kitwood argued that dementia does not itself entail loss of personhood; instead, it incorporates both sense of self and identity (Kitwood, 1997, p. 13). This approach of person-centred care goes beyond the biomedical approach by using the term "person with dementia" rather than demented (Kitwood, 1997, p. 7). Kitwood (1997, p. 8) defined personhood as: "a standing or status that is bestowed upon one human being by others in the context of relationship and social being. It implies recognition, respect and trust."

Even when the effect on cognitive function is relentless, understanding of the person behind the dementia is possible by creating relationships or meeting with the person rather than acknowledging them as objects (Kitwood, 1997, p. 12). Sabat and Harré (1992) stated that the self of personal identity persists until the "late stages of Alzheimer disease". Kitwood (1997, p. 43) argued that "to have an identity is to know who one is, in cognition and in feeling. It means having a sense of continuity with the past; and hence a 'narrative,' a story to present to others."

In Kitwood's model of person-centred care, identity is one of the five dimensions that must be involved in the care of people living with dementia to maintain their personhood (Kitwood, 1997, p. 81–85). The other four dimensions are comfort, attachment, inclusion, and occupation. This model underlines the importance of giving power back to people with dementia by supporting them to hold on to their identity and get into their experience by carefully listening to their needs in an interview or in a meeting (Kitwood, 1997, p. 82–83).

The practice of dementia care has been explored by Kitwood, who suggested certain principles to guide care staff, arguing they should focus less on what is done and not aim to change the behaviour of people with dementia (Kitwood, 1997, p. 14). Instead, their

focus should be on creating a life-giving relationship where they can grow as individuals because each experience is unique and important to hold on to (Kitwood & Bredin, 1992; Kitwood, 1997, p. 94). In addition to staff, caregivers such as partners, spouses and family need support to structure the environment around the person with dementia and the sense of self. However, the central point in caring for people living with dementia is knowing the person behind the dementia (Edvardsson & Innes, 2010; Kitwood, 1997; Kitwood & Bredin, 1992). Levy-Storms (2013) argues that tools and guidelines for staff in practice to achieve person-centred care are essential. In this section, the emphasis has been on the person behind the dementia and not the dementia; however, this has been criticized for taking too narrow an approach. The most recently emerging paradigm for dementia studies concerns a rights-based and citizenship lens for understanding the status and situation of people living with the condition.

2.5.3. Inclusive communities for dementia-friendly communities

In recent years, the idea of inclusive environments such as age-friendly cities have been developed in 25 countries worldwide, including Japan, the United Kingdom, United States, Australia and Canada (Buffel et al., 2014; Fitzgerald & Caro, 2014; Kendig, Elias, Matwijiw, & Anstey, 2014; Menec et al., 2011; Scharlach, 2012; World Health Organization, 2012). The concept of age-friendly cities is that they are designed with all citizens, but especially older people, in mind, with the creation of environments that are inclusive and empowering of older people (Buffel & Phillipson, 2018). The idea of an age-friendly community is of a place where citizens of all ages can come together and opportunities for activities and social participation are offered to enable a more healthy lifestyle for people living there (Mustaquim, 2015; World Health Organization, 2012). Ideally, communities should be places that nurture a sense of community (Lovell, 2018, p. 149–161) to help citizens to grow older within their neighbourhoods among family and society so that they can participate as equal citizens regardless of age and/or disability (Fitzgerald & Caro, 2014).

Inclusion and participation during the life course in the places where people live has also been emphasized in the context of dementia studies. Keady and colleagues argue that communities should support people living with dementia so that they have the same opportunities and help to age well within their neighbourhoods (Keady et al., 2012). The initiatives of age-friendly and dementia-friendly communities share similarities when it comes to creating inclusive and supporting environments through independence and alliance with community stakeholders (Heward, Innes, Culter, & Hambidge, 2017; Turner & Morken, 2016). Within the dementia-friendly community approach, the focus is shifting towards inclusion to undermine stigma, intolerance and discrimination of dementia (Swaffer, 2014). Thus, dementia-friendly communities go beyond the models of biomedical and social care to a community ideal where responsibility towards human rights for (social) citizenship and well-being is essential (Bartlett, 2016; Henwood & Downs, 2014).

Social citizenship (or a rights-based approach) can be seen as the third paradigm or theoretical framework for understanding dementia. Bartlett and O'Connor (2010, p. 5) state that a focus on personhood alone is not enough; when discussing dementia, the person with dementia has to be accepted as "an active social agent". In addition, citizenship has to be accorded to the people living with dementia, where they are free from injustice and where they have authority over their own life (Bartlett & Brannelly, 2019, p. 3; Bartlett & O'Connor, 2007; Nedlund & O'Connor, 2016). These obvious rights that every citizen holds and takes as self-evident have similarities to the social model of disability as discussed by Shakespeare and Watson (2002). The social model of disability (Oliver, 1990) argues that it is not only individual limitations that cause problems; often it is society failing to provide the right services and to ensure that the needs of people with intellectual disability are considered in the community. However, Oliver (1990) expressed that disability is a "social state" and not a medical circumstance. The medical and rehabilitation initiative rises from an ideology of normality and has been essential for understanding implications for treatment. Further, disability is a long-term social state that is not treatable, and the focus has to be that people with intellectual disability are "experts" of their lives and not the medical scholars. The individual's own experiences of disability are essential, and power sharing in society is the way to go to achieve inclusion in society. Shakespeare and Watson (2002, p. 57) state that people are disabled through design of the built environment leading to social exclusion. The societal approach has to be changed to support disabled people, and it has been argued that securing the rights of disabled people in areas such as access to public spaces is the means to achieve this (Shakespeare, 2017).

Yet, in policy documents for health and social care in Sweden, such as the National guidelines for dementia (National Board of Health and Welfare, 2017), positioning person-centred care as the experiences of people with dementia as active agents in their communities is not mentioned. A negative attitude persists within policy and the media, whereby the biomedical model remains dominant, and where the atmosphere and popular understanding of dementia is still inspired by problematic notions about dementia as a living death (Woods, 1989) or as zombies (Behuniak, 2011) and a slow death (Taylor, 2008). These perceptions have an impact on the stigma associated with dementia and often mean that people living with dementia are not included in discussions when it comes to their health (Batsch & Mittelman, 2012; Swaffer, 2014). In the United Kingdom, different types of groups such as the Scottish Dementia Working Group (Scottish Dementia Working Group, 2014), Open Doors and EDUCATE have been established where people living with dementia are engaged in research but also as advocates for questions that concern dementia (Swarbrick, Open Doors, Scottish Dementia Working Group, Educate, Davis, & Keady, 2016).

One way to influence social change concerning dementia is to apply a social citizenship (Bartlett & O'Connor, 2007, 2010) and narrative citizenship approach (Clarke & Bailey, 2016). According to Bartlett and O'Connor (2010, p. 37), social citizenship is defined as "a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and

participate in life to the fullest extent possible.” This definition of social citizenship emphasizes that people living with dementia are treated as equal members of the socio-political circle to which they have belonged all their life (Bartlett & Brannelly, 2019, p. 15-16). Narrative citizenship clarifies the importance of narratives shared by people living with dementia in relation to their sense of belonging to places (Clarke & Bailey, 2016).

A body of research has shown that social citizenship can be supported through everyday practice such as daily walks in a group or with a partner (Bartlett & O’Connor, 2010; Kelson, Phinney, & Lowry, 2017; Phinney, Kelson, Baumbusch, O’Connor, & Purves, 2016; Silverman, 2019) or participating in a group can enable everyday talk and build confidence (Ward, Clark, & Hargreaves, 2012; Wiersma & Denton, 2016). In this thesis, social citizenship is based on the definition of Bartlett and O’Connor (2010) but extended out to the neighbourhood context and neighbourhood nursing. This approach to citizenship can be further expanded in line with Gilmour and Brannelly’s (2010) statement that nurses in all levels of health and social care have to acknowledge people living with dementia as citizens with their own history and life experience in the context of the definition of “patient”.

2.5.4. Public spaces in the context of dementia

The definition of “public” is defined by according Peace, Holland and Kellaher (2006) as civic, communal, open, which includes places such as shopping malls and markets. Public spaces are neutral ground where citizens in the community interact and meet within the community spaces (Holland, Clark, Katz, & Peace, 2007). However, the environmental barriers related to the built environment and accessibility within public spaces for people with disabilities have been discussed (Lid & Koren Solvang, 2016) and revealed that society often has attitudes towards disability which lead to exclusion in public spaces (Manzo, 2005). In the field of dementia research, much of the focus has been on wandering and getting lost in public spaces outdoors (Bantry White & Montgomery, 2016; Lai & Arthur, 2003). Research has demonstrated that being active and able to come out to use public spaces in the neighbourhood increases independence, especially for older people and those living with dementia (Argyle, Denning, & Bartlett, 2017; Brittain, Degnen, Gibson, Dickinson, & Robinson, 2017; Brorsson, Öhman, Cutchin, & Nygård, 2013; Burton & Mitchell, 2006; Nygård, 2006). Nonetheless, questions about accessibility within public spaces have been discussed, including how people living with dementia independently navigate and find their way through local public spaces (Blackman, Van Schaik, & Martyr, 2007; Burton & Mitchell, 2006; Mitchell & Burton, 2010; Mitchell, Burton, & Raman, 2004).

In a review of the literature on dementia and neighbourhood, Keady and colleagues have shown that there is little research on how people with dementia experience public spaces and everyday life in the neighbourhood (Keady et al., 2012). Existing studies have shown that people living with dementia experience a “shrinking world” along with the progression of dementia and as a result, both physical and social space decreases in the

neighbourhood (Duggan, Blackman, Martyr, & Van Schaik, 2008; McShane, Gedling, Fairburn, Jacoby, & Hope, 1998).

From the point of view of caregivers, several studies have shown that they also experience a shrinking world, because caring responsibilities take over social relationships and activities (Silverman, 2019; Ward et al., 2012). A recent study by Li, Keady and Ward (2019) showed that couples where one has a dementia diagnosis hold on to neighbourhood connections through emotional and biographical attachment to places. Silverman (2019) and Ward and colleagues argued that walking in the neighbourhood supported people to maintain neighbourhood connections and a sense of belonging to places within the neighbourhood (Ward et al., 2018). Previous research has demonstrated that people with dementia can assess and adapt to different situations in public spaces, such as grocery shopping (Brorsson, Öhman, Lundberg, Cutchin, & Nygård, 2018) or crossing busy road intersections (Brorsson, Öhman, Lundberg, & Nygård, 2011).

However, studies have shown that people with dementia interact with their neighbourhood in day-to-day life (Brorsson et al., 2018; Kelson et al., 2017; Phinney et al., 2016; Ward et al., 2018). Less emphasis has been given to people living alone with dementia and to understanding the broader view of their neighbourhood and access to public spaces. Duane, Brasher and Koch (2013) argue that, in general, people living alone have more restricted social opportunities. More focus has been on the support that people living alone with dementia receive and how they manage their life at home rather than the neighbourhood context (Alzheimer's Society, 2013; Lehman, Black, Shore, Kasper, & Rabins, 2010; Miranda-Castillo, Woods, & Orrell, 2010). Hence, more research on everyday neighbourhood living from the perspective of people with dementia is needed.

2.5.5. Dementia-friendly communities

Mirroring the age-friendly cities movement, the introduction of dementia-friendly communities has begun to emerge, with early examples in Japan and Scotland, providing inspiration worldwide to create communities where people with dementia are at the forefront in these developments (Alzheimer's Disease International, 2017). Subsequently, the governments of the United Kingdom (under action point 12 of the Prime Minister's Challenge on Dementia) and Sweden have addressed this development of dementia-friendly communities in their national dementia strategies and plans for dementia (Department of Health, 2012; Department of Health and Social Care, 2015; Government Office of Sweden, 2018). Moreover, the definition of dementia-friendly communities started as a vague definition where the focus was often on the physical environment in the health care setting (Bartlett, 2016; Lin & Lewis, 2015; Parke et al., 2017) to later focus on the communities and people living there using a more holistic approach (Alzheimer's Disease International, 2016; Shannon, Bail, & Neville, 2018).

A dementia-friendly community has been defined as “a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential” (Alzheimer's Disease

International, 2016, p. 10). Other literature has offered diverse definitions of dementia-friendly communities, drawing on both the personhood (i.e. psycho-social) approach and the rights-based approach to dementia and arguing for an empowering social environment (Lin & Lewis, 2015; Odzakovic & Kullberg, 2016; Swaffer, 2014; Ward et al., 2018; Wiersma & Denton, 2016), awareness-raising interventions (Alden, Wigfield, Krispeter, & Karania, 2019; Baker et al., 2018; Cashin, Daley, Hebditch, Hughes, & Banerjee, 2019; Ebert, Kulibert, & McFadden, 2019; Innes, Page, & Cutler, 2015; Phillipson et al., 2018), promoting independence (Bartlett, 2016; Rahman & Swaffer, 2018) and human rights (Charras, Eynard, & Viatour, 2016; Rahman & Swaffer, 2018; Swaffer, 2015). Along with this knowledge, the existing literature argues that the implementation of dementia-friendly communities could support recognition of dementia as a public health matter in a widespread societal acknowledgement corresponding to the wishes and assets of people living with dementia (Alzheimer's Disease International, 2016; Courtney-Pratt, Mathison, Doherty, 2018).

In recent years, several local initiatives have been developed to improve the city or country towards an ideal of dementia-friendly communities. For instance, in the city of York in the United Kingdom, four keystones (place, people, resources and networks) were identified as principles for York or other cities to work towards to create a dementia-friendly community (Crampton & Eley, 2013). In communities in parts of Australia (Courtney-Pratt et al., 2018) Taiwan and China (Wu et al., 2019), the importance of opportunities for people with dementia to contribute and be involved in the community differed in these countries. For instance, in Taiwan, the involvement of people living with dementia in the development of communities was not requested from people with dementia or carers (Wu et al., 2019). This result was in contrast to the findings from Australia (Courtney-Pratt et al., 2018), Canada (Wiersma & Denton, 2016) and York (Crampton & Eley, 2013). However, it has been shown that initiatives to establish dementia-friendly communities need to be based at the local level within a community to consider cultural differences and later on expanded to the national level (Alzheimer's Disease International, 2016). In addition, the perspective and contributions of people living with dementia are still lacking in research into dementia-friendly communities across the globe (Buckner et al., 2019; Ebert et al., 2019; Herbert & Scales, 2019). Moreover, there is a need for more research and understanding on how the effects of dementia-friendly communities affect stakeholders and the everyday lives of people with dementia in their communities (Buckner et al., 2019; Herbert & Scales, 2019; Shannon, Bail, & Neville, 2018).

3.RATIONALE

The population of people living with dementia in their homes and communities is increasing rapidly around the world (He, Goodkind, & Kowal, 2016; Rodrigues et al., 2012). In line with this progress, municipality-run home care becomes a greater actor in the provision of health care; 25% of all care in Sweden is provided in the municipalities and communities (National Board of Health and Welfare, 2019b).

Previous research has shown that neighbourhood is an important locus for a sense of belonging and attachment. Despite this knowledge, the focus has been on questions of navigation, shrinking worlds and the built environment in the context of dementia (Blackman et al., 2007; Burton & Mitchell, 2006; Duggan et al., 2008). In addition, the perspective of people living dementia and their everyday life in the neighbourhood has been given less emphasis (Keady et al., 2012). The lived experience of people with dementia is often taken for granted and their lifeworld is often not presented. In the caring sciences, the world of the patients is often presented solely from a health and well-being perspective; by using a lifeworld perspective, the insights and meaning of the person's perspective can be developed from a broader context to see outside the hospital. At the heart of this thesis, a way of understanding the experience of dementia and its meaning in a neighbourhood context and practice in everyday life is demonstrated from a lifeworld perspective by focusing on the voices of people living with and those with experiences of dementia.

4.AIMS

The aim of this thesis is twofold. The first aim is to explore the neighbourhood as an everyday place for people with experiences of dementia. The second aim is to explore neighbourhood as a place for practice.

The specific aims of the five studies were as follows:

- I. To examine what types of home care services and housing are granted to people with a dementia diagnosis and how these types are associated with socio-demographic factors (sex, age, marital status, native or foreign born, and regional area).
- II. To investigate the lived experience of the neighbourhood for people with dementia and through this to better understand the meanings that neighbourhood held for the participants.
- III. To explore the experiences of people living alone with dementia in a neighbourhood context.
- IV. To explore lived, personal and professional experiences related to dementia in the local community from a health-promotion perspective.
- V. To explore and characterize task-shifting processes in competences, responsibilities and roles from the perspectives of registered and specialist nurses in municipal home care.

5.METHODS

This chapter describes the methodological framework for each of the studies, exploring the research context of each study, the choice of study design, a description of the participants, and how the data were collected. The data in this thesis were based on a cross-sectional quantitative study and a mix of qualitative data collection methods (Morse & Niehaus, 2009). The following qualitative data collection methods were used: walking interviews (Carpiano, 2009; Clark, 2017; Clark & Emmel, 2010; Kullberg & Odzakovic, 2017); semi-structured individual and group interviews (Polit & Beck, 2016); mapping social networks (Campbell et al., 2019; Clark, 2017; Emmel & Clark, 2009); home tours “walking with video” (Pink, 2009); and shadowing (McDonald, 2005). Each of these methods is described in detail in relation to the different studies. Finally, the ethical considerations for the five studies are discussed in relation to the diversity of participants and methods of collecting data in ordinary housing, the neighbourhood and municipal home care.

5.1. Research context of the thesis

This thesis is part of a wider research programme, Neighbourhoods and Dementia: A Mixed Methods Study (Keady, 2014), based in the United Kingdom, and several projects based mainly in the County of Östergötland, Sweden (Figure 1).

Figure 1. Overview of research context for studies (I-V)

Study I was funded by the Swedish Riksbankens Jubileumsfond, linked to a larger research programme, *Dementia: Agency, Personhood and Everyday Life*, based at the Center for Dementia Research (CEDER). In this study, three Swedish county councils (Östergötland, Stockholm, Västerbotten) were studied. The three county councils were selected because they were reasonably representative of the country and covered 2.8 million of the 9.5 million inhabitants (29%) living in Sweden (Statistics Sweden, 2012). Those three county councils registered all inpatient, outpatient, and primary health care events in the medical records where the health care professionals signed any dementia diagnosis for 2012. Thus, the County of Östergötland was an interesting setting to study neighbourhood and dementia, as well as municipal home care in the other four studies (II, III, IV, V), not least because of the underdiagnosis of dementia (study I).

Studies II and III were based on the *Neighbourhoods: Our People, Our Places* (N: OPOP) project, which was part of the research programme, *Neighbourhoods and Dementia: A Mixed Methods Study*. The larger research programme consists of eight sub-projects. N: OPOP was one of these sub-projects spanning three field sites: Manchester in England; the central belt of Scotland and the County of Östergötland (Sweden). The intention of N: OPOP was to investigate how neighbourhoods and local communities can support people with dementia to remain socially and physically active. Furthermore, in study II, the focus was on the Swedish field site to gain knowledge about community-dwelling people living with dementia in the neighbourhood context based on limited existing research (Keady, 2014). Study II led to study III where the focus was on neighbourhood connections for people living alone with dementia. Hence, study III was designed and based in the three field sites in England, Scotland and Sweden (N: OPOP project).

Study IV was designed in the County of Östergötland and conducted in a medium-sized municipality (Norrköping). Study IV was part of a 3-year project: *Dementia Friendly Community – the Norrköping Model*. The Norrköping municipality has higher mortality rates of cardiovascular disease than the 16 largest cities in Sweden (Wennerholm, Grip, Johansson, Honkasalo, Faresjö, 2011), which affects the development of dementia, because there is an association between cardiovascular diseases and dementia (Kivipelto et al., 2018). A higher prevalence of dementia is a strong motivation for developing dementia-friendly communities (Woodward et al., 2018), therefore Norrköping municipality was relevant for study IV.

The setting for study V, within the *Proactive Healthcare for Frail Elderly Persons* project was also in the County of Östergötland. This 3-year initiative focused on a proactive primary care intervention to predict the risks of the population of frail elderly persons in the County of Östergötland (see Marcusson et al., 2019 for further details). The larger project includes eight sub-projects; one of the sub-projects is the basis of study V, exploring the task-shifting process from the perspective of registered nurses and specialist nurses working in municipality home care.

Finally, the five studies are closely connected to each other, enabling the presentation of a broader picture of neighbourhood as a place of everyday life for people living with dementia and place of work for nurses.

5.2. Worldview in the thesis

Creswell and Creswell (2018, p. 5) define a paradigm as “a worldview”, the universal theoretical orientation about the world and the nature of research used within research studies. In this thesis, the concept of worldview is applied throughout as a result of the methodology used in the five studies. A research paradigm is also an essential set of shared viewpoints and understandings between researchers in how research problems should be acknowledged and dealt with and how components of research fit together (Denzin & Lincoln, 2018; Kuhn & Hawkins, 1963). These viewpoints should be put into practice when designing research studies (Patton, 2002).

There are different philosophical paradigms or worldviews, which present various views on the nature of the world/reality (ontology) and the ways we can obtain knowledge about it (epistemology) (Patton, 2002). Further, ontology deals with the “what is” in nature and the structure of reality and explores the nature “of being” (Crotty, 1998). On the other hand, epistemology focuses on the “nature of knowledge” and leads to an understanding by exploring how we know what we know (Crotty, 1998; Patton, 2002). These two views of ontology and epistemology have led to one prominent worldview, a phenomenological lifeworld perspective (Merleau-Ponty, 1962) that has characterized and influenced the research process of the qualitative studies (II, III, IV and V). This worldview was relevant in relation to knowledge about the meaning of neighbourhood and how the practice of municipal home care is organized in the reality of the participants’ everyday life and work through interactions with others.

A lifeworld worldview allows interviews and the shadowing technique to be used with a focus on the power of the participants and their experiences. The participants all had experiences and perspectives on their way of being that enabled our understanding of how they were intertwined with the neighbourhood (world). Some had experience of dementia but also essential authority and freedom to express their experiences to us or not. According to Merleau-Ponty (1962), our knowledge about the world does not go through our intellect but via our embodied experience. However, the lifeworld is not a creation or a choice of individuals. The lived world is explored as the world of experiences that we share with others but at same time is unique for each person according to Merleau-Ponty (1962) and is the starting point for all science. The phenomenological approach derived from Merleau-Ponty centres around the notion of the “mind-body-world system”, and this connection cannot be explained outside the situated, lived experiences of everyday life, which are both embodied and intersubjective (Merleau-Ponty, 1962).

Drawing on the worldview proposed by Merleau-Ponty (1962), the pre-existing place-world was present in the relationship between walking and talking, and people with experiences of dementia and the nurses shared their experiences of the neighbourhood by embodied movement through their place-world. The structure of the lived body is defined by Merleau-Ponty (1962) as “Each body, with its own structure, selects ways to adapt, which are never repeated either with others or with itself at other moments and places.” In this way, our experience of the world is through our bodies (Merleau-Ponty, 1962, p.

82). By doing or action, we interpret and experience the world in which we live. Through our lived bodies, the actions permeate. A person both lives through their body and is their body. The lifeworld perspective is essential in this thesis to understand the worldview of the participants. The focus in the thesis is on the experiential dimension and is not only a description of the world where the participants live. Through a lifeworld worldview perspective, we can understand their surrounding world and experiences of everyday life.

5.3. General methodology and designs

To address the aims of the specific studies and the aim of the thesis, both quantitative and qualitative research designs were used as appropriate for each research question and aims. This is in line with Patton's (2015, p.244-245) description of a research design as a plan that sets the stage for how the research will be conducted. In this thesis, several study designs and data sources were used to address the aims of each study and the aim of the thesis from diverse aspects and knowledge (Thomas, 2003). An overview of the study methods and designs is presented in Table 1.

Table 1. Overview of the study methods and designs

Study	Qualitative and quantitative design	Participants and data	Data collection	Time period for data collection	Data analysis
I	Cross-sectional explorative and descriptive (quantitative design)	Data n = 17,405 people diagnosed with dementia	Three regional databases with medical care records were matched with the Register of Total Population and the National Register of Care and Social Services for the elderly and for persons with impairment by Statistics Sweden	2012-2014	Multiple logistic regression analysis
II	Phenomenological (qualitative design)	n = 14 community-dwelling people living with dementia	Walking interviews	2013-2016	Interpretative phenomenology
III	Inductive and explorative (qualitative design)	n = 14 community-dwelling people living alone with dementia	Semi-structured interviews, walking interviews, home tours, social network mapping	2013-2017	Thematic analysis
IV	Inductive and explorative (qualitative design)	n = 22 participants with lived, personal and professional experiences of dementia	Semi-structured individual interviews, group interviews	2017-2018	Thematic analysis

V	Inductive and explorative (qualitative design)	n = 18 participants (registered and specialist nurses)	Qualitative technique of shadowing, field notes	2017–2018	Thematic analysis
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A quantitative design was used to examine and quantify what types of home care services and housing were granted to people with a dementia diagnosis and to assess associations between variables. A qualitative design was used to understand the less well-researched phenomenon of neighbourhood in a dementia context and the task-shifting process in home care by involving those with experience and perspectives on the phenomenon (Bradshaw, Atkinson, & Doody, 2017).

Study I had a cross-sectional explorative and descriptive design, where a dataset of home care services and housing associated with socio-demographic factors in three county councils was gathered and analysed. Study I provided a good grounding to continue with a focus on the neighbourhood context by showing, for example, that most people with dementia were living in ordinary housing (72%). Hence, the first study gave an overview, informed the other four studies and shaped the design and aim towards the meaning of the neighbourhood.

Study II had a phenomenological design where community-dwelling people diagnosed with a dementia participated in some municipalities in the County of Östergötland using walking interviews. Study II gave a better understanding of the meaning that neighbourhood held for people with dementia. However, study II also raised questions about how people living alone with dementia experienced their day-to-day life in the neighbourhood, which provided the impetus for study III.

Study III had an inductive and exploratory qualitative design, including community-dwelling people living alone with dementia in three field sites involving multiple data collection methods (semi-structured interviews, walking interviews, social network mapping and home tours). The three studies (I, II and III) provided valuable information and raised other questions about the need to investigate not only lived experiences but also the personal and professional experiences related to dementia by developing more knowledge of how a dementia-friendly initiative in the local community could be established.

Study IV had an inductive and explorative qualitative design aimed to include the perspectives of people living with dementia (lived experiences), carers (personal experience), staff working in social and health care or voluntary employees (personal/professional experience). Semi-structured individual and group interviews were conducted in this study. Studies I–IV raised questions about the need to enhance the neighbourhood nursing perspective (Cumberlege, 1986), where nurses are more aware of their role to support people with dementia, especially those living alone, to stay connected to their neighbourhoods. To gain more knowledge of the neighbourhood nursing perspective, the working situation of registered and specialist nurses in municipal home care has to be explored.

Study V had an inductive and explorative qualitative design where the perspective of registered and specialist nurses was included using shadowing. This design was appropriate to follow the day-to-day work situation of registered and specialist nurses where task-shifting processes were implemented.

5.4. Participants, population and procedures

The characteristics of participants included in the qualitative studies (II, III, IV, V) and their experiences of dementia are presented in Table 2. An overview of the diverse experiences of dementia is presented to gain an understanding of the findings and the aims of the thesis.

Table 2. Characteristics of the participants and their experiences of dementia in studies II, III, IV and V

Study	Participants	Sex (males/ females)	Setting	Experience of dementia*		
				Lived	Personal	Professional
II	14 community-dwelling people living with dementia	11/3	Östergötland	X		
III	14 community-dwelling people living alone with dementia	3/11	Greater Manchester in North England, the Central Belt of Scotland, Östergötland	X		
IV	22 participants: 8 people living with dementia, 4 care partners, 10 professionals, working as nursing staff, social worker, care manager	8/14	Municipality in Norrköping	X	X	X
V	18 participants: 12 registered nurses, 6 specialist nurses	2/16	Two municipalities in Östergötland		X	X

*Lived experiences refers to people with a dementia diagnosis; personal experiences refers to carers and/or children; professional experiences refers to health care professionals working in the municipality (home care, day care centres) and voluntary organizations.

Study I investigated what types of home care services and housing were granted to people with a dementia diagnosis and how these were associated with socio-demographic factors (sex, age, marital status, native or foreign born, and regional area). All persons aged 50 years and older in 2012 with a dementia diagnosis and living in one of three Swedish county councils (Östergötland, Stockholm and Västerbotten) were included. A total of 17,405 individuals with a dementia diagnosis were identified from the databases in these three county councils. Further, the county councils consisted of 54 municipalities

(large, medium/small, rural) based in the southeast (Östergötland) and in Stockholm (capital of Sweden), and north of Sweden (Västerbotten). Study I included 6705 men and 10,700 women with a dementia diagnosis.

In study II, walking interviews were conducted with people diagnosed with dementia, with the aim of investigating the lived experience of the neighbourhood for people with dementia and through this, to better understand the meanings that neighbourhood held for the participants. Fourteen community-dwelling people with dementia were recruited from the memory clinics, primary health care and day care centres in the County of Östergötland. The health care staff working in these organizations were asked to identify participants according to the inclusion criteria. The participants had to have a dementia diagnosis, live in ordinary housing (not in special housing) and have the capacity to give informed consent. In total, 11 men and 3 women were recruited; 6 men lived with a spouse, and all participants were diagnosed with dementia (Table 2). The length of time they had lived with dementia varied. Some participants managed their everyday activities independently; others had some help from caregivers and municipal home care services.

The procedure in studies II and III was similar because some of the participants from study II were included in study III from the Swedish field site. With the aim of exploring the experiences of people living alone with dementia in a neighbourhood context, community-dwelling people living alone with a dementia diagnosis were invited to participate in the study. The recruitment process in the three field sites was different. In the UK field sites, local and national voluntary and community organizations assisted in recruiting participants. In the Swedish field site, the County of Östergötland, the health care staff working in the memory clinics, primary health care and day care centres helped with this process. All people living alone with a dementia diagnosis without a co-habiting partner/children/next of kin in the three field sites were selected to participate in the study. Further, they were required to be living in ordinary housing, community dwelling, in a one-person household and had to be able to give oral and/or written informed consent. In total, 14 participants gave their consent to participate; for more information about the participants, see Table 2. Four participants who were included in study II were also participants in study III. All participants had lived experience of a dementia diagnosis, although some participants chose not to reveal the specific type of dementia. The focus was on lived experiences of dementia, not the stages of dementia. As in study II, some participants could manage their own day-to-day life and others had help from municipal home care services.

In study IV, semi-structured individual and group interviews were conducted with people living with dementia, carers, people working within practice and those with personal experience of dementia in everyday life, using purposive sampling. This study aimed to explore lived, personal and professional experiences related to dementia in the local community. Participants were required to give written or verbal informed consent. During the recruitment, several organizations in municipal home care, day care centres and others shared information about the study. Twenty-two participants with lived, personal and professional experiences of dementia were interviewed; eight participants

were living with dementia, four were care partners and ten were professionals (nursing staff, social worker and care manager). Of those, eight were male and 14 were women; for more information about their experiences, see Table 2. Participants who were living with dementia had a formal diagnosis of dementia. As in studies II and III, the focus was on their experiences of dementia, not on the stages of dementia or the disease trajectory.

In study V, purposive sampling was used as in study IV, with the aim of exploring and characterizing task-shifting processes in competences, responsibilities and roles from the perspectives of registered and specialist nurses in municipal home care. The care managers at two municipalities in the County of Östergötland took part in the selection of participants and helped by sending/distributing information about the study by email to their employees, according to the inclusion criteria. The participants had to be a registered nurse or specialist nurse working in one of the settings from the main municipal home care project (Marcusson et al., 2019), have work experience as a registered nurse for at least 1 year and a minimum of half-time employment. This recruitment process identified 18 participants, and of those, 12 were registered nurses and 6 were specialist nurses, such as district nurses (defined as specialist nurses in the thesis). In total, 16 participants were women and two were men. They had worked in municipal home care from 3 months to 4.5 years, and had a median 17 years of experience as registered and specialist nurses. Although their experience of dementia was not in focus throughout the study process, they had both personal and professional experience of dementia through their work and as carers, which was observed during shadowing. They had contact with and cared for many patients with dementia who were living at home; therefore, the selection of their experiences of dementia was based on this observation and sharing of experiences during the data collection.

5.4.1. Regional databases with medical care records and register data (study I)

In study I, data were collected based on knowledge on the type of home care services and housing that people with a dementia diagnosis was granted. There is a lack of information on this in Sweden despite a solid tradition of national registers, which include data for older people but do not specify people living with dementia (National Board of Health and Welfare, 2012). The data collection involved several steps. In the first step, the three county councils provided data on all inpatient, outpatient, and primary health care events where health care professionals had noted any dementia diagnosis (ICD10: F00 Alzheimer disease, etc., F01-F02-F03-F05.1-G-30-G31.1-G31.8A). Then, Statistics Sweden matched the individual data (the 10-digit personal identity number) with the Register of Total Population, focusing on data on sex, year of birth, marital status, and country of birth. In the third step, Statistics Sweden matched the datasets with the National Register of Care and Social Services for the elderly and for persons with impairment at the Swedish National Board of Health and Welfare. The information in this database was based only on individual information about the type of home care services and housing legalized by the Social Services Act (SFS-Svensk

författningssamling, 2001). All persons aged 50 years or older in 2012 with a dementia diagnosis were included. This year was chosen because of the validity of the data from the specific register year 2012 in line with recommendations from the Swedish National Board of Health and Welfare.

The de-identified data on individuals were then categorized into five age groups (50–59, 60–69, 70–79, 80–89, and >89 years), marital status, country of birth, county council and size of municipality. There were seven types of home care services, in line with the regulations for social care services for older persons (National Board of Health and Welfare, 2012; SFS-Svensk författningssamling, 2001): home help and personal care, safety alarm, meals on wheels, day care service, short-term and respite care and guide service. Special housing was also included but as a separate service that could be granted to older people; it was not included in the seven types of home care services. Special housing is defined as a residence where a 24-hour home care service is available in a flat based on a decision from a care manager for people aged 65 years or older (National Board of Health and Welfare, 2012). This categorizing was achieved to analyse with descriptive, univariate and multiple logistic regression models.

5.4.2. Walking interviews (studies II and III)

Walking interviews were conducted between 2013 and 2016 in studies II and III to investigate the lived experience of the neighbourhood for people with dementia, by enabling spontaneous conversation with participants (Carpiano, 2009) about place and social connections within it while walking along. Walking interviews are reported to be truer to life than other methods (Clark, 2017; Clark & Emmel, 2010; Foley et al., 2019; Hall, 2009; O’Neil & Roberts, 2019, p. 15–39). Before conducting the walking interviews, a rapport-building sit down interview was held with the participants in their home before going out for a walk in the Swedish field sites (studies II and III). In Sweden, the walking interviews were performed as a second interview in study III, whereas in the United Kingdom the walks came first. These differences reflect perceived cultural differences. An overview of how data collection was undertaken in study III regarding the walking interviews is shown in Figure 2. All walking interviews were conducted during the day, and the participants decided the time and route they wanted to walk. The researchers followed along and some participants took on the role of a tour guide, deciding the direction and duration of the walk. Some participants had a walking aid with them, and two of the participants had their spouses with them as support. None of the participants withdrew during the interview.

The walking interviews had the character of a “walk and talk” type conversation compared with formal sedentary interviews. There was no interview guide to be followed; instead the questions that were asked were about the places and local services in the neighbourhood while walking. Open and probing questions (Lincoln & Guba, 1985) were used, such as: “Can you describe a typical day in the neighbourhood?” followed by probing questions such as “Tell me about that experience?” to inspire the participants to talk about the lived experiences while walking in the neighbourhood. The walking

interviews were audio-recorded. The walking tours with the participants lasted from 25 to 97 minutes. The walking interviews were transcribed by the researchers in the team and a certified transcriptionist. Field notes were taken during the data collection and used in the analysis according to an interpretive phenomenological approach (Moustakas, 1994).

5.4.3. Multiple data collection methods (study III)

In study III, the walking interviews in all three field sites were used where the participants living alone with dementia took the researcher on a tour through their neighbourhood. Movement through the neighbourhood creates a connection and dialogue between the participants and the researcher (Carpiano, 2009; Clark & Emmel, 2010; Kullberg & Odzakovic, 2017). Data were gathered between 2013 and 2016. The process of conducting walking interviews was not the same for all field sites as mentioned earlier. Later on, home tours were conducted in the UK field sites with the permission of the participants, inspired by the “walking with video method” developed by Pink (2009); they were video-recorded but not used in the analysis. The aim of the home tours was for the participants to take the researcher on a tour of their home and show us important rooms and spaces in that context. Most participants also agreed to participate in social network mapping (Campbell et al., 2019; Clark, 2017; Emmel & Clark, 2009) in the home by mapping out their social contacts, which did not follow any interview guide. The questions were open and emerged from the interviews using prompts such as: “Could you describe your social networks?”, “Tell me who you know?”, “Who would be the first person that you would contact if you need some help?” In some situations, we asked probing questions (Lincoln & Guba, 1985) such as “Tell me, how has that affected you?” The interviews lasted for between 25 and 134 minutes and were audio-recorded and transcribed by certified transcriptionists; some interviews (from the Swedish field site) were transcribed by the authors. The interview transcripts were exchanged among the authors as they were translated into English. Because study III included multiple data collection methods, thematic analysis was used across the different datasets (Braun & Clarke, 2006).

Some participants participated in just one data collection method, others in several. In Sweden, some participants that took part in follow-up interviews after 4–12 months. In the UK field sites, the participants had the possibility of repeating some of the walking interviews and social mapping after 8–12 months. For more information on the process of data collection, see Figure 2.

Figure 2. Overview of the process of data collection in study III

5.4.4. Semi-structured individual and group interviews (study IV)

To gain insights on suggestions for health-promotion interventions in the local community by people with lived, personal and professional experiences of dementia, semi-structured individual or group interviews were used (Polit & Beck, 2016). The interviews were conducted during 2017 and lasted until 2018. The participants decided how they wanted to be interviewed, individually or in a group, whichever was most comfortable for them.

The participants decided the time and place of the interviews. All authors of study IV conducted the interviews. The interviews were held in different locations based on the participants' wishes; some interviews were held in participants' homes, at their workplaces, in libraries or hired venues. The group interviews consisted of two or three participants who were working colleagues and people living with dementia who participated in a day care centre. During the data collection, none of the participants withdrew their consent. The interviews followed an interview guide (Appendix I) with open and probing questions based on the literature and extant results from studies I, II and III. For example, one of the questions was "What kind of improvements in the community would you like to see that could enhance the well-being of people living with

dementia?” followed by probing questions (Lincoln & Guba, 1985) such as “Could you tell me more?”

Interviews lasted between 21 and 150 minutes (mean, 42 minutes) and were audio-recorded and transcribed by a certified transcriber. The semi-structured individual and group interviews were analysed by thematic analysis following Braun and Clarke (2006).

5.4.5. Shadowing method (study V)

The qualitative method of shadowing (McDonald, 2005; McDonald & Simpson, 2014) was conducted during 2017 and 2018. Shadowing was chosen to include the unexpected and episodic nature of municipal home care where task-shifting processes took place during the practice of registered and specialist nurses.

Czarniawska (2014) argues that the benefit of using shadowing as a method includes its movement, whereby the researcher can follow the participants and dynamics where they actually take place. Shadowing took place with the 18 participants at two municipalities during the day, starting at the beginning of the working day until their shift finished. The author of the thesis, who is a district nurse, conducted all shadowing, which is an advantage to generate rich data (McDonald, 2005). Data were collected in December 2017 and October 2018. Shadowing started with a presentation of the study, which was performed on each occasion of data collection. The actions and surroundings for municipal home care were shadowed from the participants’ perspectives (Gill, Barbour, & Dean, 2014) not from the researcher’s or the shadower’s (author of the thesis) perceptions.

In total, 23 shadowing occasions and 155 hours (median, 5 hours) of direct shadowing were performed and documented by means of handwritten field notes on the task-shifting process, photographs (only of physical spaces) and other documentation; for example, regulations about medication. Photographs were used as triggers in conversation with participants and during the data analysis. No interview guide was followed due to the methodology of shadowing (McDonald, 2005). The questions that were asked arose from the field by shadowing the participants. Questions were asked in connection with the activities and actions of participants gain an understanding of the task-shifting process. In some situations, follow-up or probing questions (Lincoln & Guba, 1985) such as “How did you feel in that situation?”, “How did you experience that moment in the room?” or “What are your suggestions for the future of home care?” were asked to encourage the participants to share more of their experiences. The field notes were created during and after the shadowing. At the end of the research process, all field notes were transcribed by the author of the thesis into a 274-page Word document and analysed by thematic analysis according to Braun and Clarke (2006).

5.5. Ethical considerations

In this thesis, ethical aspects need to be carefully considered as in all research projects involving people with lived, personal or professional experiences of dementia. In addition, ethical issues were considered with regard to shadowing the registered and specialist nurses working in municipal home care. Thus, in line with the Declaration of Helsinki (World Medical Association, 2013), the work of this thesis has been guided by the ethical principles of respect for autonomy, non-maleficence, beneficence and justice (Beauchamp & Childress, 2013). First, permission was obtained for the five studies from the Regional Ethical Review Board in Linköping, Sweden (record references: 2013/319-31 (study I), 2013/200-31 (studies II and III), 2014/359-32 (studies II and III), 2017/62-31 (study IV), 2017/369-31 (study V)) before collecting data. In addition, the Swedish Regional Ethical Review Board and the NHS Health and Social Care Research Ethics Committee in the United Kingdom (record reference: 15/IEC08/0007) gave their permission for study III. The ethics board in each authority in the county councils of Östergötland, Stockholm and Västerbotten, Statistics Sweden, and the Swedish National Board of Health and Welfare also gave their approval (study I).

5.5.1. The principles of respect for autonomy and informed consent

Beauchamp and Childress (2013, p. 67-113) argue that the principle of respect for autonomy means that the researcher has given reliable information to the participants to ensure that they understand the project and that their participation is voluntary and autonomous. By ensuring autonomy, an appropriate decision can be taken by the participants before signing the informed consent.

In study I, no informed consent process was necessary (CIOMS, 2016) because the statistics in the database were regulated by the Social Services Act (SFS-Svensk författningssamling, 2001). Hence, there were no activities that involved any people-to-people direct contact. The participants living with a dementia diagnosis in studies II, III and IV were given oral and written information about the research project by the researchers several times to ensure that they were aware and reminded of their participation according to a process consent approach (Beauchamp & Childress, 2013, p.74-79; Dewing, 2007, 2008).

The informed consent process was fulfilled by oral and written consent before starting the interviews, home tours, social network mapping and shadowing in all four studies (II, III, IV, V). The participants with dementia were able to give oral and/or written consent by themselves without surrogate decision makers (Beauchamp & Childress, 2013, p. 343) such as caregivers making the decisions for them. During this process, the participants could ask questions about the research projects and methods. They were also informed and reminded that they could withdraw from or temporarily stop the interview without giving a reason. A person-centred approach to consent was included in all studies, especially studies II, III and IV, which involved the participants with dementia (Dewing, 2002; Hellström, Nolan, Nordenfelt, & Lundh, 2007). In these studies, participatory principles were in focus in the research process due to the methodology of each data

collection method. The interests of the participants with dementia were considered throughout the thesis.

In studies II and III, the participants decided the route of the walking tour and if they wanted to inform their neighbours and anyone else they encountered during the walk. The participants with dementia decided by themselves if they wanted to go alone with the researchers or if a caregiver or friend should accompany them on the walk. Of the 14 participants in study II, only two participants wanted their spouse to walk alongside, mainly due to their health/mobility problems.

In study III, the participants, or in some cases the caregiver, decided the time and place of the interviews. In the UK field sites, there were two daughters who participated in the walking interviews, social network mapping and home tours to support the participants according to their wishes. The daughters' perspectives were not included in study III. There were some follow-up interviews in study III; the participants decided if they wanted to participate in a second or third round of interviews. Some participants declined because of their health or because they had moved to another address and/or to special housing.

In study IV, the participants with or without a dementia diagnosis decided if they wanted to be interviewed individually or in a group, depending on what was most comfortable for them. In study V, both oral and written information about the research project was given several times, initially to the participants as well as during the shadowing to the patients that we visited. Written information about the research project and about the research team was given to all participants so that they could decide for themselves if they wanted to participate without any involvement from their care managers. None of the participants declined to give informed consent or withdrew their participation. The patients on the day when shadowing was performed were also given oral and written information about the researcher and about the research project, emphasizing that the aim was to shadow the registered nurses not use any personal details about the patients. The written information was provided in lay language and did not include any concepts that were difficult to understand (Patton, 2002); the name, picture of the researcher, and telephone number of the project leader were included in case of any questions afterwards. This information was often given directly when entering the home, depending on the patient's position in the home. The patients were all positive about the research project.

5.5.2. The principle of non-maleficence

The second principle of non-maleficence requires that that there be no risk of harm, privacy and confidentiality are protected, and the health needs and priorities of the participants are considered (Beauchamp & Childress, 2013, p.120-184; World Medical Association, 2013). In study I, all data in the database were de-identified and assigned serial numbers by Statistics Sweden to protect confidentiality in line with the Declaration of Helsinki (World Medical Association, 2013). The researchers in study I did not handle any personal data such as personal identity numbers; all data were de-

identified during the research process. Only the serial numbers of the patients were used when analysing the data. The database was kept in safe storage and only the researchers working with the data analysis had access.

In the qualitative studies (II, III, IV, V), all encounters were made on the basis of not doing any harm to the participants and respecting their dignity because there was a risk of entering their private sphere (Lichtner, 2014). The researcher (author of the thesis) had professional experience of visiting people at home due to her role as a district nurse and so a pre-understanding of entry into the home context was a help in this study. All data were under pseudonyms to maintain the confidentiality of the participants. Only the research team had accessed to the data, which were kept safely in locked storage at the universities.

In studies II and III, the walking interviews were performed outside in the neighbourhood alongside the participants and their caregivers using digital recording equipment. The participants decided whether they wanted to reveal to their neighbours or others in the neighbourhood that they met why they were walking with researchers. Some participants informed their neighbours that they were participating in a research project.

During data collection, the researchers asked the participants to lead the walk (Kusenbach, 2012) in line with the walking interview methodology (Clark, 2017; Clark & Emmel, 2010) and despite their cognitive impairment (Kullberg & Odzakovic, 2017). Almost all participants led and took control of the walk. One participant had some difficulties finding the way home because of the weather conditions during one winter period. The researchers then led the walk home to ensure that the participant was safe and unharmed. In addition, the researchers took responsibility for the health of the participants by ensuring that the participants were well enough to walk on the chosen day and whether they displayed any signs of sickness or tiredness (Kullberg & Odzakovic, 2017), in which case the interviews did not take place to avoid any potential harm on the participants. Instead, the researchers would suggest coming back another day. Only one participant had some difficulties with the walk due to his health while going up a hill. One participant in study II forgot the day for the interview so the researcher had to call the home care staff. The interview was conducted with the participant later on the same day.

Visual data in the form of photography during the home tours and shadowing were generated in line with informed consent. Photographs were only taken with the permission of the participants.

Another ethical aspect that had to be considered was that the data from study III were exchanged among the researchers in the team. The interviews from the UK field sites were shared with the author of the thesis and encrypted with a password to open the files. Thereby, the confidentiality of the data was secured because they were encrypted, anonymized and only the research team had access to them.

In study IV, the participants decided if they wanted to participate in a semi-structured individual interview or a group interview (Polit & Beck, 2016). The participants living with dementia were interviewed at home, in the day care centre or a hired venue where they felt secure and wanted to be interviewed in a group setting. They signed the informed

consent by themselves. The participants with personal and/or professional experience of dementia were interviewed at their work place, home, in a library or in a hired venue to ensure their privacy towards the work place. Both semi-structured individual and group interviews were conducted alone with the researchers.

Further, in study V, there were some field work ethics to consider (Johnson, 2014; Shaw, 2008); as in studies II and III, unexpected events could occur in the field. The study setting for shadowing was in the neighbourhood and in people's homes, therefore it was important to ensure the privacy of the non-participants involved. The confidentiality of non-participants was an issue when professionals in primary health care, municipal home care and/or other work places took part in shadowing; emergencies could occur at any moment when the author of the thesis was a shadow of the participants.

To guard against any harm to the non-participants, no data were kept that could expose or undermine their identity. If the non-participants had some questions about the researcher during the shadowing, the first author always answered their questions and explained the purpose of my participation. During the shadowing, there were no situations where this became a problem. On some occasions, the patients or non-participants mistook the researcher for a newly employed or student nurse because the researcher (author of the thesis) was wearing the same type of clothes as the participating nurses or personal clothes but without any name badge. However, the choice of clothes did not affect the shadowing; nothing that the researcher noticed required adaptation. Throughout the shadowing, all efforts were made to consider the ethics of the situation so that the participants were not harmed in any way. The author of the thesis explained that the aim of the research was not focused on the capacity to work, only on the situations in which participants were involved. Drawing on the background of the author of the thesis and pre-understanding as a district nurse, she tried to keep in balance and to recognize some care situations that were beyond the role as a researcher. It was not always easy, but in a few situations, the author of the thesis acted only to protect the patients from harm. In one situation, when a meeting about the working situation in municipal home care was held, the author of the thesis decided to not shadow out of respect for the participants.

5.5.3. The principle of beneficence

The third principle of acting for the benefit of others and holding onto beneficence (Beauchamp & Childress, 2013, p. 194-248) was accomplished in all five studies. This thesis provides new knowledge about people living with dementia in their neighbourhoods and using municipal home care, where all participants were taking actions and participating in research projects based on a person-centred approach. In this thesis, the research was done with them and not about them.

During the recruitment of participants in study IV, we were in contact with some gatekeepers who believed that people with dementia could not provide us with valuable information for our study. This opinion was not new to us as dementia researchers but challenged the principle of beneficence. The gatekeepers did not have the same point of view and knowledge about people with dementia as we did; despite this, we have been

true to this principle by focusing on the benefits of research with people with dementia. Despite such situations, some gatekeepers helped us with the recruitment of the participants.

All five studies filled a gap in current research and had social value (CIOMS, 2016) in highlighting the importance of information about the lived experiences of dementia in the neighbourhood and municipal home care. This can only be a benefit for establishing neighbourhood nursing and for the next generation of nurses. The participants in the qualitative studies (II, III, IV, V) commented that the reason they participated was to help others in the same situation and to gain new knowledge for future practice and municipal home care.

5.5.4. The principle of justice

The final principle of respect for justice includes being treated equally with equal access to resources (Beauchamp & Childress, 2013, p. 256-302). This principle has been accomplished throughout the four qualitative studies (II, III, IV, V), in the study design, recruitment, data collection and data analysis. When conducting research on dementia, a dementia advocacy approach should be adopted and considered as stated: “Nothing about us without us” (Bryden, 2015). This quotation by Christine Bryden (2015), taken from the disability movement, builds on the view that people with dementia should have equal right to inclusion in every decision, and that includes participating in research (Swaffer, 2014). As with the previous principle, the researchers and the gatekeeper’s point of view regarding the capability of people living with dementia, that they should be treated equally, differed, especially in study IV. Consequently, this was a challenge to obtain the principle of respect of justice through the research process. Nonetheless, people living with a dementia diagnosis have been treated with respect and treated equally in our team throughout the research process. The researchers have listened to their wishes and perspectives when using the different data collection methods; for example, walking interviews. Our previous knowledge of meeting people with dementia as nurses and social workers has been helpful in addressing them as citizens with the same resources as others without cognitive impairment and with unique experiences of dementia.

The participants were included in the research projects because of their experience of dementia and municipal home care. Further, the participants in studies II, III, IV and V had the same access to information during the research process regardless of their age, living conditions, social status, ethical background or disability, based on equality and respect during their participation in all four qualitative studies.

5.6. Data analysis

In this section, the quantitative and qualitative data analysis process is presented and the different approaches applied to analyse the data are described. First, the quantitative

analysis process is explained in more detail (study I). Then, the qualitative analysis process using interpretive phenomenology (study II) and thematic analysis (studies III, IV and V) is described. Finally, an overall analysis of the five studies and the findings are presented.

5.6.1. Quantitative analysis process

The quantitative data in study I were analysed with the IBM Statistical Package for the Social Sciences (SPSS) version 24. Descriptive statistics were used to summarize and demonstrate the data (Overholser & Sowinski, 2007) for socio-demographics (sex, age, marital status, native or foreign born, and regional area) and home care services, presented numerically by percentages and size (n). Pearson's chi-squared test was used to test if there were differences between groups to find out which variables accounted for any variances found. This test was suitable for our data and provided significant information (McHugh, 2013); for example, if there were differences between women and men diagnosed with dementia and what type of home care services they were granted.

In the next step of the analysis, univariate and multiple logistic regression analyses were performed based on the ability to control coexisting variables and confounders (Rothman, 2012, p. 218, 226). Further, univariate and multiple logistic regression analyses were used to find associations between the seven outcome variables on home care services and the independent variables on demographic data. From this analysis, independent variables with a p value <0.10 were entered in the multiple logistic regression analysis.

Eight multiple logistic regression models were carried out: one for each of the six home care services; one for special housing; and one was for not being granted any home care service. The results from the multiple logistic regression models are presented by odds ratios (ORs) and 95% confidence intervals from the multiple models, which estimated the degree of statistical precision of the data (Rothman, 2012, p. 169). A p value ≤ 0.05 was considered statistically significant for the results. The Nagelkerke goodness-of-fit test (Nagelkerke, Smits, le Cessie, & van Houwelingen, 2005) was assessed to test how well the eight models with variables fitted our data. To calculate the validity of the fitted models, the area under the receiver operating characteristic curve was used (Tosteson & Begg, 1988) to assess the discrimination of the fitted models.

5.6.2. Qualitative analysis process

The choice of methods to analyse the data from the qualitative studies was driven by the aims and research questions from the four studies (II, III, IV, V) (Patton, 2015). The data analysis focused on the participants' experiences and perspectives and explored the phenomenon of neighbourhood. Given the importance of exploring the neighbourhood

as a phenomenon, an interpretive phenomenological approach (Moustakas, 1994) was used in study II. In the three other qualitative studies (studies III, IV and V), thematic analysis (Braun & Clarke, 2006) was chosen to obtain a detailed view of the different data sources.

5.6.2.1. *Interpretive phenomenology*

In phenomenological approaches, the focus is to gain a richer understanding of the world and/or meaning of everyday experiences. Throughout this approach, it is important to explore the phenomenon of people with the same experiences, which indicates that walking interviews with people with lived experiences of the phenomenon is central (Patton, 2015). This methodology is driven by one essential question: What is the meaning, structure and essence of the lived experience of this phenomenon for this person or group of people? (Patton, 2015). The word phenomenon is from the Greek “phaenesthai”, to show itself or to appear (Moustakas, 1994, p. 26). The phenomenon was later defined by Heidegger as “something that brings to light, to place in brightness, to show itself in itself, the totality of what lies before us in the light of day” (Heidegger, 1977, p. 74–75). The phenomenon in this thesis was the meaning and experience of dementia in the neighbourhood, which is in line with the aims.

Phenomenology is used in different disciplines and contexts (Patton, 2015). However, in this thesis, the research method framework developed by Moustakas (1994) was applied by using an interpretive phenomenological approach to analyse the walking interviews, which supports the aims and research questions. One of the reasons for embracing interpretive phenomenology according to Moustakas (1994) was the philosophical approach whereby lived experiences and connections to the world (neighbourhood) are in focus, which is in line with the theoretical framework of this thesis. The notion of a phenomenological approach to a mind-body-world system by Merleau-Ponty (1962) can explore this connection, which cannot be understood without considering the outside world and the lived experiences of everyday life in relation to embodiment.

The transcripts of the walking interviews were analysed according to four steps of Moustakas’ modified version of the Stevick-Colaizzi-Keen method (Moustakas, 1994, p. 121–122). In the first step of the analysis, an understanding of the data was attained by reading the transcripts. Thereafter, our own knowledge captured in field notes and experiences of the phenomenon were added to the whole description, including our own pre-understanding. The authors have their own pre-understanding even though some of them were not present at the interviews; reading the transcripts of the interviews gave them in-depth understanding of the neighbourhood.

In the second step, the focus was on re-reading the transcripts first to identify important statements that answered the aim. Then, meaning units were developed from the statements and written in a spreadsheet to gain a representation of the initial themes.

To describe the phenomenon, mind maps were created as tools in this step, where the methodological terms of “noema” and “noesis” were used in the mind maps. The mind maps were driven by the question “what does the participant (name) pay attention to during the walk?” while reading the transcripts. The concepts of noesis and noema can be described as a link towards our perception of the world. Noesis is our thought towards the object. Noema refers to the object of our perception, which is “the appearance of something in our world” (Moustakas, 1994, p. 69–83). These two concepts can be demonstrated through an example of the mind maps from two of our participants. Anders and Ingvar were walking in the neighbourhood, and while walking, Anders drew attention (noesis) to, for example, the physical forms of flowers (noema); Ingvar mentioned the importance of movement as walking (noema). For further information, see the example of mind maps from Ingvar and Anders in Figure 3. This practice of working with mind maps led to the essential themes, according to Moustakas’ modified version of the Stevick-Colaizzi-Keen method.

Anders

Ingvar

Figure 3. Mind maps for two of our participants: Anders and Ingvar

The mind maps for Anders and Ingvar show noema (the pink circles in the maps) and the others circles shows noesis. In the mind maps of Anders and Ingvar, we can see that through Anders’s and Ingvar’s thought, noesis, their perception of the lived experiences of neighbourhood, appeared as actions, that is, the noesis brings perception of the importance of walking almost everyday. The intentional act of both participants was to talk about the importance of movement as walking (noema), which supported their selfhood and identity while living with a dementia diagnosis (noema) in the neighbourhood. Their perceptions appeared for them while walking in the neighbourhood, and the lived experiences of dementia appeared as an intentional act. As shown on the mind maps, Anders and Ingvar were showing and talking from their perception (noesis). Anders was showing and describing the flowers (noema) in the garden and Ingvar talked about the advice from the doctor at the hospital to use the same routines and the importance of walking (noema).

In the third step, a creative description based on the quotes from the transcripts was produced based on the previous step with the mind maps. In the fourth and last step, the essences of the phenomena were found based on the overall description of all mind maps.

5.6.2.2. *Thematic analysis*

For the three qualitative studies (studies III, IV and V) in this thesis, based on multiple data collection approaches and shadowing, an inductive approach to thematic analysis (Braun & Clarke, 2006) was chosen. The choice of thematic analysis was based on the flexibility of this method for different sources of data collection (Boyatzis, 1998; Braun & Clarke, 2006), which worked well across studies III, IV and V. The aim of the analysis in the three studies was to develop a rich description where the experiences and perspectives of participants were central. By using an inductive approach, the themes derived from the data were strongly linked to the participants' experiences and perspectives (Patton, 2002). The data analysis process of the three studies followed six phases according to thematic analysis by Braun and Clarke (2006).

In the first phase of the analysis, the interview transcripts from the walking interviews (study III), the semi-structured individual interviews (studies III and IV) and the group interviews (study IV), social networking mapping (study III), home tours "walking with video" (study III) and transcribed field notes (study V) were read several times over many days to gain an overall picture of the data. Throughout this phase, notes on the interview transcripts were taken to identify meaning codes within the data. In the analysis of study IV, the participants had different experiences of dementia, but their experiences were equally appreciated during this analysis process (Lincoln & Guba, 1985). The author of this thesis performed the analysis, and the co-authors were involved in this process by reading and discussing the themes.

In the second phase, codes from the previous phase were examined to find any repetitive themes in the datasets. In the third phase, sub-themes were identified from the codes. The sub-themes were then reviewed and developed in the fourth phase to gain an overall description of the coding that represented the data. In the fifth phase, the sub-themes were defined and then the identification of the main themes began. The main themes were evaluated in relation to the datasets from the interview transcripts and transcribed field notes for the datasets. In this phase, the authors discussed the final main themes and sub-themes to ensure consensus and agreement about the themes and to ensure traceability and verification (Bradshaw et al., 2017; Nowell, Norris, White, & Moules, 2017). Finally, in the sixth phase, the writing process began to get a complete description of the main themes and sub-themes with quotations according to the aims of studies III, IV and V).

5.6.2.3. *Overall analysis of the studies*

A reflexive thematic analysis (Braun & Clarke, 2006, 2019) of the findings from each of the five studies was used to synthesize an overview of people's experiences and perspectives. The primary focus of the analysis was on insights into people's lives, personal and professional experiences of the neighbourhood as everyday places of connection, and practice in the context of dementia, in line with the aims of this thesis. Although the five studies had different approaches to qualitative and quantitative strategies, a complementary and reflexive standard has been used throughout the analysis process (Braun & Clarke, 2019; Malterud, 2001). This approach is consistent with Malterud (2001), who supports the rationale of integrated strategies using both qualitative and quantitative methods rather than incompatible views in research.

The process of analysing the five studies together followed six phases in the data analysis process (Braun & Clarke, 2006, 2019). In the first phase, the findings (studies II, III, IV, V) were read several times and notes were taken to become familiar with the data. The data were inductively coded directly from the bottom up to be as close as possible to the experiences and perceptions of the participants and the results (study I). All coding was done by the author of the thesis. This course of action was in line with Braun and Clarke's (2006) counsel of coding, where one author should perform all coding. Thereafter, the supervisors gave guidance by checking for sense and to ensure consensus during the analysis process to maintain the validity of the data (Nowell et al., 2017).

In the second phase, the initial codes were examined to find repetitive themes in the dataset. Then, in the third phase, the codes were organized into potential sub-themes. In the fourth phase, the sub-themes from the previous phase were reviewed and refined by reading through the sub-themes and ensuring that they formed a reasonable outline of the data. In the fifth phase, the sub-themes were defined and sorted into main themes to provide the essence of whole dataset. Finally, both main themes and three sub-themes emerged from the analysis, and are presented in the findings section. The original studies (II, III, IV, V) were then read again against the main themes and sub-themes to ensure the validity of the researcher's interpretation of the overall findings in this thesis (Braun & Clarke, 2006; Nowell et al., 2017).

6.FINDINGS

In this section, the findings of the five studies in the context of this thesis are summarized; first, they are presented in the order of publication of the articles. Second, in the next section, the overall analysis and presentation of the findings are described.

6.1. Summary of the five studies

6.1.1. Study I: People diagnosed with dementia in Sweden: what type of home care services and housing are they granted? A cross-sectional study

The aim of this study was to examine what types of home care services and housing are granted to people with a dementia diagnosis and how these types are associated with socio-demographic factors (sex, age, marital status, native or foreign born, and regional area). In total, 17,405 individuals with a dementia diagnosis in the three county councils of Östergötland, Stockholm and Västerbotten were identified as having a dementia diagnosis. We found that dementia was underdiagnosed, especially in Östergötland, compared with the estimated prevalence of dementia reported by the National Board of Health and Social Care (2014). Of the total population with dementia, 72% were living in ordinary housing and 28% were living in special housing (compared with national figures from the National Board of Health and Social Care (2014) that estimated 58% in ordinary housing and 42% in special housing in 2012). Of the 12,499 individuals who were living in ordinary housing only 50% were granted some type of home care services. Overall, 52% of 17,405 people with dementia in Sweden were living alone.

Living in ordinary housing with a dementia diagnosis without any home care services was more common among men (44%), for those up to 80 years of age (50%–71%), for married persons (50%) and persons born outside Sweden (40%). A similar situation (i.e. not receiving any home care services) was found for those individuals living in Östergötland (36%) and Västerbotten (38%), those living in a medium/small municipality (38%) and in rural municipalities (40%). We found from the multiple logistic regression model that receiving no home care services was associated with age and decreased with higher age and being unmarried.

Home care services were granted more often and increased with age, and unmarried persons had significantly more home care services, as well as persons with dementia living in larger municipalities. The two most common types of home care service were home help and personal care (41%), and safety alarm (29%); only 14% of the individuals were granted day care services. We found some gender differences; women were granted home help and personal care at a higher level compared with men (OR = 1.32), as well as safety alarms (OR = 1.27). On the other hand, a greater proportion of men were granted

short-term and respite care than women (OR = 0.66). Those individuals who were unmarried were more likely to be granted home care services than married persons in terms of home help and personal care (OR = 3.80), safety alarms (OR = 3.03), meals on wheels (OR = 3.30) and day care services (OR = 1.29). Surprisingly, we found that individuals born in a country other than in Sweden were more likely to be granted safety alarms (OR = 1.50), meals on wheels (OR = 1.29), and day care services (OR = 1.34) than native-born Swedes. We found from the multiple logistic regression model that the size of municipalities had an impact on the care services granted. In large municipalities, day care services were more frequent (OR = 1.00) compared with rural municipalities (OR = 0.61). Special housing (28%) was also more common in rural municipalities (OR = 1.50), but less in the Stockholm (OR = 0.52) and Västerbotten (OR = 0.63) compared with Östergötland (OR = 1.00).

6.1.2. Study II: “Overjoyed that I can go outside”: using walking interviews to learn about the lived experience and meaning of neighbourhood for people living with dementia

The aim of this study was to investigate the lived experience of the neighbourhood for people with dementia and through this, to better understand the meanings that neighbourhood held for the participants. From analysis of the walking interviews, four themes were developed: life narratives embedded within neighbourhood; the support of selfhood and well-being through movement; the neighbourhood as an immediate social context; and restorative connections to nature. The essence of these themes was revealed as: “A walkable area of subjective significance and social opportunity in which to move freely and feel rejuvenated”.

In the theme “life narratives embedded within neighbourhood”, the participants showed us places embedded in the neighbourhood that were linked to events from their life and personal history. Walking helped to embrace these life narratives when moving during our conversations between past, present and future.

The theme “support of selfhood and well-being through movement” revealed that walking as a movement through the neighbourhood was essential for the participants in maintaining their mind and body and supporting well-being. The walks were part of their day-to-day activity that helped to manage a life with dementia.

In the theme ‘the neighbourhood as an immediate social context’, the neighbourhood was expressed as a social context where participants could meet, chat or wave (also from indoors) to someone in the places and spaces that surround their home. Those participants living alone revealed that their social contacts were mainly staff working in municipal home care and for those living in couples, the partner was a primary source for social contact. Walking was a resource to stay connected and active for the participants living with dementia.

In the theme “restorative connections to nature”, connection to nature and being outdoors were restorative practices for some participants and that included walking. They sought out green spaces and natural beauty and the less busy parts of the neighbourhood. The restorative connections to nature symbolized hope and a chance to escape from home. From these four themes, the essence was found to be a walkable area where people with dementia could find freedom to move, which supported a sense of autonomy and control over their lives but also to escape the isolation associated with their home life.

6.1.3. Study III: “It’s our pleasure, we count cars here”: an exploration of the “neighbourhood-based connections” for people living alone with dementia

The aim of this study was to explore the experiences of people living alone with dementia in a neighbourhood context. From the analysis, four main themes emerged: making the effort to stay connected; befriending by organizations and facilitated friendships; the quiet neighbourhood atmosphere; and changing social connections.

From the theme “making the effort to stay connected”, participants across all three field sites addressed their efforts to stay connected to the neighbourhood by creating new ways of maintaining social networks and relationships. Some participants made plans for spontaneous encounters in the neighbourhood due to the social loss of contact with family, friends and neighbours often due to the stigma associated with a diagnosis of dementia.

In the theme “befriending by organizations and facilitated friendships”, befriending by organizations was revealed to be an important buffer against isolation. By participating in several activities provided in the United Kingdom by third-sector and charitable groups, and in Sweden by the municipalities, bonds of friendships were created. Despite such differences, it was clearly indicated that befriending from organizations helped many participants to avoid loneliness and depression.

In the theme ‘the quiet neighbourhood atmosphere’, many of the participants commented that they felt some arenas in the neighbourhood were too quiet which caused insecurity during some periods when there were no people in sight. To see people outside increased a neighbourhood connection and helped sustain a sense of neighbourhood identity.

In the theme “changing social connections”, the impact of stigma surrounding dementia was highlighted by participants, which caused experiences of involuntary solitude or loneliness. Many social connections with friends and others had disappeared due to dementia. However, participants took control over their lives by searching for new daily social connections in the neighbourhood and were by no means passive in the face of the challenges in their everyday life. Some participants expressed positive experiences of being alone. They wanted to be alone to have opportunities for privacy and a sense of freedom.

6.1.4. Study IV: “Just treat us for the person we are, not for the disease”: a dementia-friendly initiative for an inclusive local community from a health-promoting perspective

The aim of this study was to explore lived, personal and professional experiences related to dementia in the local community from a health-promotion perspective. The analysis of semi-structured individual and group interviews revealed four themes: health promotion through knowledge and awareness; the importance of being active for health and well-being; the value of meeting places in public spaces for health promotion; and health-promoting improvements in the welfare system.

In the theme “health promotion through knowledge and awareness”, the participants with lived experiences of dementia observed how society had preconceived ideas about dementia. This could affect them in a negative way; they were not respected as active citizens with their own resources or with respect in the community. Negative attitudes and lack of awareness of dementia was something that participants with personal and professional experiences of dementia also acknowledged. To increase the awareness of dementia in the society, some suggestions on interventions were given, such as exhibitions and workshops about dementia in local public spaces.

In the theme “the importance of being active for health and well-being”, the participants with varied experiences of dementia shared with us the importance of having opportunities to be active every day, both physically and socially. Participants noted the value of having activities such as walking outside or being socially active in a group for people with lived experience of dementia.

The theme “the value of meeting places in public spaces for health promotion” revealed the value of social participation in public spaces, for example, libraries or parks, to maintain a social role in the community. Such opportunities for engagement were described as essential for those living with dementia. The participants commented on how they wanted to see the local community become more inclusive for everyone, not only for those living with dementia. The need for more benches in public spaces was highlighted by the participants with personal and professional experiences, which could lead to new social contacts.

In the theme “health-promoting improvements in the welfare system”, some participants with different experiences wanted the day care centres and teams to be more centrally involved in person-centred care and health-promoting improvements. These were some of the changes they wanted to see in relation to planning for inclusive “dementia-friendly communities”.

6.1.5. Study V: Task shifting in municipal home care from the perspectives of registered and specialist nurses in Sweden: a qualitative study using shadowing

The aim of this study was to explore and characterize task-shifting processes in competences, responsibilities and roles from the perspectives of registered and specialist nurses in municipal home care. In this study, four themes were revealed from analysis of the shadowing: the black box in the health care system; alternative solutions in the workplace; a profession on the edge of change; and transfer of tasks towards the neighbourhood.

In the theme “the black box in the health care system”, the registered and specialist nurses struggled with the commonly held view of their role and their workplace within the health care system, interpreting it as being invisible, as if placed in a black box.

In the theme “alternative solutions in the workplace”, observations from shadowing showed that there was a lack of fundamental health care resources needed to perform nursing tasks. The registered and specialist nurses had to find new solutions to maintain their work and to provide the best care they could for patients living at home and in the neighbourhood.

In the theme “a profession on the edge of change”, participants expressed how their profession was on the edge of change because more of their tasks and responsibilities were shifting to assistant nurses, neighbours and family members. The participants were in some sense downgraded in their profession, and there were few who expressed appreciation for their role and competences.

In the theme “transfer of tasks towards the neighbourhood”, we found that the socio-economic level of the municipality, neighbourhood and inhabitants had an impact on what specific tasks were shifting. In neighbourhoods where the socio-economic levels were low, the participants had to help to a higher degree with basic tasks such as cleaning an apartment with the patient’s adult children. The registered and specialist nurses identified that they were part of the neighbourhood and neighbours and families were part of municipal home care because they often helped out, for example, with medication.

6.2. Overall representation of the findings and discussion

The findings of this thesis have been integrated into a combined analysis based on the five studies to arrive at an overall representation of the findings. The thematic analysis revealed five main themes: walkable attachment to the lived neighbourhood; daily activities promote health and well-being; opportunities for social connections; just treat us as active citizens; and neighbourhood: a place for practice. The main themes are presented as squares and sub-themes are circles in Figure 4.

Figure 4. Presentation of the five main themes

6.2.1. Walkable attachment to the lived neighbourhood

Belonging to the neighbourhood was essential in supporting a person's identity, sense of self and well-being (studies II, III and IV). Connections between the place of dwelling (home) and the neighbourhood were important, such as seeing people outside through the window and/or balcony as shown in Figure 4A (studies II and III). The visual link of observing the neighbourhood (from the balcony and/or window) in the moment created a sense of belonging to the lived neighbourhood where life and movement were ongoing (study II). A body of research aligns with these findings and has also shown that windows were resources that upheld a sense of belonging to the wider world outside, for example, by getting a smile through the window for older people (Coleman & Kearns, 2015; May & Muir, 2015; Musselwhite, 2018) and for people living with dementia (Ward et al., 2018). To see other people moving and interact with them creates meaning, especially for people living with dementia (Ashworth, 2006). It was especially important for those participants living alone with dementia, as for Alma, who commented that her window supported a connection to the outside world and kept her sense of loneliness away for some time:

Look what a nice view I have. And I can see everyone who goes to the day care centre. But I can also see those who are walking and shopping; it may seem a bit curious. (Alma, Sweden; study III)

The analysis also indicated that places were embedded with life stories, social connections, memories and culture, which were linked to the lived neighbourhood through routine movements (studies II, III and IV). The daily journeys to open meeting places, to shops or to walk the dog were built on continuity and a sense of self in both time and place (studies II, III and IV).

6.2.1.1. *Neighbourhood belonging through embodied connection*

The connection between people's life stories and significant places linked to memories were driven by movement through the neighbourhood. Participants had bodily knowledge "in the legs" (Merleau-Ponty, 1962) as an embodied connection to places and further enhancing a cognitively focused sense of attachment (studies II and III). These findings are in line with Wunderlich's (2008) and Grenier et al. (2019) research, which argued that through walking, a sense of attachment to places grows and it becomes our way of engaging with the world as an embodied practice. In our study, we found that an embodied attachment to the neighbourhood helped participants to recall life stories of importance that were built over time (studies II and III). This type of attachment was supported by an intentional act (Merleau-Ponty, 1962) that the participants with dementia performed through their perception of the world. It was always directed towards something, such as going to places from the past and in the present as Lennart and Yngve did by walking to a local cemetery and an old mechanical factory. Both Lennart and Yngve had work-related connections to these places (study II):

We have the church there, you see up there by the clock yard, where he lives; he (former working colleague) has an overview of the neighbourhood. I know most people who are in the cemetery who have lived ... and worked with me. (Lennart, Sweden; study II)

The house there was a mechanical factory, where that car is standing. There used to be three companies, but now there's only one company left. There are new buildings all over there ... (Yngve, Sweden; study II)

The intentional act by Lennart and Yngve had a meaning and told us about their experience of something that was important for them and kept them in close connection with the neighbourhood. Their lived experiences of meaningful places in the neighbourhood emerged through bodily knowledge in relation to such well-known places (Merleau-Ponty, 1962). Beyond the biographical path, for Lennart, Yngve and others, it was actually the power of free movement that reinforced how people with dementia took control of their lives and created a sense of autonomy that they lived for in their day-to-day lives (studies II, III and IV). Some participants with dementia had to have help from staff working in home care to go outdoors, and the opportunity to walk around in the neighbourhood was important for them in everyday life (studies II and

IV). Through this movement of their bodies, they could hold on to the neighbourhood as an expression of holding on to the world.

A sense of attachment to restorative places helped with self-confidence and taking control of dementia (studies II and III). Hence, green and natural spaces in the neighbourhood were sought out as offering a sense of freedom, away from the quiet home, where connections with people and nature in the neighbourhood could be created (studies II and III), as outlined by Anders and Fanny:

It's easy for me to go out into nature, I love it and I will always do it. I'm happy and overjoyed that I can go and stay outside. When I go out, I can find red clover and everything in nature. (Anders, Sweden; study II)

Then one always meets someone one can talk to ... but I am out sometimes, and there are [usually] a few people around. (Fanny, Sweden; study III)

These quotes indicate that just meeting other people in the neighbourhood or seeing people outdoors while walking decreased a sense of loneliness (studies II and III). In the neighbourhood, even the staff working in municipal home care encountered emotional and multi-sensorial engagements in places through their bodily movement (of daily visits) (studies IV and V). There was a connection between people and places because of the freedom to move the body in the neighbourhood (studies II, III and IV). It was obvious that walking allowed for social encounters to support the sense of self, helping to counterbalance the challenges of cognitive decline by the interaction between the body (legs) and the world (neighbourhood) (studies II, III and IV).

6.2.2. Daily activities promote health and well-being

Across all four qualitative studies (studies II, III, IV and V), the participants shared how walking and physical activities strengthened the sense of self and movement of the body for those living with a dementia diagnosis. This highlights how people living with dementia need to have opportunities to exercise the body (studies II, IV and V) in order to share their lifeworld with us through their bodily movement in the neighbourhood. For instance, activities such as walking and exercise were reported to support memory and well-being (studies II, III and IV). But for Simon, caring for a bird's nest in the garden everyday was essential to him, something that he did every day to maintain his well-being, which had connections to his interest in nature (Figure 4B, study II).

Some participants commented on how important walks were for their health. Ingvar, for example, had been living with Alzheimer disease and vascular dementia for 2 years when the interview took place, but he also had other health issues that required him to use a walker. Ingvar was 62 years old, had lived alone in the same flat for the last 20 years, in the same neighbourhood where he had grown up. Ingvar refused any help from home care; his son was helping him instead with errands and finances. During the interview, Ingvar showed us his kitchen window where he could see his former school, and he recalled some history about his mother that motivated him to write poems and other texts

during his youth. Hence, Ingvar had become an author and loved writing and reading poems; he continued writing despite his diagnosis. In the interview context, Ingvar drew particular attention to the importance of movement when living with dementia, as recommended by his doctor at the hospital:

I go out almost every day because my doctor has said that being around people, having the same routines every day and walking is good for my brain. ... I take control over myself then, and it has got much better. (Ingvar, Sweden; study II)

Other, not only Ingvar, shared their engagement for walking and as a way to remain in good health (studies II and IV), because through walking they were using their bodies and were connected to the meaning of being in the world with others. For example, both Berit and Margaret, two women living alone with a dementia diagnosis, had experiences of participating in group activities and exercise organized by the day care centre or a third party. They shared their experiences of staying active as something essential for well-being and health (studies III and IV):

I go to a group that Philip [son] ... he knew the fella who ran it ... I was only there last week. They had a dancing session last week when I went. It is good for your brain, and they're all very friendly. (Margaret, England; study III).

... In the morning, the first activity is to go shopping. Later, it's time for some gymnastics (Keep Fit) where we sit on a chair and do some exercises, and then gymnastics again in the afternoon, so Tuesday is booked. (Berit, Sweden; study IV)

These descriptions from Berit and Margaret indicate the value of being active where both body and mind can be engaged (studies II, III and IV). This indicates further that people with lived experience of dementia wanted and often had weekly activities; for example, participating in a choir, cycling to the supermarket or going out with the dog several times during the day to maintain health and well-being. These activities were strategies that people with dementia performed as active agents with their own resources to promote their health, that is, self-management of the condition.

6.2.2.1. *Keeping both mind and body in shape*

Not all participants had the capacity to arrange activities by themselves; some of them had a carer, children or partner who arranged activities to secure their well-being and independence (studies III and IV). Jennifer shared her experience of being a carer for her mother with dementia, who lived alone in a flat. For Jennifer, it was important that people with dementia had opportunities to take part in activities that supported them both physically and psychologically:

... To have opportunities to train skills, both physically and mentally ... Physical activities are very important for those living with dementia who

have the capacity to participate in these activities. (Jennifer, Sweden; study IV)

It was not only Jennifer who recounted the importance of physical activities and emphasized that a person's resources and needs have to come first when living with dementia. Guell, Shefer, Griffion, and Ogilvie (2016) has also shown the importance of keeping the body and mind active by walking as daily practices of active living among older people. Astrid shared with us how a health-promotion perspective is missing when people were talking about dementia in the context of it being a public health issue (study IV):

...We also want to eat well and exercise to keep our minds and bodies in shape... people with dementia can do so much to be healthy but we just need to start speaking about this and for ourselves... (Astrid, Sweden; Study IV)

Here, Astrid draws on her own lived experiences of dementia; she describes a stigmatizing attitude from others towards dementia that focuses only on problems, not on how you could live well with dementia (study IV). The voices of people living with dementia are often not heard in society due to stigma and low awareness of dementia and a failure to appreciate people's capability to take control and care for their own health and well-being (studies II and IV). Our participants expressed a need for public education about dementia where all citizens come together to work for health-promoting strategies in the neighbourhood and society, which could be further developed in initiatives for dementia-friendly communities (studies II, III, IV and V).

6.2.3. Opportunities for social connections

Most of the participants with lived experience of dementia in this thesis were living alone (without a co-habiting partner/children/next of kin) (studies I, II, III and IV) and in a one-person household (studies I, II and IV). This is in line with the results of study I where we found that 52% of 17,405 people with dementia in Sweden were living alone. Despite this expanding number of people living alone with dementia, there were few open public spaces to escape from isolation in the local neighbourhood (studies II, III and IV). Anna was one of the many participants who took her own action for spontaneous encounters. At the time of the interview with Anna, she had lived with Alzheimer disease for 6 years. Anna was 78 years old and had lived alone in a flat on the third floor with an elevator for the last 2 years. Anna commented to us that she had moved to the new flat just so that she could go out when she wanted. Anna enjoyed her walks in the neighbourhood with her walker as she actively tried to find new social contacts and just to meet someone to have a chat with. Hence, Figure 4C illustrates Anna's meeting point with benches, where Anna would sit and watch the cars during the summer:

...This summer was too long, then it [seating area in neighbourhood] almost becomes a small meeting point for pensioners. It's our pleasure, we count

cars here. I can sit here for a while and sometimes there's nobody to talk to, sometimes there is someone that I can talk with. (Anna, Sweden; study III)

It was not only Anna who appreciated the benches; other participants both with lived and professional experiences described how they wanted more benches in the neighbourhood (studies II, III and IV). Social attachment to the neighbourhood often starts while sitting on a bench that provides opportunities to meet and chat with the person beside you (studies II, III and IV). The benches were not just a resting spot, they were a way to be included in the social world of others, as for Anna. Other studies have also found that benches created opportunities for social connections between citizens in the communities and a place for social engagements between citizens (Cao, Heng, & Fung, 2019; Ottoni, Sims-Gould, Winters, Heijnen, & McKay, 2016).

Many participants in the three field sites experienced the challenge of finding new friends and being included in well-established social networks (study III). They made efforts daily to stay connected with existing friends and to establish new ones, as a response to their depleted social networks (studies II and III). Some participants such as Anna, Fanny, Fredrik and Charlotte had only lived in the neighbourhood for a few years; they observed that it was challenging to find new friends or meeting places where they could create new social contacts because many residents already had well-established social relationships (studies II, III and IV). In addition, contact with old friends and even members of the family had decreased following a dementia diagnosis (studies II, III and IV). Hence, they took every chance they could to seek out social meeting places where they could find someone to meet and chat with (studies II and III), as June did to keep the relationship going with her friends:

I can still go out like ... Well, my friends come. We go to [local venue] and we sometimes have a pub lunch. (June, Scotland; study III)

Participants described how popular public spaces or different clubs in the neighbourhood offered opportunities for meeting people and to avoid being alone (studies II, III and IV). These public spaces, including cafés, parks and pubs, were essential for people living with dementia and gave them the chance for spontaneous encounters (studies II, III and IV). Mike made daily visits to a café near his home just to drink his morning coffee and to meet some old friends. Mike shared with us how he appreciated chatting with the owner of the café: "He always has a chat, but he's quite funny at times." (study III). Such daily opportunities for encounters with staff or others were much fewer in Sweden; meeting places in the neighbourhood where people could have a chat outside are often limited in Sweden because of the cultural tradition to invite people into your home (studies II, III and IV).

6.2.3.1. Accessible meeting places support social inclusion

Throughout the interviews, the importance of accessible meetings places where people with dementia could maintain a social role in the neighbourhood was highlighted

(studies II, III and IV). Places such as libraries or parks where social participation could be established were important to help mitigate the quietness in the neighbourhood for those living alone with dementia (studies III and IV). There were few outdoor and accessible meeting places that were publicly funded in the Sweden. This indicated that people living with dementia had to rely on others to participate in social activities to maintain their well-being (studies III and IV). For example, the day care centres or others types of support could help, but in most cases this was initiated by the participants living with dementia themselves (studies II, III and IV). In the United Kingdom, third-sector and charitable groups increasingly organize activities for people with dementia and not the public sector as in Sweden, where support is mainly from the local municipalities (study III). Doris and Mike, two of the participants, told us how the day care centre and a support worker from a charitable organization saved them from social isolation, depression and the loneliness they felt after being diagnosed with dementia:

I'm happy about [the day care centre] because it has saved me. I was terribly alone a lot and I can honestly say the day care centre was what saved me.
(Doris, Sweden; study III)

I found out about it when I got my diagnosis. They gave me a leaflet and gave me a number to ring. Linda from [charity] came and took me to the book club that is run by [the organization]. They are a really important part of my life now. (Mike, England; study III)

These initiatives offered the participants a chance of social inclusion and acceptance of the person they were, which led to inclusion in different social networks and participation in open public spaces. The day care centre provided social opportunities that many participants such as Doris described, but few people with dementia were granted this service from the municipalities (studies III). Only 14% of 17,405 people living with a dementia diagnosis were granted day care services with a place at a day care centre (study I). This highlights the need for more open public places where all residents irrespective of age could meet in the neighbourhood setting, to exchange experiences and find new social contacts (studies III and IV). There were few opportunities to build prolonged relationships over time because of the lack of social awareness of what a dementia diagnosis meant (studies II, III and IV). This was highlighted by Rebecca, who was a social worker in one municipality:

Instead of [the municipality] closing every open meeting place [in public spaces], people with dementia should be given opportunities to come out into the neighbourhood so that they can boost their well-being and use the public places to meet people. (Rebecca, Sweden; study IV)

Social inclusion in public places gave opportunities for a sense of connection between neighbours, and others such as staff from municipality home care, which built up over time and improved the well-being of people living with dementia (studies II, III, IV and V). There were some differences between the field sites regarding supportive

neighbouring (study II). However, the main message from the participants overall was that more open public meeting places where all citizens could be included on their own terms should be established in the neighbourhoods (studies II, III and IV).

6.2.4. Just treat us as active citizens

Stigma and lack of awareness of dementia were underlined in the dialogue we had with people with diverse experiences of dementia, which had an impact on social inclusion such as working from a health-promotion perspective (studies II, III and IV).

Participants with lived experience of dementia described how they were not included in debates in society or in social circles as a result of the low level of awareness of dementia. They were not treated as active citizens with their own resources in the neighbourhoods or in wider society from the moment they received their dementia diagnosis. Astrid commented on this stigmatization of dementia during a walk by showing with her whole body how upsetting this was, as illustrated in Figure 4D:

In general, I feel that people must respect us a bit more, we're not stupid...
Just treat us as the person we are, not for our condition. (Astrid, Sweden;
study IV)

It was not only Astrid who indicated this negative view of dementia in wider society (studies III and IV). Vera, a nurse, stated that there was a low level of knowledge about dementia not only in society but even in the home care service because home care visits have been reduced irrespective of diagnosis:

All the patients have had their time reduced. But it's not specified precisely
for people with dementia; some patients with dementia don't even register
that we've entered their home until we're gone. (Vera, Sweden; study IV)

More inclusive neighbourhoods and/or communities have to be established from a health-promotion perspective with a focus on the needs of people with dementia (studies II, III and IV). The policy discourse of practice has shifted to citizenship and inclusion where people living with dementia are involved in decisions in society (Swaffer, 2014) and being a part of their neighbourhood as active citizens (study IV). Van Wijngaarden, Alma, and The (2019) report similar findings where people living with dementia expressed a lack of inclusion in society and wanted to share their experiences and dementia journey with others. There should be interventions where education about dementia is offered in outdoor and accessible places for health care and nursing staff to increase awareness about dementia and decrease isolation among those living with dementia (studies II, III and IV).

6.2.5. Neighbourhood: a place for practice

Finally, the neighbourhood was not only described as a walkable, social and citizenship arena in the context of dementia, it was also a place where practice was ongoing around

the clock (studies II, III, IV and V). Figure 4E shows an image of this, where the place of municipal home care is sited within the neighbourhood just by looking out from the staff kitchen. The participants with personal and professional experiences of dementia, such as the nurses from municipal home care, saw themselves as part of the neighbourhood along with people with dementia and other community-dwelling individuals (studies IV and V). Many of the participants had no help from home care or municipality home care; instead, carers, children, family or neighbours provided care and helped out with errands (studies II, III and IV), which is in line with the results of study I. More and more of the tasks performed by health care and nursing staff were shifting over to residents in the neighbourhood (studies III, IV and V). Hence, neighbourhood characteristics played a significant role when it came to building trust among the residents. Neighbourhoods that were lacking resources had a lower social trust in society and needed more help with basic tasks for registered and specialist nurses than neighbourhoods that were affluent (study V). Fewer people living with dementia in rural areas had any home care services compared with those living in medium-sized areas (study I). In addition, in neighbourhoods with higher socio-economic resources, there was a higher degree of social trust between the nurses and residents. Zahra, one of the district nurses (specialist nurse) from municipal home care who worked in a neighbourhood with a high level of socio-economic resources, pointed out during one of the shadowing occasions:

Out here in the countryside, usually the families and/or neighbours helped if the patients were unable to go out by themselves to buy their medicines from the pharmacy, so that differs from the city. (Zahra, Sweden; study V)

The place for practice was out among the residents living in the neighbourhood (studies II, III, IV and V). There was a dialogue on day-to-day actions and sociability that took place between home care, municipal home care and third-sector organizations providing support to people living with dementia. This points to new opportunities to work more in the spirit of neighbourhood nursing where citizens with their own resources contribute to promoting and increasing good health and well-being in the neighbourhood.

7.CONCLUDING DISCUSSION

In this final chapter of the thesis, the principal findings are discussed and linked to neighbourhood as an everyday place for people with experiences of dementia, as well as a place for practice. The findings of the thesis are discussed in relation to other research studies, and messages for education, policy, practice and future research are identified. Finally, methodological issues are considered, the limitations are outlined and the conclusion to the whole thesis provides an endpoint.

The aim of this thesis was twofold. The first was to explore neighbourhood as an everyday place for people with experience of dementia. The second aim was to explore neighbourhood as a place for practice. Returning to the questions presented in the introduction: Is the classification of dementia according to Woods (1989) still relevant? How can we work together with people living with dementia to develop inclusive local communities where their voices are heard and citizenship is considered essential? How can we increase awareness about dementia in our neighbourhoods? How can we as nurses create a new practice paradigm for neighbourhood nursing together with the citizens?

7.1. The neighbourhood as an everyday place for people with experience of dementia

The main findings from this thesis have shown what meaning the neighbourhood holds for people with experience of dementia in the context of their everyday lives. People living with dementia connect to the neighbourhood through lived experience that emerges, in part, by walking and moving the body in the neighbourhood setting. In this way, people living with dementia maintain connections to people, places and wider social networks. Connection to the lived neighbourhood has been highlighted within ageing and dementia discourse, but also by Ward et al. (2018) who found that people living with dementia shape the places where they live by being connected to others in the neighbourhood. This is in line with the findings from this thesis and adds new knowledge by presenting the perspective of people living alone with dementia (studies I, II, III and IV). Most people with dementia were living alone in the sample recruited for this thesis (studies II, III and IV); about 52% of a population of 17,405 people with dementia in the three county councils of Östergötland, Stockholm and Västerbotten were living alone (study I). This increasing population of (mainly) older people living alone with dementia has also been acknowledged in the United Kingdom, Canada, France and Germany (Alzheimer's Society, 2013; Ebly, Hogan, & Rockwood, 1999; Eichler et al., 2016; Nourhashemi, Amouyal-Barkate, Gillette-Guyonnet, Cantet, Vellas, & REAL.FR Group, 2005). However, there is limited knowledge about everyday life in the neighbourhood and how people manage their lives and what matters to them.

A number of studies have highlighted that female participants living alone with dementia expressed a sense of loneliness in the daytime more than men (deWitt, Ploeg, & Black, 2009; deWitt, Ploeg, & Black, 2010; Frazer, Oyeboode, & Cleary, 2012; Lloyd & Stirling, 2015; Svanström & Sundler, 2015). This thesis confirms that a sense of loneliness and solitude was more common among women (studies II and III) especially during the daytime. People living alone with dementia that we spoke to wanted to see more opportunities for social interaction in public places, such as in libraries or parks, to help mitigate the quietness in the neighbourhood (studies III and IV). Overall, the participants wanted more open public meeting places where all citizens could be included and to share a talk or walk together (studies II, III and IV). The power of social interaction as pointed out by our participants (studies II, III and IV) and by Hand and colleagues could improve the agency of older people (Hand, Laliberte Rudman, Huot, Pack, & Gilliland, 2018). In dementia-friendly community initiatives (Alzheimer's Disease International, 2016), there needs to be more focus on people living alone with dementia because this population is increasing and the meaning of being together with others in social networks has to be better understood.

People living with dementia shared their awareness of everyday stigma. After being diagnosed with dementia, many people came to realize that other people had low levels of awareness of dementia (studies II, III and IV). This is in line with earlier research in which Haapala, Carr and Biggs (2019) and Phillipson et al. (2018) argued that awareness of dementia has to start in local communities where people live and that more interactions with people living with dementia is necessary. Olsen and colleagues argued that the media has an important role to play in terms of the type of messengers that are communicated through newspapers and television; all too often people living with dementia are not presented in the mass media (Olsen, Taylor, Whiteley, Ellerton, Kingston, & Bailey, 2019). As our participants living with dementia expressed, they are not treated as active citizens with their own resources in the neighbourhood. Increasing the awareness of dementia in the neighbourhood has to start with everyday citizenship where people living with dementia and other citizens are creating interactions through conversations, written text or walking together (Nedlund, Odzakovic, Hellström, & Kullberg, 2019). Through everyday social interaction with the wider community, people with dementia can raise awareness and understanding of the condition.

7.2. Neighbourhood as a place for practice

Neighbourhood is a place for practice, where care is provided during all hours of the day (studies II, III, IV and V). Approaching the neighbourhood as a place for practice is not an entirely new way of thinking in Sweden within the context of the caring sciences. However, previous studies have largely focused on aspects of health and disease, not the wider context of the lifeworld of patients (Dahlberg, & Dahlberg, 2019; Dahlberg, Dahlberg, & Nyström, 2008; Ekebergh, 2007). The findings from this thesis highlight the limits of this existing body of research. In studies IV and V, we found that

professionals working in the neighbourhood and people receiving municipal home care saw neighbourhood as a place for dialogue and sociability. However, to date, there has been little theorizing or discussion in the nursing literature in Sweden that has focused on the importance of neighbourhood, despite it offering a life-long setting for people to reside and the potential to age in place.

In recent years, neighbourhood characteristics have been found to be important to build trust between citizens and for their well-being (Pasanen, White, Wheeler, Garret, & Elliot, 2019; Wheeler, White, Stahl-Timmins, & Depledge, 2012). To date, few studies have explored the connection between neighbourhoods and practice. This thesis adds new knowledge to the extant research by showing how levels of socio-economic resources are important for neighbourhood nursing (studies II, III and V). For example, the participants in study V described how, in rural areas and in neighbourhoods with higher socio-economic resources, neighbours and family helped out with errands as a result a higher degree of social trust between them. These findings are in line with an earlier study by Sampson, Raudenbush and Earls (1997), which also found that neighbourhoods with a clear social organization led to a collective efficacy that had a positive impact on social trust.

These aspects of neighbourhood are important to consider when developing a formal model for neighbourhood nursing; as Cumberlege (1986) argued, nurses need to have knowledge about the neighbourhood. Reinhard et al. (1996) also argued that the neighbourhood is a part of the person, family and community. Despite this, little attention has been given in education, practice or research in Sweden regarding the potential and role of neighbourhood nursing. In recent years, awareness and discussion about the challenges in providing evidence-based care outside the hospitals have been raised in Sweden (SOU, 2016:2). According to the Swedish Government Official Report, good local care should be available in primary health care and municipal home care based on teamwork between different health care professionals (SOU, 2018:39). It is timely to shift care towards a neighbourhood nursing model, not only because of global ageing, which has affected Sweden, but also because 25% of all health care is provided by the municipalities (National Board of Health and Welfare, 2019b). Knowledge from this thesis can be applied, together with the different actors in health and social care, to help accomplish this. Crucially, all citizens, including older people living at home and people living with dementia, need to be a part of the planning process.

By way of comparison, in the Netherlands, a form of care has been established called “care in the neighbourhood” whereby community nurses are working within geographical areas with small numbers of patients and are supported by multidisciplinary teams (Drennan, Calestani, Ross, Saunders, & West, 2018). This model has many similarities to the original model of neighbourhood nursing (Cumberlege, 1986) but has a different approach to district nursing. The Dutch model can be an inspiration for a similar model in Sweden, and this thesis thereby informs the development of a neighbourhood nursing perspective from the dementia context. In particular, it has underlined how differing relationships can be forged at a local level through walking and movement, leading to a higher awareness of the meaning of neighbourhood. However, the professional education

of registered and specialist nurses also has to consider the direction of future development. Perhaps it is time for a new profession in nursing, with municipal nurses working in the neighbourhood together with the citizens and small teams with patients and professionals?

8.METHODOLOGICAL CONSIDERATIONS

Validity and reliability are discussed in study I as a result of the quantitative methodological approach. In the qualitative studies (studies II, III, IV and V), Lincoln and Guba's (1985, p. 289-331) criteria for credibility, dependability, confirmability, and transferability for trustworthiness are discussed in connection to the research process.

8.1. Validity and reliability (study I)

The definition of validity in study I refers to the extent of careful construction of the data from regional databases with medical care records and register data to ensure that the data actually measures what it is intended to measure. Reliability indicates the extent to which the database on home care services and housing can reproduce the same results two or more times under equal conditions (Gallestey, 2008). These two concepts of validity and reliability have been addressed during the research process of study I.

First, the cross-sectional design of study I was used to gain deeper understanding of the home care services and housing for people living with dementia. By using a cross-sectional approach, comparisons between groups of those not receiving any home care services, compared with those who were granted home care services, were possible. The data present in study I were based on valid sources that build on high-quality available data. Next, one of the strengths of study I was that data presented were based on valid information on inpatient, outpatient, and primary health care events where a dementia diagnosis was noted in the patient medical record during 2012 in the three county councils. Other strengths were that the data were based on the 10-figure personal identity numbers for each unique person in the cohort of 17,405 people, which were sent to Statistics Sweden and then matched in the Register of Total Population (to sex, year of birth, marital status, and country of birth in 2012). These strengths together provide a security that the data are valid and reliable. Statistics Sweden, a government agency that delivers official statistics, has been included in the process of the databases.

In general, the validity of the data based on home care services available in the National Register of Care and Social Services for elderly and for persons with impairment can be questioned, which is also described in the report (National Board of Health and Welfare, 2012, p. 11). In the report, the 290 municipalities report on all home care services on 1 October 2012 (one day); however, there is a chance of a measurement error between their reported value and the actual value. This difference may be based on the person who is reporting on the home care services from the municipalities; for example, s/he could categorize meals on wheels as home help. However, as acknowledged in the

National Register of Care and Social Services for older people and for persons with impairment (National Board of Health and Welfare, 2012, p. 11), this is currently the onlyway to gain any reliable data because of the character of the data reported. For instance, it was not possible to obtain a measurement of home help hours because of errors in reporting from the municipalities. Despite this, the register offers important information on home care services and housing, which is essential knowledge when exploring the neighbourhood.

Differences between the county councils were also found regarding underdiagnosis of dementia in Östergötland from the data provided in study I and the official estimated prevalence of dementia. Results from these measurements indicate that only 36.9% of the estimated prevalence of dementia in Östergötland was identified, which demonstrates the extent of underdiagnosis.

8.2. Trustworthiness (studies II–V)

8.2.1. Credibility

In the context of this thesis, credibility is defined as a way in which the experiences of dementia from an everyday place such as the neighbourhood is central. The lifeworld of the people we have interviewed and shadowed is their true world and by that, credibility can be achieved. The first criterion, credibility (Lincoln & Guba, 1985, p.301-316), was achieved over several phases to present confidence in the truth of the data. First, the different methodological approaches used in studies II, III and IV included several contacts before conducting the interviews. This approach to conducting interviews established a relationship of trust between the participants and researchers. In study V, the researcher also followed participants (5 of the 18 participants) twice to explore further the organization and task shifting. Second, by working closely with the participants and doing interviews at home, in the neighbourhood and in different organizations in municipality home care, credibility was achieved by a prolonged engagement and familiarity with the phenomena (Lincoln & Guba, 1985, p. 301–305), and understanding of the neighbourhood was established.

During the period of data collection (studies II, III, IV and V), the researcher built up trust with the participants and/or their carers (studies II and III) and with a curiosity about the context to learn more of their neighbourhood through the walking interviews (studies II and III), multiple data collection methods (study III), semi-structured individual and group interviews (study IV) and shadowing (study V). These different methodological approaches allowed the researcher and the participants to share the “power” of the research context by sharing the same world of the neighbourhood. Each of the interview approaches was selected carefully to explore the phenomena and the aims and research questions. One innovative method to explore the local community, as in study IV, is the use of walking interviews with individuals or in groups, to capture the experience of the neighbourhood. The researchers were present in place along with the

participants, which became more of a talk and walk than an interview, and from this a connection was built based on equality and trust in the research process. During the walking interviews, the participants became more secure and free in their body language; they talked more and took the initiative to show places in the neighbourhood. The movement of the body gave people living with dementia “power”, and they were less threatened than if they had been interviewed face to face at home.

Through this combination of qualitative methods, the data were triangulated (Denzin, 1978; Lincoln & Guba, 1985). The analysis of the five studies was helpful in meeting the overall aim of the thesis as a result of the credibility of the data and the mix of both qualitative and quantitative approaches developed from different countries and research projects (Lincoln & Guba, 1985, p. 306).

In the process of analysing the data, the author of this thesis has kept close to the data in all four studies (studies II, III, IV and V), along with debriefing with co-authors and supervisors with many years of experience in dementia research, to arrive at a clear judgement and credibility of the data (Nowell et al., 2017). According to Lincoln and Guba (1985, p. 308), it is of value to have reflections and debriefing with others in the research group or others not included in the team to present an “honest” account of the data. This has been accomplished in this thesis by presenting the data to others at conferences and other occasions in the community to be sure that the data are of good quality and free from the emotions and feelings of the researchers. To achieve credibility in the phenomenological study (study II) as in studies III and IV, the interviews were conducted by several researchers and in other field sites, which results in a broader and rich picture of the data (Denzin, 1978; Polit & Beck, 2016) that can be transferred to different research fields of practice, social sciences and environmental geography.

In study V, some participants were involved in member checking by looking at the pictures taken during the shadowing. Otherwise, no member checking of the data has been done with the participants.

However, the voices and experience of dementia have been in focus throughout the research process in this thesis; this has been confirmed in previous studies to be important where people living with dementia are included in research as participants with unique experiences (McKeown, Clarke, Ingleton, Ryan, & Repper, 2010; Moore & Hollett, 2003; Nygård, 2006).

8.2.1.2. Credibility of the author

In order to adopt a phenomenological worldview (Merleau-Ponty, 1962), the pre-understanding and credibility of the author (Patton, 2002, p. 552–553) needs to be explored and reflected on from the author’s own perspective. The author in the role of a researcher is as much a part of the research process as the participants; the presence of the researcher also has an impact on the experiences of the phenomena as s/he is moving in the same surrounding world (Merleau-Ponty, 1962). As mentioned in the preface, the author is a district nurse and has experience of making home visits where

the main activity is to observe and perform medical tasks such as everyday observation of health and well-being. The main focus of the author's professional practice has always been to take time to talk and gain more understanding of a person's everyday life. From the point of view of a researcher, the author has used similar skills to understand the participants' interactions with the world outside, only this time as a researcher. The author has not acted from the perspective of a district nurse only as a researcher. Attention has been focused on everyday life in the neighbourhood and on understanding the world of people with experience of dementia and registered and specialist nurses.

8.2.2. Transferability

Transferability is the second criteria of trustworthiness (Lincoln & Guba, 1985, p. 316) and, in this thesis, it has been applied by providing rich information from all stages in the four studies to the readers to open up their lifeworld with new knowledge and apply this to other research contexts. This criterion was fulfilled throughout the research process in all five studies from the description of the neighbourhood, participants, phenomena and essences (study II) so that the readers can appraise the applicability of the data to other contexts. By integrating data from different contexts in the neighbourhood, home, municipal home care and different countries, the findings from the thesis can be transferred to other contexts.

This thesis included a large number of participants with both lived experience of dementia and personal and professional experience of health care professionals such as nursing staff and registered and specialist nurses. This selection of participants gives a clear picture of the data but also has implications for policy, practice and education. Especially in the field of nursing and dementia, this thesis can be helpful by increasing nurses' understanding of patients by entering their lifeworld, which differs from primary nursing practice (Beck, 1994). However, it is important to acknowledge that our own experiences of the phenomena cannot be transferred to others, because their experiences are rooted in the meaning of place. However, data from this thesis can teach us about the everyday experience of neighbourhood. Hence, another strength in supporting transferability is that the data collection methods are strongly linked to the fact that the choice of data analysis, such as walking interviews, is well-suited to a phenomenological approach.

The recruitment of participants in studies II and III was based on their individual lifeworld experiences; this type of sampling procedure has created a "true" picture according to people living with dementia. The participants had their own narrative truth (Randall, 1999). In studies IV and V, purposive sampling (Creswell & Poth, 2017) was used, and the lived experience of dementia according to the participants was essential. The findings in the four studies and in the overall analysis were built on the experiences of participants, with quotations to enhance transferability.

8.2.3. Dependability

From the author's perspective, dependability (Lincoln & Guba, 1985, p. 316-318) in this thesis is when the findings are based on the experiences from the participants' lifeworld. A lifeworld paradigm (Merleau-Ponty, 1962) with a focus on the meaning of place and lived experience was adopted to set up the research question and design in this thesis. This revealed the connections between neighbourhood and people with experience of dementia, and how those connections had an impact on their everyday life and work through interactions with others. Their experiences of dementia in the neighbourhood can be used as a statement or give inspiration to the reader to understand people with dementia, which can be new knowledge to use in their day-to-day life.

The third criteria, dependability, includes statements of the findings that are constant over time. In studies II, III and V, no interview guide was used due to the methodological approach of walking interviews, multiple data collections methods and shadowing. The questions that emerged while walking or shadowing were in connection to place and people's experiences. This approach allowed the researcher to get close to the empirical data; the data presented in the thesis is close to the raw data from the field that have not been changed. In study II, the "empirical anchorage" (More, 2018, p. 13) as a criterion for validity has been accomplished by the author of the thesis exploring her own pre-understanding of the phenomena and taking fieldnotes afterwards. In phenomenology, the researcher is part of the research process, and by acting in the field, the findings in studies II and III are built on raw data by following the lifeworld perspective. The researchers reflected on and were fully aware of "self" in the research process. In the semi-structured individual and group interviews (study IV), an interview guide was followed, and the questions were the same for each participant. When analysing the data, the same approach was used and followed according to the interpretive phenomenological approach (Moustakas, 1994) and relevant phases in thematic analysis (Braun & Clarke, 2006).

8.2.4. Confirmability

The criterion of confirmability (Lincoln & Guba, 1985, p. 318-327) is according to the author, a co-production together with others in the research team and/or with the participants, where awareness about the data is brought to the table for discussions to avoid any mis-judgement of the data. It is more a case of sharing, viewing and discussing in collaboration with others. The fourth criteria, confirmability was achieved during the different phases of data analysis by discussion with the co-authors and supervisors to reach objectivity of the data. In studies II and III, the data analysis and themes were discussed several times to secure objectivity with the data because data collection also took place in England and Scotland. In study IV, the data were analysed between two researchers and were then discussed with the whole research group. In

study V, the analysis was discussed several times within the research team to avoid any potential for mis-judging the data.

9. IMPLICATIONS

The findings from this thesis have implications for education, policy, practice and future research. Health and social care education for professionals in home care and Swedish dementia organizations, registered and specialist nurses, citizens in local communities, policy makers, and people with an interest in dementia and neighbourhoods should benefit from the findings of this thesis.

9.1. Education

- Practice needs to take better account of the lifeworlds of people with dementia rather than focusing narrowly on disease stages.
- People with dementia should be directly involved in education for future health and social care professionals in order to share their lifeworld and lived experiences.
- The implications and differences in socio-economic status among municipalities should be given greater prominence during practice education because newly graduated nurses will be working in municipal home care in the future as a result of the ageing population and the policy drive for ageing at home.
- Nursing and specialist programmes have to shift their focus from hospital care and move to develop a new arena where municipal home care has to become central for neighbourhood nursing.
- New development of nursing theory towards neighbourhood nursing should be considered in line with the theories of place attachment. Nursing theory developed some years ago needs to be updated and applied to today's circumstances, not least where the role of a registered nurse has changed in line with technological progress and care policy.

9.1.1. Policy

- It is time to move from “disease stages” and the biomedical model towards a personhood and citizenship perspective when developing policy for health and social care for people living with dementia.
- A new educational field of municipal home care and dementia has to be developed because, in the next 3 years, it is estimated that Sweden will face a huge lack of district nurses (about 86%), and among registered nurses the gap is estimated to be about 72% (Statistics Sweden, 2018).
- The increasing population of people living alone with dementia has to be acknowledged in policy documents and in national guidelines for dementia.

- Especially in Sweden, policy needs to be developed in collaboration with people living with dementia; they should be involved in all stages of this work. Dementia-friendly communities should not be developed without attending to their lived experiences.
- A greater range of social arenas in neighbourhoods have to be established where people with dementia have the opportunity to meet others.

9.1.2. Practice

- Neighbourhood nursing could enrich the neighbourhoods, where citizens with dementia, together with professionals from municipal home care, primary care and neighbours, work together as a team and plan for care practice and opportunities for social activities.
- All health care and social professionals should have a high standard of knowledge and understanding of dementia from a personhood and social citizenship perspective.
- Walking around the neighbourhood and other innovative methods can provide more information about the person with dementia than formal questions about their health status when sitting at home.
- Life and movement outside the home via a window or balcony creates a sense of belonging for people with dementia, especially for those living alone. This knowledge is important to address when developing dementia-friendly communities and special housing.
- A focus on the outdoor environment and what impact it has on people living with dementia has to be added in the development of care programmes.

9.1.3. Further research

This thesis comprising five studies has led to new arenas for future research when it comes to neighbourhoods, dementia and practice. Everyday life in the neighbourhoods of people living alone with dementia should be better acknowledged in research. There are many questions to be answered when it comes to gaining more understanding of the meaning that neighbourhoods hold for people living alone with dementia. By using innovative methods as presented in this thesis, everyday experiences of municipal home care could also be further investigated, for example, by using home tours to explore connections to objects and possessions in the home. More research is also needed from the perspectives of registered and specialist nurses from municipal home care with a focus on the neighbourhood, and people receiving home care and what matters for them with care based on a neighbourhood nursing model. In addition, knowledge from people living with dementia could be integrated into a model of neighbourhood nursing in dementia where the work of Julia Cumberlege (1986) could provide the starting point for a Swedish approach to neighbourhood nursing.

9.1.4. Limitations

When considering the findings of this thesis, a number of limitations should be considered. Overall, the thesis has offered a new perspective on everyday life in the neighbourhood from a context of living with dementia. The neighbourhood's character in studies II, III, IV and V were mainly socio-economic wealthy neighbourhoods, which could limit the findings of the thesis. Most participants also wanted to show off their home because they had well organized and clean homes. The interviews and shadowing in neighbourhoods were carried out only during the day time, which gave only one picture of the neighbourhood. In some socio-economic poor neighbourhoods, the participants (studies II, III and V) noted that during the evenings and nights, their neighbourhood becomes less safe and secure because of different types of crime going on outside their door. These aspects of neighbourhoods are important to recognize and discuss in research and among professionals in health and social care. A further limitation is that most of the participants were women and born in Sweden, except for study II where most were men. In studies II, III and IV, most of the women were living alone with dementia. In Sweden, people living with dementia are mostly women, as are those who live alone (Swedish Dementia Registry, 2017). This could explain our gender bias and that women with dementia more often have formal care compared with men. In study V, most of the participants were women working in municipality home care. This thesis indicates that gender has to be considered when it comes to experiences of dementia.

Another limitation to consider in this thesis is the lack of information about the stages of dementia. The lifeworld and experiences of the participants living with dementia are presented according to a lifeworld perspective and a personhood model where the intention is not to objectify the participants by labelling them according to the stages of their condition. However, in studies II, III and IV, a clear description of the participants' daily activities is presented instead to provide a picture of their routine activities.

This thesis has mostly provided a picture from a Swedish context and a Swedish welfare system, which could limit the transferability of the findings to other countries. On the other hand, UK field sites have been included in study III, and colleagues from the United Kingdom have contributed to the analysis and findings. One of the main differences in the United Kingdom concerns the organization of the welfare system, which is in contrast to the Swedish system. Arguably, the United Kingdom has come further in terms of the social inclusion of people living with dementia than in Sweden. Despite this, many similar issues are shared between the United Kingdom and Sweden, as well as other countries, where the population of people living with dementia is projected to increase and where the majority will live at home and will require some level of home care (Alzheimer's Disease International, 2018; Tarricone & Tsouros, 2008). Hence, despite our differences, we face many of the same challenges in the near future.

10.CONCLUSIONS

This thesis has presented new knowledge on how the neighbourhood can be understood as a place linked by connections that people actively search out, and where the meaning of place emerges via movement of the body through the world. It is also a site where practice supports everyday life for people with dementia. This new awareness and insight gives an understanding of neighbourhood as an arena of walkability, social interaction, citizenship and practice, which are a central part of people lives. There is an ongoing dialogue between people living with dementia, neighbours and professionals working in municipal home care through their movement in the neighbourhood. It thereby holds meaning in terms of being included in the social world of others. Neighbourhood matters for people living with dementia, especially for those living alone in ordinary housing. Attachment to life and movement is essential to maintain belonging to the world at a neighbourhood level. Ultimately, this thesis points to the need to re-think nursing practice, where neighbourhood nursing as a model with a lifeworld perspective has to be established in dialogue with citizens. People living alone with dementia are active agents who search for opportunities in the neighbourhood to create meaning and sustain their social world. These findings are essential to consider for dementia-friendly community initiatives and in the development of home care and neighbourhood nursing.

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L. Sandström 19

Intervjuguide för Demensvänligt samhälle- Norrköpingsmodellen

Din/er medverkan i intervjun är frivillig. Hela intervjun spelas in. Det är enbart forskare inom projektet som kommer att få tillgång till datamaterialet. Intervjun beräknas ta omkring 45 – 60 min.

Informerat samtycke.

Inled med att berätta om studiens syfte

Tema	Fråga
Bakgrundsinformation (kan komma sist)	Ålder, familj, civilstånd, boendeform, antal år i bostaden, utbildning och tidigare arbets- och yrkeserfarenhet
Vardagslivet	Berätta om en vanlig dag Berätta vad du/ni brukar göra om dagarna Vad ska du/ni göra idag? Vilka i omgivningen kan du/ni kontakta om något skulle inträffa? Brukar du/ni umgås med någon som bor i närheten? Vilka andra kontakter brukar du/ni ha? Var äter du frukost, lunch och kvällsmat? (själv eller tillsammans med andra?) Hur tvättar du/ni kläder? Hur skulle du vilja ha det? Om du skulle önska och ge förslag till förbättringar-förändringar?
Boende	Berätta om hur du bor Beskriv din bostad Hur trivs du/ni i bostaden? Känner du dig trygg här? Favoritplats inomhus? Har du/ni någon särskilt viktig plats utomhus nära din bostad? (t.ex. trädgård, balkong, terrass) Landmärken för att hitta? Vart vänder du/ni er om något går sönder i bostaden? Hur fungerar service och bemötande från fastighetsägaren eller från bostadsrättsföreningen? Hur skulle du/ni vilja ha det? Om du skulle önska och ge förslag till förbättringar-förändringar?

Närmiljön/ Bostadsområdet/Grannskapet: utomhusmiljö och byggd miljö	<p>Berätta om din/er utomhusmiljö</p> <p>Är det lätt att komma in och ut från din bostad? Är du/ni utomhus dagligen? Tar du/ni dagliga promenader? Vart? Har du/ni någon särskilt viktig plats i ditt bostadsområde?</p> <p>Notera hur tillgänglig utomhusmiljön är – antal dörrar/trappor att passera osv? till utemiljön</p> <p>Hur skulle du/ni vilja ha det? Om du skulle önska och ge förslag till förbättringar- förändringar?</p>
Förflyttning/Kommunikationer/ transport	<p>Hur brukar du/ni förflytta dig/er? (om ja-hur upplevs det?)</p> <p>Promenerar du? Vart? Och varför? Åker du bil? buss? Spårvagn? Tåg? Cykel? Hållplatser? Tidtabell? Betalning? Biljetter? Färdtjänst? Om så, hur beställer du/ni? Via telefon?</p> <p>Har du ledsagning från hemtjänsten?</p> <p>Hur skulle du/ni vilja ha det? Om du skulle önska och ge förslag till förbättringar- förändringar?</p>
Socialt nätverk/förankrade sociala band/deltagande/mötesplatser	<p>Berätta om människor som är viktiga för dig/er och var ni möts</p> <p>Var brukar du/ni träffas? Dagverksamhet? Andra mötesplatser?</p> <p>Vilka kontakter har du/ni med människor som bor i närheten? Brukar du/ni hälsa på människor du/ni möter i bostadsområdet? Brukar du/ni umgås med människor som bor i bostadsområdet?</p> <p>Hur skulle du/ni vilja ha det? Om du skulle önska och ge förslag till förbättringar- förändringar?</p>
Bemötande och tillhörighet	<p>Om du behöver hjälp på något sätt – vem vänder du dig till?</p> <p>Känner du/ni tillhörighet till din kommun/ditt bostadsområde?</p> <p>Hur blir du/ni bemött av andra? (t.ex. av grannar, hemtjänsten, i livsmedelsaffären, på banken, hos frisören osv?) Kan du lita på andra människor i ditt bostadsområde?</p> <p>Har du/ni tankar om hur man pratar om personer med demens?</p>

	<p>Hur skulle du/ni vilja ha det? Om du skulle önska och ge förslag till förbättringar-förändringar?</p>
Service i närmiljön/bostadsområdet	<p>Berätta hur du/ni handlar (livsmedel, kläder och skor etc) hämtar post, betalar räkningar, tar ut pengar, besöker frisör besöker fotvård ordnar id-kort och pass besöker café, konditori, restaurang besöker biograf eller teater eller musikevenemang</p> <p>Hur skulle du/ni vilja ha det? Om du skulle önska och ge förslag till förbättringar-förändringar?</p>
Primärvård, hemsjukvård och sjukvård	<p>Berätta hur du/ni besöker vårdcentralen, ringer eller kontaktar vårdcentralen, förnyar recept, besöker apoteket Hur blir du bemött på vårdcentralen och apoteket?</p> <p>Om du behöver komma till sjukhuset för besök på en mottagning eller uppföljning -hur kontaktar du/ni sjukvården? Hur tar du/ni dig till sjukhuset? Hur hittar du/ni på sjukhuset? Hur blir du bemötta på sjukhuset?</p> <p>Hur skulle du/ni vilja ha det? Om du skulle önska och ge förslag till förbättringar-förändringar?</p>
Kommunal och annan service	<p>Har du/ni kontakt med hemtjänsten? Vad får du/ni för stöd från hemtjänsten?</p> <p>Har du/ni varit i kontakt med en biståndshandläggare?</p> <p>Har dagverksamhet varit aktuellt för din del?</p> <p>Hur skulle du/ni vilja ha det? Om du skulle önska och ge förslag till förbättringar-förändringar?</p>
Kommunikation och information	<p>Berätta- följer du nyheter? - läser du/ni lokaltidningen? Läser du andra tidningar?</p> <p>Använder du mobiltelefon? Använder du surfplatta? (i så hur?)</p>

	<p>Tittar du på TV (i så fall var och vad?) lyssnar på radio?</p> <p>Har du/ni några tankar om det som skrivs och rapporteras om personer med demens?</p> <p>Hur skulle du/ni vilja ha det?</p> <p>Om du skulle önska och ge förslag till förbättringar-förändringar?</p>
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Slutfråga

Är det något du önskar?

Hur upplevde du/ni att bli intervjuad så här?

Kan jag/vi få komma tillbaka för att stämma av med dig/er vad som kom fram i denna intervju?

Papers

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