

# **Ge alla en chans att vara med**

## **Brukarinvolvering i forskning med och för sköra äldre personer**

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Ge alla en chans att vara med – Brukarinvolvering i forskning med och för  
sköra äldre personer

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Denna uppsats tillägnas till alla de fantastiska äldre personer jag mött inom  
vården och all den vårdpersonal som varje dag kämpar för alla människors  
rätt till ett gott liv och god hälsa.

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### ABSTRACT

**Aims:** The overall aim with this thesis was to explore how the voices of frail older people can be heard and acknowledged through user involvement in research on aging and health. Two studies are included with the specific aims; I) to explore frail older people's experiences of involvement in research, and II) to explore nursing home staff experiences of co-designing health care services with frail older persons. **Method:** Study I was an individual interview study inspired by constructivist grounded theory, with a total of 17 persons above 75 years of age, screened as frail. Study II was a focus group study with 17 nursing home professionals. **Findings:** In study I the core category, "Challenging oneself on the threshold to the world of research", symbolises a perceived distance between frail older people and the research world, but also challenges that frail older people could go through when choosing to be involved in research. In study II the results are summarised in the overarching theme "Moving from object towards person" which describes the co-design process as a real eye-opener for staff in terms of realising the capability of both the frail older persons and themselves.

**Conclusions:** Frail older people should have the same rights as other groups to make their voices heard in research that concerns them. User involvement seems to be a possible way for more relevant research for frail older person. However, the opportunity to be involved in research should be based on their real capabilities, and not limited by stereotypic views of ageing and frailty.

**Keywords:** User involvement, Frailty, Epistemic injustice, Nursing homes, Healthcare staff, Person-centered, Capability, Older people

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## SAMMANFATTNING PÅ SVENSKA

Risken för att drabbas av skörhet ökar med åldern men är något som går att förebygga och motverka. För att sjukvården på bästa sätt ska kunna hjälpa sköra äldre personer behöver vårdinsatser vara baserade på forskning gjord utifrån sköra äldre personers behov. Men sköra äldre personer har idag svårt att få sina behov tillgodosedda i sjukvården då forskningsunderlaget för hur vården är upplagd är baserat på yngre och friskare personer. Sköra äldre personers erfarenheter och behov har inte varit styrande. Ett sätt att få forskning för sköra äldre personer mer anpassad och relevant för deras behov är att de själva blir involverade i forskningen. Genom att sköra äldre personer får inflytande över vad forskning handlar om och genomförandet finns det möjlighet att ny kunskap bildas för utifrån det som de sköra äldre själva känner är mest värdefullt. Då kvarstår frågan hur och på vilka sätt sköra äldre personer vill och kan delta forskning. Det är något vi vet väldigt lite om då det saknas både forskning om och erfarenheter av att involvera sköra äldre personer i forskning. Det övergripande syftet med den här uppsatsen var därför att undersöka hur sköra äldre personers röster kan bli hörda och erkända genom brukarinvolvering i forskning om åldrande och hälsa. Först gjordes en studie där sköra äldre personer intervjuades om sina erfarenheter av involvering i forskning följt av fokusgrupper med personal från två särskilda boenden som hade ett gemensamt utvecklingsprojekt där personalen samskapade vård och omsorg med de sköra äldre personer som bodde på boendena. Ett viktigt övergripande fynd är att sköra äldre personer lever in en tillvaro där de fått anpassa sina vardagliga aktiviteter efter de kroppsliga och sociala förändringar som kommer av åldrandet. Därför kommer involvering i forskning med möjligheter till något utöver det vanliga, och att få dela med sig av sina erfarenheter. För att möjliggöra involvering av sköra äldre personer i forskning verkar det vara betydelsefullt att de ges möjligheter utifrån sina personliga förutsättningar. Våra resultat pekar också på att samarbeta i något nytt kan leda till en förändring av roller och hur sköra äldre personer ser på sin egen roll, och de roller som personal och forskare har. De sköra äldre personerna i projektet hade kapacitet att vara involverade som överraskade både dem själva och personalen på de särskilda boendena. Det verkar alltså som om det på förhand kan vara svårt att avgöra vilka resurser och färdigheter sköra äldre personer har och att det är först när de får chansen att vara involverade som de kommer till ytan. Vi menar att det är problematiskt att exkludera sköra äldre personer från forskning och att det i samarbetet, mötet och relationen mellan forskare och sköra äldre personer finns potential för att skapa nya perspektiv och kunskap. Sköra äldre personer kan bidra till forskning om de får chansen men då måste det ske i balans med deras förutsättningar och förväntningar.

## LISTA ÖVER PUBLIKATIONER

Denna uppsats bygger på följande studier, som refereras till i texten med deras romerska siffror. Den publicerade artikeln återgivs med tillstånd av förläggare

- I. Berge I, Barenfeld E, Dahlin-Ivanoff S, Haak M, Lood Q. Challenging oneself on the threshold to the world of research – Frail older people’s experiences of involvement in research. BMC Geriatrics 2020;20(1):410.
- II. Berge I, Dahlin-Ivanoff S, Barenfeld E, Haak M, Lood Q. A real eye-opener: Nursing home staff experiences of co-designing nursing home health care services together with frail older persons. Inskickad till vetenskaplig tidskrift.

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## DEFINITIONER

Brukarinvolvering	Innebär att brukaren är en aktiv partner som är involverad i diskussioner och beslut, bidrar med sin unika kunskap och sitt perspektiv, snarare än att vara ett objekt som bara studeras (1).
Epistemisk orättvisa	Uppstår när personer som har legitima skäl att var med och skapa ny kunskap inte får möjlighet att vara det (2).
Kapabilitet	Definieras som den enskilde personens faktiska förmåga att uppnå dess egna uppsatta och värdefulla mål i livet (3).
Personcentrering	Är en handlingsetik som argumenterar för att alla människor har förmåga att uttrycka sina behov och använda sina resurser om de ges rätt förutsättningar (4).
Skörhet	Är ett tillstånd av minskad reservkapacitet och minskad motståndskraft, kopplat till åldrandeprocessen (5).

## 1 INTRODUKTION

Både i Sverige och globalt är det allt fler som lever till en hög ålder (6) och i och med det ökar heterogeniteten inom gruppen äldre personer. Att tillgodose äldre personers behov av hälso- och sjukvård beskrivs därför ofta som en utmaning för välfärden (7) och för en optimerad resursanvändning behövs interventioner som riktas mot den grupp som är i störst behov av det. En sådan grupp är sköra äldre personer, men dagens högspecialiserade vård är inte utformad efter deras komplexa behov (8). Det beror till exempel på att sköra äldre personer ofta exkluderas från interventionsstudier till förmån för ett yngre och friskare urval (9), vilket påverkar både relevansen och generaliserbarheten av forskningsresultat. Tidigare studier har dessutom visat att sköra äldre personer på grund av sin hälsostatus kan vara en grupp som är svåra att rekrytera till forskningsprojekt (10). Brukarinvolvering beskrivs allt oftare som ett sätt för forskning att bli mer anpassad och relevant för målgruppen genom att de får inflytande över vad forskningen handlar om och hur den genomförs. Däremot har brukarinvolvering i forskning om åldrande och hälsa ofta haft utgångspunkt i forskarnas perspektiv (11, 12). Det saknas kunskap om såväl betydelse som relevans och användbarhet av brukarinvolvering i forskning med och för sköra äldre personer (13) vilket utmanar den akademiska världen att hitta sätt att nå ut till denna grupp. Därför syftade denna uppsats till att undersöka hur sköra äldre personers röster kan bli hörda och erkända genom brukarinvolvering i forskning om åldrande och hälsa. Fokus för uppsatsen är forskning *om* brukarinvolvering, för att lägga en grund för hur brukarinvolvering ska kunna appliceras i forskning med och för sköra äldre personer.

### 1.1 TEORETISKT RAMVERK

Det teoretiska ramverket för denna uppsats vilar på Sens (3, 14) rättviseramverk om kapabilitet och personcentrering som handlingsetik. Sens (3, 14) kapabilitets-ansats bygger på synen att varje människa har vissa förutsättningar och förmågor. Frihet innebär att de får möjligheten att göra och vara det som de har anledning att sätta värde på (3, 14), i denna uppsats att vara involverade i forskning. Handlingsetiken i personcentrering i sin tur vägleder oss som forskare hur vi ska förhålla oss till de som vi involverar i forskning (15).

#### 1.1.1 KAPABILITET

Kapabilitet beskrivs av Sen (14) som ett rättviseramverk byggt på den normativa utfästelsen att alla personer ska ha samma rättigheter till god hälsa

och välbefinnande och att förutsättningarna och möjligheterna för detta måste förstås i relation till varje enskild persons kapabilitet (14). Kapabilitet definieras som den enskilde personens förmåga att uppnå dess egna uppsatta och värdefulla mål i livet (3). Det handlar inte nödvändigtvis om vad en person gör utan handlar om att vilka resurser och förutsättningar som finns för den enskilde att göra val mellan olika aktiviteter för att nå de egna uppsatta målen, vilken frihet eller möjlighet för handlande som finns. En persons förmågor (Functionings) är enligt Sen (14) vad en person gör och är och vad personer sedan faktiskt uppnår (achievements) genom sin kapabilitet och kan i varierande grad överensstämma med de mål som varje enskild person valt att sätta värde på (16, 17).

### 1.1.2 PERSONCENTRERING

Personcentrering är en handlingsetik som argumenterar för att alla människor har förmåga att uttrycka sina behov och använda sina resurser om de ges rätt förutsättningar. Inom personcentrerad vård handlar det om att som personal se att bakom varje patient finns en person och att vården ser till att bekräfta varje enskild persons unika historia och sammanhang, dess styrkor såväl som svagheter. Varje patient är mer än en biomedicinsk diagnos (4). Denna handlingsetik inom personcentrering går också att applicera inom forskning och innebär då att forskaren på samma sätt som vårdpersonalen försöker förflytta perspektivet från forskning som uppgift till den person som är involverad i forskning som brukare och dess behov (15). Brukare används som begrepp i denna uppsats eftersom brukarinvolvering är ett vedertaget begrepp, men utgångspunkten har varit att förstå brukare som forskningspersoner, med förmåga att dela beslutsfattandet med forskaren för att stärka varje persons auktoritet och valmöjligheter. Det handlar alltså om ett skifte i fokus, från att forska om människor som objekt till att forska med dem som subjekt.

## 1.2 SKÖRHET

Tidigare forskning har visat att sköra äldre personer är i stort behov av vård- och omsorgsinsatser. Skörhet är ett begrepp som används inom geriatrisk och gerontologisk forskning för att beskriva det biologiska åldrandet. Diskussioner pågår om hur man på bästa sätt ska definiera skörhet, men det finns konsensus att det är ett tillstånd av minskad reservkapacitet och motståndskraft (5). Enligt Fried och kollegor (16) kan fysisk skörhet identifieras med hjälp av följande indikatorer: allmän svaghet, trötthet/nedsatt ork och uthållighet, ofrivillig vikt-nedgång och låg fysisk aktivitet (16). I denna uppsats har dessa indikatorer använts för att definiera vem som är en skör äldre person, tillsammans med skörhetsindikatorerna synnedsättning och kognitiv svikt som visat sig vara viktiga indikatorer för fysisk skörhet.

Andra begrepp som associeras med såväl biologiskt åldrande som skörhet är funktionsnedsättning och samsjuklighet. Men även fast det finns kopplingar mellan begreppen är det viktigt att skilja dem åt för att kunna förstå vilka faktorer som påverkar en person under dess livsspann. Samsjuklighet är kroppens patologiska åldrande och risken för sjukdomar ökar om en person är skör, vilket i sin tur kan leda till en nedsättning av aktivitetsförmågan eller död i förtid (17). Nedsättning av aktivitetsförmågan handlar om att inte kunna vara oberoende i aktiviteter i det dagliga livet (18) och påverkar starkt en skör äldre persons kapabilitet att uppnå de mål som den satt som värdefulla.

## 1.3 BRUKARINVOLVERING I FORSKNING

Brukarinvolvering i forskning är ett sätt att öka samverkan mellan akademien och personer utanför akademien, så kallade brukare. Vem som anses vara brukare kan till exempel vara de målgrupper som forskning ämnar hjälpa; äldre personer, närstående, yrkesverksamma inom till exempel hälsosjukvård eller beslutsfattare. Involvering av brukare i forskning för att stärka samverkan mellan akademi och medborgare efterfrågas i allt högre utsträckning som krav från uppdragsgivare och forskningsfinansiärer (18-21). Däremot har olika former av samverkan mellan forskare och personer utanför akademien en lång tradition och har historiskt tagit sig olika uttryck. Det finns flera närbesläktade begrepp som beskriver detta inom olika forskningstraditioner, till exempel de engelska begreppen; user-driven research, community based participatory research, co-design (samskapande), participatory design, co-production of knowledge, patient and public involvement, patient-driven research, transdisciplinary research, och collaborative research (1). I den här uppsatsen används begreppet brukarinvolvering för att beskriva den forskningsansats som studeras. Detta eftersom begreppen ovan har gemensamt att de handlar om att involvera brukare i forskning som de har intresse och behov av. Det handlar om att ha legitima skäl att delta i skapandet av ny kunskap.

Brukarinvolvering i forskning handlar alltså om att involvera aktörer utanför den akademiska världen i forskning som berör dem. I kontrast till deltagande i forskning som traditionellt sett handlar om att lämna blodprov, fylla i enkäter eller intervjuas som datakälla (22) handlar brukarinvolvering om att aktivt vara med och påverka forskningsprocessens olika delar. Det kan till exempel handla om att vara med och bestämma forskningsfrågor, att delta i utformningen av projektansökningar, i datainsamling och analys, eller vid sammanställning och spridning av resultat till olika samhällsaktörer. Genom brukarinvolvering skapas utrymme för ny kunskap att bildas genom samarbete mellan forskare och personer utanför akademien, där båda grupperns olika kunskapsområden

erkänns och ges likvärdig status (23). Detta har beskrivits öka relevansen av forskningsresultat för såväl den grupp lekmän som involverats som för samhället i stort (23, 24). Till exempel har positiva effekter och resultat av brukarinvolvering rapporterats i termer av forskningsresultat med högre metodisk och etisk kvalitet, ökad relevans och påverkan på samhället, samt effektivare spridning av resultat och positiva effekter på hälsoresultat (25). Det finns också beskrivningar av effekter av brukarinvolvering i tre nivåer: 1) för den enskilda personen som involverats som brukare, 2) för den grupp av personer som involverats som brukare och 3) för forskare och forskningen (26). Trots detta finns det i dagsläget ingen konsensus kring vilken grad av brukarinvolvering som är optimal i olika sammanhang eller i relation till olika målgrupper. Att utvärdera brukarinvolvering i forskning är både komplext och komplicerat (27), och det råder en generell brist på studier om brukarinvolvering i forskning.

Ett annat potentiellt problem vid utformandet av studier om och med brukarinvolvering är det ökade kravet från forskningsfinansiärer att forskning ska bedrivas i samverkan med aktörer utanför akademien. Detta krav har beskrivits kunna leda till en press på forskare att designa studier med brukarinvolvering utifrån finansiella orsaker snarare än för att stärka forskningsprojektet (28). Detta riskerar att leda till att brukarinvolvering ses som ett måste, och att brukare inte får något riktigt inflytande, med risken att de upplever sig vara med som symbolisk representation. Istället för att känna sig stärkta i sin egenmakt riskerar de alltså att känna sig marginaliserade och utnyttjade (26). Även om forskare försöker på bästa sätt skapa ett jämlikt samarbete och delat ansvar med brukare så har forskarna också alltid ett övertag baserat på sin utbildning och samhällsposition (29). Det finns också en utmaning för forskare att lyckas omsätta brukarnas kunskaper och problem till forskningsfrågor som går att studera vetenskapligt (30). Vissa kritiker mot brukarinvolvering argumenterar till och med för att det leder till en ökad risk för manipulering och orättfärdigt användande av makt (31). Därför är det viktigt att vara medveten om varför, hur och med vem som brukarinvolvering ska tillämpas i forskning. Det finns till exempel två generella motiv till brukarinvolvering i forskning: konsumentperspektivet och det demokratiska perspektivet (20). Konsumentperspektivet är en del av den samhällsförändring som skett i de postindustriella samhällena till senmoderna, som har ändrat våra sociala relationer men också relationen mellan staten och individen. Det kännetecknas av ökad individualism och en välfärd som allt mer kommit att anpassa sig efter ett marknadstänk. Brukarna ses som konsumenter av olika tjänster och brukarinvolvering utifrån det här perspektivet bygger på att brukarna som konsumenter bör ha inflytande genom involvering i tjänsternas utveckling (20). Problem som kan uppstå kring det här perspektivet är vem som ses som konsument och vems röst som görs hörd vid utveckling av

tjänster. Därför bygger den här uppsatsen på det demokratiska perspektivet, där brukarinvolvering i forskning motiveras av att försöka stärka olika gruppers egenmakt. Detta gäller särskilt grupper i samhället med låg status och som har svårt att göra sina röster hörda (20), såsom sköra äldre personer. Detta bygger på antagandet att brukarinvolvering i forskning bör syfta till att stärka en grupps möjligheter att göra sina röster hörda, och då måste det finnas en önskan och en strävan att skifta makt från forskarna till den grupp som involveras som brukare (32).

## 1.4 RATIONAL

I dagens samhälle finns en utbredd negativ syn på äldre personer, så kallad ålderism som innebär att människor diskrimineras på grund av sin ålder (33). Detta påverkar även forskningen i och med att äldre personers röster inte alltid anses vara värda att lyssna på, vilket i sin tur påverkar vilken sorts kunskap som kan bildas. I det långa loppet kan detta leda till det som Fricker (2) har beskrivit som epistemisk orättvisa (2) som innebär att personer som har legitima skäl att vara med och skapa ny kunskap inte får möjlighet att vara det. Enligt Fricker (2) kan epistemisk orättvisa uppstå av två olika anledningar; 1) vittnesorättvisa som omfattar fördomar om trovärdigheten hos till exempel sköra äldre personers uttalande, vilket gör att de inte anses vara trovärdiga att ha som källor till ny kunskap, och 2) hermeneutisk orättvisa som sker på en högre nivå i samhället när det finns kunskapsluckor om vissa grupper relaterat till deras status. Till exempel saknas det kunskap om hur sköra äldre personer kan tolka och förstå sina sociala upplevelser vilket kan vara en orsak till att deras behov är relativt outforskade (2).

Epistemiska orättvisor kan vara en orsak till att tidigare forskning ofta har exkluderat sköra äldre personer, på grund av föreställningar om att de inte skulle orka delta eller ha nytta av sitt deltagande (9). Hög ålder är till exempel ofta ett exklusionskriterium i kliniska studier, ofta utan att det motiveras utifrån studiernas syften. Istället har det beskrivits vara baserat på negativa antaganden om äldre människor som mer krävande och mindre kompetenta än yngre och friskare människor (9, 25, 34). Sköra äldre personer exkluderas också indirekt från forskning eftersom de ofta har flera sjukdomar och därför utesluts från att delta i forskning på grund av strävan efter ett renare urval (9). De har därmed få möjligheter att göra sina röster hörda och erkända i forskning som de som grupp skulle ha nytta av. I de fall som sköra äldre personer har deltagit i forskning har de främst använts som datakällor, för att utveckla och utforma tjänster. Få studier har strävat efter att involvera sköra äldre personer som jämlika aktörer eller partners som besitter värdefull kunskap och erfarenhet (35).

## 2 SYFTE

Det övergripande syftet med uppsatsen var att undersöka hur sköra äldre personers röster kan bli hörda och erkända genom brukarinvolvering i forskning om åldrande och hälsa.

Specifika syften för de två delarbetena var:

- I. Att utforska sköra äldre personers erfarenheter av involvering i forskning
- II. Att utforska erfarenheter hos personal på särskilda boenden vad gäller samskapande av hälso- och sjukvård med och för sköra äldre personer

## 3 METOD

Uppsatsen har en kvalitativ och explorativ ansats för att studera olika aspekter av hur sköra äldre personers röster kan bli hörda och erkända genom brukarinvolvering i forskning om åldrande och hälsa. Studierna är gjorda inom ramen för UserAge, som är ett interdisciplinärt, nationellt forskningsprogram med forskare från fyra olika universitet. Målet med forskningsprogrammet är att undersöka brukarinvolvering i forskning om åldrande och hälsa från olika perspektiv och i relation till olika grupper av brukare. Inom programmet genomförs studier med olika metoder, både med kvalitativ och kvantitativ ansats (1). I denna uppsats studeras brukarinvolvering utifrån sköra äldre personers perspektiv. En översikt över metoder, deltagare och analys för respektive studie ges i tabell 1.

Tabell 1. Översikt över uppsatsens delarbeten

	Urval	Studiedesign	Datainsamling	Dataanalys
<b>Studie I</b>	Sköra äldre personer, $\geq$ 75 år, tidigare erfarenhet av forskning (n=17)	Induktiv, Kvalitativ, Grounded theory	Individuella intervjuer	Grounded theory, Charmaz (36)
<b>Studie II</b>	Personal på särskilda boenden som deltagit i samskapande utvecklingsprojekt (n=17)	Induktiv, Kvalitativ, Fokusgrupps metodik	Fokusgrupps-diskussioner	Fokusgrupps-analys, Kreuger och Casey (37)

### 3.1 DESIGN

Studie I designades utifrån Charmaz (38) konstruktivistiska grounded theory som är en av flera olika inriktningar inom grounded theory. Metoden är lämplig för att studera processer och utforska handlingar i dess sammanhang. Designen bygger på att forskning och data konstrueras i interaktion mellan forskare och



deltagare och syftar till att bidra med förståelse snarare att förklara processen som studeras (38), i det här fallet involvering i forskningsprocessen. Eftersom konstruktivistisk grounded theory dessutom har en explorativ ansats valdes denna design för studie I, i syfte att ge en ökad förståelse av sköra äldre personers involvering i forskning, baserat på deras tankar och erfarenheter.

I studie II tillämpades fokusgruppsdesign för att utforska erfarenheter hos personal på särskilda boenden. Fokusgruppsdiskussioner bygger på socialkonstruktivism genom interaktion mellan deltagarna i diskussion, för att på så sätt klargöra deras åsikter och erfarenheter. Genom gruppinteraktion syftar fokusgruppsdiskussioner till att ge deltagarna en möjlighet att stimulera varandra i diskussionerna för att utforska nya ämnen som kan dyka upp och på så sätt skapa data om deras kollektiva förståelse (39, 40).

### 3.2 DELTAGARE OCH DATAINSAMLING

För att kunna undersöka sköra äldre personers erfarenheter av involvering i forskning i studie I rekryterades deltagare som var 75 år och äldre, som hade blivit screenade som fysiskt sköra (41) och som deltagit i en tidigare randomiserad kontrollerad studie (42). Kontaktinformation till potentiella deltagare erhöles från de ansvariga forskarna i den studie där de äldre personerna tidigare hade deltagit i. Totalt kontaktades 31 personer när de var på sjukhus, eller per telefon om de redan blivit utskrivna från sjukhuset. Personer som inte svarade i telefon (n=3) blev kontaktade brevlades med information om studien och kontaktuppgifter till ansvarig forskare. Av de 31 personerna var det sju personer som inte gick att nå och sju personer valde att inte delta. Således blev 17 sköra äldre personer inkluderade i studien och deltog i individuella intervjuer som genomfördes i deras hem (se tabell 2). Intervjuerna gjordes på svenska med hjälp av en intervjuguide med olika frågeområden som handlade om deltagarnas erfarenheter av involvering i forskning, forskningsprocessens olika delar och vad som kunde påverka deras möjligheter att vara involverade i forskning. Frågeområdena uppdaterades under studiens gång för att ge extra fördjupning i preliminära intressanta områden det i enlighet med teoretisk sampling (36, 43). Intervjuerna började med en öppen fråga: "Kan du berätta för mig vad det var som gjorde att du valde att vara med i en forskningsstudie?". Uppföljande frågor användes av intervjuaren för att deltagarna skulle fördjupa och bredda sina svar så som till exempel "Kan du ge ett exempel på.." och "Hur menar du när du säger..." (36). Memos skrevs efter varje intervju för att beskriva uppkomna tankar och idéer hos forskaren samt beskriva de icke verbala situationerna och aktiviteter som skedde under besöket. Efter 13 intervjuer visade analysen inte på några nya teoretiska insikter i frågorna som studerades. De efterföljande fyra intervjuerna

bidrog inte till nya fynd och därför ansågs kategorierna som identifierats i analysen vara mättade. Intervjuerna pågick mellan 14 och 86 minuter, medelvärdet var 49 minuter. Alla intervjuer spelades in digitalt och transkriberades ordagrant.

Tabell 2. Deltagarna i studie I

<i>Variabler</i>	<i>Värde</i>
Ålder, median (spridning)	85 (76-95)
Män, n (%)	9 (53)
Beroende i ADL, median (spridning)*	3 (1-9)
Högre utbildning, n (%)**	6 (35)
Ensamboende, n (%)	10 (59)
MMT, median (spridning)***	28 (21-30)
Screenade skörhetsfaktorer, median (spridning)****	3 (2-4)
<i>Nedsatt uthållighet, n (%)</i>	16 (94)
<i>Trötthet (senaste tre månaderna), n (%)</i>	12 (71)
<i>Fall tendens/rädsla för fall, n (%)</i>	9 (53)
<i>Hjälp med inköp, n (%)</i>	9 (53)

\* Grad av beroende i aktiviteter i det dagliga livet (ADL)(18). Eftersom kontinens inte är att betrakta som en aktivitet var således nio maxpoäng. \*\* Högskoleutbildning (universitet eller högskola). \*\*\*Mini-mental test(44). \*\*\*\* FRESH-Screen (41).

Studie II genomfördes på två kommunala särskilda boenden som båda var med i utvecklingsprojekt som syftade till att samskapa utformning och innehåll i vården och omsorgen genom att lyfta fram perspektiv från de sköra äldre personer som bodde på boendena (45). Personal som deltagit i projektet bjöds in genom personalansvariga på de två boendena. Totalt inkluderades 17 personer. I urvalet eftersträvades homogenitet dels genom den delade erfarenheten av att varit involverade i samma utvecklingsprojekt men också att de alla hade erfarenhet av att jobba med sköra äldre personer som bor på ett särskilt boende. Även heterogenitet eftersträvades för att öka bredden på deltagarnas perspektiv och erfarenheter (39, 40). Deltagarna var därför både kvinnor och män, med olika ålder, arbetslivserfarenhet och modersmål (se tabell 3). En deltagare var anställd som verksamhetsutvecklare och de övriga var anställda som undersköterskor.

Totalt genomfördes fyra fokusgruppsdiskussioner, två på vardera boende. Alla fokusgruppsdiskussionerna gjordes under deltagarnas ordinarie arbetstid och varade mellan 56 och 74 minuter. I varje fokusgrupp deltog en forskare som moderator och en forskare som observatör. Moderatören började diskussionen med att bjuda in till en öppen diskussion där alla skulle få möjlighet att uttrycka sig fritt. Därefter startades diskussionen med en öppningsfråga om vilka det var som bodde på ett särskilt boende och hur en vanlig arbetsdag kunde se ut, för att därefter följas upp med frågor om samskapandeprocessen de haft i sina utvecklingsprojekt. Moderatören hade ansvar för att alla deltagare fick komma till tals och för att stimulera till interaktion mellan deltagarna. Forskaren som deltog som observatör gjorde anteckningar om icke verbala händelser och kunde komma med uppföljande frågor i slutet av diskussionerna. Alla fokusgruppsdiskussioner spelades in digitalt och transkriberades ordagrant.

Tabell 3. Deltagarna i studie II

Variabler	Värde
Kvinnor, n (%)	15 (88)
Ålder, median (spridning)	47 (34-65)
Arbetslivserfarenhet, median (spridning)	20 (4-30)
Annat modersmål än svenska, n (%)	4 (24)

### 3.3 DATAANALYS

I studie I genomfördes dataanalysen parallellt med datainsamlingen i enlighet med grounded theory (36). Först lyssnades och lästes intervjuerna i sin helhet för att därefter koda rad för rad. De initiala koderna var mycket nära data och var formulerade som handlingar och deras kopplingar till olika känslor. Därefter sorterades koderna i preliminära kategorier som stöd för nästa steg i analysen som var fokuserad kodning. Detta steg syftade till att gå igenom större mängder data och sammanställa och förklara data i konceptuella koder som sorterades i de preliminära kategorierna. Konstant jämförande (constant comparison) (36) användes för att jämföra data både inom och mellan olika intervjuer. Under hela analysprocessen användes memos för att kunna beskriva hur de slutgiltiga kategorierna arbetades fram. Intervjuerna analyserades flera gånger i en iterativ process mellan essensen av intervjuerna och betydelsen i de framväxande kategorierna och subkategorierna. Analysen diskuterades upprepade gånger mellan artikelförfattarna.

I studie II baserades analysen på metoden beskriven av Kreuger och Casey (37). Först lyssnades de inspelade fokusgruppsdiskussionerna på upprepade

gångar, och transkriberingarna och fältanteckningarna lästes noggrant. Detta första steg resulterade i preliminära teman som diskuterades mellan författarna. I nästa steg sorterades data under frågeställningarna vad som hade gjorts under samskapandeprocessen, hur det hade gjorts och varför. Den sorterade data kondenserades därefter för att beskriva innehållet av fokusgrupperna. Kondenseringen diskuterades noggrant och betydelseerna efter kondenseringarna jämfördes sedan med de preliminära temana som var resultat av första steget i analysen och resulterade i att de preliminära temana reviderades. Till slut diskuterades reviderade teman i hela författargruppen för att nå en slutgiltig gemensam förståelse av betydelseerna i fokusgruppsdiskussionerna.

### 3.4 ETIK

Den regionala etikprövningsnämnden i Göteborg godkände studie I den 2018-01-30: DNR T097-18 och studie II den 2018-11-14: DNR 813-18. All persondata i projektet registrerades och handhavdas enligt Europeiska Unionens (EU) direktiv GDPR (General Data Protection Regulation).

Innan deltagande i projektets studier fick alla deltagare både muntlig och skriftlig information om studiens syfte och utförande, samt vad det skulle krävas av dem om de bestämde sig för att delta. Deltagarna informerades också om att allt deltagande var frivilligt och anonymt, att deras deltagande kunde avslutas när de ville och att deras persondata skulle förvaras konfidentiellt så ingen obehörig skulle kunna få del av den. Alla som valde att delta i någon av studierna gav sitt skriftliga samtycke.

För personer med nedsatt kognitiv förmåga i studie I gavs extra hänsyn. Alla som gjorde intervjuer med dessa vara legitimerade yrkesutövare med vana att arbeta med sköra äldre personer. Det fanns gott om tid vid varje intervju tillfälle för att kunna hantera eventuellt uppkomna osäkerheter eller oro (socialt prat innan och efter).

## 4 RESULTAT

I studie I beskrev de sköra äldre personerna hur de växte i rollen som forskningsdeltagare. Kanske beroende på den kontrast de kände över att leva i en skör tillvaro kännetecknad av anpassning av aktiviteter i relation till sin hälsosituation. Den bekräftelse de fick ledde till att de vågade utmana sig själva på forskningsvärldens tröskel och till att de kände sig stolta över sitt deltagande. På ett liknande sätt beskrev personalen i studie II sina erfarenheter av att samskapa med sköra äldre personer, att när de äldre gavs chansen så kunde de växa in i rollen av att vara en kapabel person som kan bidra till ett utvecklingsprojekt. Detta beskrevs av personalen som en kontrast till den generella bilden av en skör äldre person som bor på ett särskilt boende. Resultaten från respektive studie beskrivs i mer detalj nedan.

### 4.1 STUDIE I

Erfarenheten av involvering i forskning från sköra äldre personers perspektiv förstods som en process (figur 1) som startade i kategorin *Att bidra till skillnad för sig själv och andra* vilket gav deltagarna drivkrafter att bli involverade i forskning och ställa sig på forskningsvärldens tröskel. Detta beskrivs i subkategorierna: *Att få ett avbrott i vardagen*, *Att vilja lyfta vardagsnära problem*, *Att vilja berika forskningen med sitt historiska perspektiv* och *Att göra gott för andra*. De äldre personernas involvering påverkades av att de befann sig i en kontext där deras förutsättningar påverkades av deras erfarenheter av *Att leva i en skör tillvaro*. Att vara involverad i forskning innebar att de som deltagare utmanade sig i det ovana i *att befinna sig på någon annans hemmaplan*. Denna utmaning påverkade om de var nöjda med hur deltagande såg ut eller om de kunde hitta nya drivkrafter till involvering. Det beskrivs i subkategorierna: *Att tvivla på sin roll* och *Att växa som forskningsdeltagare*. Hela denna process symboliseras i kärnkategorin *Att utmanar sig själv på forskningsvärldens tröskel*.



Figur 1. Visualisering av processen involvering i forskning från sköra äldre personers perspektiv

### 4.2 STUDIE II

Personal på särskilda boendes erfarenheter av att samskapa hälso- och sjukvård med sköra äldre personer visade på det övergripande temat *Att röra sig från objekt mot person* som beskriver hur den samskapande processen blev en ögonöppnare för hur personalen såg på de sköra äldre personerna men också på sig själva. När de arbetade tillsammans i ett gemensamt projekt blev personalen medvetna om de sköra äldre personernas personligheter och upptäckte förmågor som tidigare dolts av personal-boende relationen. Den samskapande processen förändrade dynamiken mellan personalen och de sköra äldre personerna från att vara personal som bara tog hand om boende mer som objekt till att de sköra äldre blev personer som de kunde samarbeta med i ett gemensamt projekt. Denna förändring tolkades starta med att personalen upptäckte de sköra äldre personernas oväntade förmågor vilket hjälpte personalen att möta de sköra äldre personerna där de befann sig för tillfället. Detta gav i sin tur deltagarna nya insikter och perspektiv som fick dem att inse att de kunde vara mer av en person i sin yrkesroll och stärkas i att bli företrädare för vad de sköra äldre personerna hade för behov. Hela den här processen beskrivs i fem subteman: *Att upptäcka sköra äldre personers oväntade förmågor*, *Att möta varje person där den är*, *Att vinna nya insikter och perspektiv*, *Att bli mer av en person i sin yrkesroll* och *Att bli företrädare för äldre personers behov*.

### 4.3 SLUTSATSER STUDIE I OCH II

Resultaten från studie I och II bidrar med förståelse om hur sköra äldre personer kan och vill involveras i forskning, och att de har en varierande kapacitet att kunna delta. På vilket sätt är dock svårt att veta innan de fått chansen att involveras. Genom ett personcentrerat förhållningssätt och genuint samarbete med forskare och personal kan sköra äldre personer till exempel få chansen att känna efter vad de vill och kan göra. Våra resultat talar alltså för att det är problematiskt att på förhand bestämma hur sköra äldre personer kan vara involverade och att det i mötet, relationen och samarbetet finns potential för nya perspektiv och kunskap att skapas. I relationen mellan forskare eller personal och de sköra äldre personerna finns möjligheter men också hinder utifrån de olika världar och perspektiv de representerar. Det verkar till exempel finnas en motsättning mellan personal på särskilda boendes förståelse av kapabiliteten hos sköra äldre personer och deras erfarenhet av hur det kan förändras under och efter ett gemensamt samskapande utvecklingsprojekt. Att involvera både personal och sköra äldre personer i ett samskapandeprojekt skapade värden som påverkade mer än bara projektet i sig, genom att det förändrade dynamiken i relationen dem i mellan och förstärkte förståelsen för såväl varje persons kapabilitet och betydelsen av att mötas som personer.

## 5 DISKUSSION

Det finns ett ökat intresse för brukarinvolvering i forskning (22), men det finns fortfarande frågetecken kring vem som ska ges möjlighet att vara involverad, när i forskningsprocessen de ska involveras och hur (1). Både de sköra äldre personerna i studie I och personalen i studie II verkade bli förvånade över den förmåga som fanns inom gruppen sköra äldre personer att bidra till forskning. Denna samstämmighet talar för att det kan finnas ett övergripande tema som skulle kunna förklaras med att sköra äldre personer påverkas av epistemisk orättvisa, alltså att deras utsagor inte tas på allvar. Det skulle också kunna bero på att det saknas forskning om hur deras upplevelser och perspektiv kan förstås då det traditionellt inte varit av intresse (2). Föreställningar om vad det innebär att vara äldre verkar också påverka äldre personers förutsättningar och möjligheter att vara involverade i forskning. Tidigare forskning om hur vi införlivar åldersstereotyper i vårt medvetande beskriver hur åldersstereotyper blir internaliserade under hela vår livslängd, och att de kan påverka människor på ett omedvetet plan. Både positiva och negativa åldersstereotyper blir självuppfyllande profetior riktade mot befintliga åldersrelaterade stereotyper. Synen på olika åldersstereotyper börjar i barndomen och utvecklas över en persons hela livslängd mot ålderdom och det finns en korrelation mellan hur vi ser på kronologisk ålder och psykologisk, social och biologisk hälsa (46).

Våra resultat visar på att sköra äldre personer i likhet med andra grupper finner det meningsfullt att bidra till utveckling och ny kunskap (26, 47). Att ge sköra äldre personer förutsättningar att involveras i forskning är extra viktigt då de har beskrivits av Avanzo med kollegor (48) som en grupp som ofta har förlorat sina möjligheter att påverka sin omgivning (48). Det går att argumentera för att möjligheten till brukarinvolvering i forskning är en grundläggande demokratisk princip som kan stödja sköra äldre personer att bli fullvärdiga medborgare. Hur utfallet av brukarinvolvering med sköra äldre personer blir verkar dock bero mycket på hur relationen mellan de sköra äldre personen och den som de samarbetar med är, men också vilket utrymme som ges för att relationen ska kunna utvecklas. I studie II två ledde samskapande av hälso- och sjukvårdstjänster till exempel till att personalens relation med de sköra äldre personerna förändrades, även utöver ramen för projektet. Det gemensamma projektet underlättade för dem att bli personer i relation till varandra. På likande sätt beskrev de sköra äldre personerna i studie I att de utmanade sig själva till att vara involverade i forskning och hur det resulterade i att de växte i rollen som forskningsdeltagare, trots att de upplevde att det kändes som om de befann sig på någon annans hemmaplan. Resultaten visar därmed hur central relationen mellan de sköra äldre personerna och de som leder projektet (personal eller forskare) är.

Att kunna bemöta sköra äldre utifrån deras nivå och behov verkar också vara av betydelse för att kunna involvera den heterogena gruppen sköra äldre personer i forskning. Våra resultat pekar på att det finns en stor variation vad gäller hur sköra äldre personer kan involveras i forskning utifrån deras egna förutsättningar och önskemål. Ett förhållningssätt som forskare som vill involvera sköra äldre personer i forskning kan ha för att möta den heterogeniteten är enligt Buck med kollegor (28) att vara både flexibel och lyhörd. Det innebär att ge utrymme för de personer som involveras som brukare att påverka hur och i vilken omfattning de önskar vara involverade under projektets gång, det vill säga att det inte är bestämt på förhand. Buck med kollegor (28) liknar ett sådant samarbete med en gemensam strävan mot ett mål, där samarbetet syftar till att optimera både brukarnas och forskarnas roller och kunskap och på så sätt underlätta ett reellt delande av makt (28).

Att som forskare vara flexibel och lyhörd kan dock utmana traditionella forskningsideal som objektivitet och strävan efter ett rent urval. McCormack (15) beskriver att dessa forskningsideal bör kombineras med en strävan efter samarbete och ökat engagemang från personer utanför akademien samt en ökad uppskattning för deras unika kunskap (15). Samtidigt visar resultaten i både studie I och II att relationen mellan sköra äldre personer, forskare och personal påverkas av ett maktförhållande i och med att det var personalen och forskarna som bestämde vem som skulle involveras och hur involveringen skulle genomföras. Gaby med kollegor (49) menar att maktförhållanden i relationer påverkar utfallet då de olika berörda parterna kan ha olika förväntningar, intressen, behov och känslor utifrån deras olika kontexter och expertisområden. I studie I kunde detta ses i och med hur de sköra äldre personerna upplevde att de befann sig på forskarens hemmaplan och i studie II fanns exempel på detta i hur personalen var de som blev stärkta i att vara uttolkare av de sköra äldre personernas verkliga behov. Dessa ojämlika relationer, skapade av rådande ideologier och strukturer som kan reducera forskningsdeltagare till objekt, kan utmanas genom att forskare har ett personcentrerat förhållningssätt gentemot deltagarna. Ett personcentrerat förhållningssätt inom forskning bygger på att alla involverade är personer som är relationella varelser, att det är i våra relationer till andra människor som vi kan växa, och att det är i mötet mellan forskare och deltagare som ny kunskap kan skapas (49). Våra resultat påvisar, i likhet med det som Gaby med kollegor (49) beskriver, att brukarinvolvering i forskning kan leda till en känsla av stärkt egenmakt genom att brukarna får bygga sin kapacitet i samarbete. Både studie I och II visar på att om det finns ett genuint intresse över att göra sköra äldre personers röster hörda och erkända, så går det att genom dialog skapa ett utrymme för kommunikation där sköra äldre personer med sin expertis kan få komma till tals och där olika perspektiv kan ses som en styrka i samarbetet. För att den kunskap som skapas i relationen med sköra äldre personer ska

kunna förstås utifrån sitt sammanhang krävs det däremot också att forskaren antar ett kritiskt reflexivt förhållningssätt. Detta kräver att forskaren själv är medveten om sin egen ställning och status (49). Ett personcentrerat förhållningssätt inom forskning kan vara ett sätt för forskaren att vara mottaglig och flexibel för de sköra äldre personernas förutsättningar och utifrån det bidra till att optimera de sköra äldre personernas inflytande.

Att vara involverad i forskning som brukare ställer också krav på brukaren och kan i sin tur leda till exkludering av sköra äldre personer i förmån för yngre och friskare personer som anses bättre lämpade att vara aktiva brukare involverade i ett forskningsprojekt. Ett forskningsprojekt är till exempel ofta omfattande och tidskrävande och kan löpa över flera år. Många sköra äldre personer har en kort förväntad livslängd (9) vilket får konsekvenser för hur man bör tänka kring involvering av sköra äldre personer i forskning. Deras involvering kan behöva en aspekt av här och nu. En annan aspekt är att brukarinvolvering ofta diskuteras utifrån termer som att brukare ska vara aktivt involverade i motsats till att passivt delta i forskning som datakälla (22). Frågan är utifrån vems perspektiv och förutsättningar det ska bedömas om någon är aktivt involverad eller ej. De sköra äldre personerna i studie I hade alla deltagit i en tidigare studie, framför allt som datakällor (42). Vissa skulle då kunna argumentera för att de inte varit synnerligen aktiva i forskningsprocessen, men fynden i studie I talar för något annat. De sköra äldre personerna beskrev en stor stolthet över att de hade deltagit i forskning och de upplevde verkligen att de aktivt gjort sina röster hörda. Från vems perspektiv och förutsättningar ska ett sådant deltagande utvärderas? En annan fråga som väcks är om mer brukarinvolvering alltid leder till forskning av högre kvalitet. Enligt Barber med kollegor (27) finns det ingen konsensus om hur brukarinvolvering ska utvärderas (27) och det är svårt att uttala sig om det underliggande antagandet att ju mer involverad brukare är i forskningsprocessens olika delar desto högre kvalitet på forskningen blir det. Detta relaterar också till den risk med brukarinvolvering i forskning som rapporterats kunna uppstå från krav från finansärer och beslutsfattare. Det kan påverka forskningsberoende och till att forskare har brukarinvolvering i sin forskning för att tillfredsställa finansärer och inte utifrån att det skulle gynna forskningens frågeställningar och syfte (28).

## 5.1 METODDISKUSSION

Denna uppsats är baserad på två studier med kvalitativ metod. Anledningen till att vi valde två kvalitativa metoder är att uppsatsen har en explorativ ansats och studierna syftade till att utforska tidigare utforskade områden. Båda

studierna bygger på en socialkonstruktivistisk syn där syftet med studierna inte är att hitta den objektiva sanningen utan att bidra med förståelse för de studerade fenomenen. Det socialkonstruktivistiska perspektivet har också guidat oss i att ny kunskap sker i mötet och utbytet mellan forskaren och forskningsdeltagaren (50).

Forskning om åldrande och hälsa är ett komplext område som involverar forskare från många olika traditioner. Det kan bland annat ses i vårt interdisciplinära forskningsprogram UserAge (1) där flera olika vetenskapliga metoder tillämpas för att studera brukarmedverkan utifrån olika perspektiv. De kvalitativa studierna i denna uppsats kommer därmed att kompletteras med en mångfald av studier gjorda med såväl kvalitativa som kvantitativa metoder.

Genom att använda skörhet istället för kronologisk ålder så undviks problemet med att klumpa ihop den stora heterogena gruppen äldre. Trots det finns det risker. Krumer-Nevo (51) menar att göra kvalitativa studier med sköra äldre personer som är en grupp som samhället stereotyp har identifierat som sårbara kan leda till att grupper delas upp i ”vi” och ”dem”. Vissa egenskaper i ”dem” skiljs då från oss själva och det är dessa egenskaper som gör att gruppen ”dem” ses som sårbara. Krumer-Nevo (51) hävdar vidare att kvalitativ forskning blir en arena för andrafring (othering), där forskaren och till exempel personen som intervjuas både skapar bilder av sig själva och den andra, vilket kan resultera i en förstärkning av stereotyperna istället för att presentera ett nytt perspektiv. Att identifiera någon som ”dem” riskerar att leda till att personen blir ett objekt istället för en person med komplexa egenskaper (51). För att motverka andrafring av deltagarna i våra studier inspirerades vi under forskningsprocessen av etiken från personcentrering och försökte flytta över inflytande till deltagarna genom att vi som forskare tog en position som nyfikna lyssnare. Nyfikna på att höra vad de hade att säga och tydliga med att det var de som forskningspersoner som var experter på de fenomen som vi var ute efter att undersöka. I socialkonstruktivistisk forskning ses dessutom forskaren som en aktiv part i kunskapskapandet och det blir då viktigt för forskaren att reflektera över sin egen roll i studierna. Detta betonas som extra viktigt av Charmaz (36) inom grounded theory. Att arbeta reflekterande innebär att forskaren genom sin forskning förhåller sig reflekterande till forskningsdeltagarna och hur de representeras i studierna (36). I studie I skrevs memon som fältanteckningar över varje intervju och under analysen för att under hela forskningsprocessen bibehålla reflektion över den egna rollen som forskare. Grounded theory användes i studie I eftersom den är lämplig för att undersöka processer som inte tidigare har undersökts. Ofta används grounded theory för att konstruera en självständig teori, en teori som förklarar något i ett begränsat sammanhang. Målet i studie I var inte att konstruera en självständig teori utan att bidra med en ökad förståelse för de processer som

lägger grunden för hur sköra äldre personer kan tänka sig att vara involverade i forskning (36).

Genom att vi rekryterade deltagare till studie I från ett annat forskningsprojekt är det möjligt att det var de mest forskningspositiva personerna som valde att delta då de som minst valt att delta i två olika studier. Detta kan ha påverkat resultatet och det hade varit intressant att intervjua ett urval av mer forskningsnegativa personer. Det är tyvärr svårt att genomföra då det är både omöjligt och oetiskt att göra forskning på personer som inte önskar delta. Valet att rekrytera via telefon eller via brev kan också ha lett till det som kallas indirekt exkludering (9), eftersom de rekryteringsmetoderna kanske inte passar alla potentiella deltagare. Rekryteringsförfarandet innebar också att vi inte kunde ha full kontroll över urvalsprocessen, vilket kan ha påverkat urvalet.

Till studie II gav fokusgruppsmetodologin oss möjlighet att studera den kollektiva förståelsen av personal på särskilda boendens erfarenheter av att samskapa med sköra äldre. Tidigare forskning har visat på att personal är en viktig grupp som både kan möjliggöra och hindra sköra äldre personers möjligheter till att vara involverade i forskning (13). Genom att samla personal i fokusgruppsdiskussioner om sina erfarenheter kunde studie II visa på en variation av förståelse och hur deltagarna skapade förståelse i samspel med varandra (52). Ett annat resultat kunde ha nåtts om deltagarna i studie II istället hade intervjuats individuellt, fokus hade då varit på den enskilde personens förståelse av fenomenet istället för den kollektiva förståelsen. En styrka med fokusgrupper som beskrivits av Dahlin-Ivanoff och Holmgren (52) är att det ger makt till deltagarna då det är deltagarna som är experter på området som diskuteras och att de är i numerärt överläge (52). En annan styrka med fokusgruppsdiskussionerna i studie II är att deltagarna kände varandra sedan tidigare och att de hade gemensamma upplevelser som de tog tillfället i akt att diskutera. Det blev därmed dynamiska diskussioner och innehållet av diskussionerna berodde mer på graden av involvering hos deltagarna än antalet deltagare i varje grupp. Just möjligheten att få reflektera i grupp är en av styrkorna med fokusgruppsmetoden, och har beskrivits som ett sätt att skapa medvetenhet (39, 53, 54). Det finns däremot en risk med att göra fokusgruppsdiskussioner med personal från samma organisation i och med att det kan finnas informella ledare och olika status bland deltagarna som kan hindra dem från att fritt uttrycka sina åsikter. Det kan också finnas en rädsla för att på något sätt bli bestraffade om de kritiserar den egna organisationen (37). Till exempel kan deltagarna i studie II ha känt ett tvång att delta i fokusgrupperna då de skedde i samarbete med deras arbetsplats, trots att de fick information om att deltagande i studien byggde på frivillighet.

## 6 SLUTSATS

Från ett mänskliga rättigheter perspektiv bör sköra äldre personer ha samma rättigheter som andra grupper att göra sina röster hörda och påverka forskning som angår dem. Att exkludera människor från forskning baserat på ålder, utan en tydlig motivering, är att betrakta som åldersdiskriminering och ett hinder för Världshälsoorganisationens (WHOs) mål för hållbar utveckling i relation till rättvisa, minskad ojämlikhet och god hälsa (55). Brukarinvolvering i forskning skulle kunna vara ett steg mot såväl rättvisa som jämlik och god hälsa, om forskningen utgår från sköra äldre personers verkliga resurser. Våra resultat talar för att det finns möjligheter att utforska nya utrymmen att skapa kunskap i möten mellan forskare och sköra äldre personer. För att det ska bli möjligt visar våra resultat dock att forskarna då behöver ha ett flexibelt och reflekterande förhållningsätt. Sköra äldre personer är en heterogen grupp och varje person bör få chans att bli involverade utifrån sina förmågor och önskemål. Vi menar därmed att sköra äldre personers involvering i forskning måste förstås utifrån deras kapabilitet, att involveringen måste ske utifrån den sköra äldre personens perspektiv, förutsättningar och förmågor. För att kunna bedriva forskning med brukarinvolvering med sköra äldre personer måste de ges chansen att tacka ja till involvering utifrån sina uppsatta mål, men också ha friheten att säga nej till de delar som de ej har kapabilitet för. Detta innebär utmaningar för forskare som önskar involvera sköra äldre personer, i och med att det är svårt att på förhand veta hur ett gemensamt forskningsprojekt kommer utveckla sig. Denna uppsats bidrar med kunskap om hur utmaningar kan överbryggas, bland annat genom att den ständiga referenspunkten är med och inte bara för. Förhoppningen är att denna kunskap kan ligga till grund för framtida projekt som syftar till att involvera sköra äldre personer i forskning.

## 7 FRAMTIDA PERSPEKTIV

Några av de poänger som denna uppsats tar fasta på är viktiga budskap till dagens akademiska värld. Det första är att se potentialen i sköra äldre personer och ge dem en chans att vara involverade i forskning. Involvering av sköra äldre personer i forskning kan vara en nyckel i de utmaningar världen står inför globalt, med en demografisk utveckling med en allt mer åldrad befolkning. Forskningsvärlden måste se sin roll i de epistemiska orättvisor som finns i samhället och forskare bör fundera över vilka konsekvenser det kan bli om äldre personer exkluderas utan motivering utifrån studiens syfte. Det gäller även indirekt exkludering och hur det påverkar forskningens relevans. För det andra, finns det i våra explorativa resultat nya viktiga frågor att utreda vidare. Till exempel är ett förslag för framtida forskning att utforska hur sköra äldre personers involvering i forskning kan implementeras och optimeras genom ytterligare kvalitativa, men också genom kvantitativa studier. Det vore exempelvis intressant att kvantitativt undersöka vilka sköra äldre personer som väljer att delta eller vara involverade i forskning, och hur detta påverkas av skörhet och deltagande i andra aktiviteter. En annan viktig grupp vars perspektiv saknas i denna uppsats studie är forskarnas och studier kring forskares syn på involvering av sköra äldre personer i forskning vore ett viktigt bidrag till optimeringen av brukarinvolvering i forskning om åldrande och hälsa.

## TACK

Forskningen som ligger bakom denna uppsats är inget som skett i ett isolerat vakuum, det är många som har varit involverade i att denna uppsats tillkomst. Stort tack till alla som bidragit med kunskap, stöd och engagemang.

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RESEARCH ARTICLE

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# Challenging oneself on the threshold to the world of research – frail older people's experiences of involvement in research



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## Abstract

**Background:** User involvement of people outside academia in research is argued to increase relevance of research for society and to empower the involved lay persons. Frail older people can be a hard to reach group for research and thus an underrepresented group in research. There is a lack of knowledge how collaboration with frail older people should be best performed. Therefore, the aim of this study was to explore frail older people's experiences of involvement in research.

**Methods:** In this study we have invited people, 75 years of age or older screened as physically frail and who have previously participated in a study as data sources, to share their experiences by intensive interviewing. Data was collected and analysed in parallel inspired by a constructivist grounded theory approach.

**Results:** The results demonstrate how frail older people have different incentives, how their context of ageing and the unusual position of being involved in research altogether influenced how, where and in what way they wished to be involved in research. This is described in three categories: *Contributing to making a difference for oneself and others*, *Living a frail existence* and *Being on somebody else's turf*. The categories compose the core category, *Challenging oneself on the threshold to the world of research*, which symbolises the perceived distance between the frail older people themselves and the research world, but also the challenges the frail older people could go through when choosing to be involved in research.

**Conclusions:** Frail older people have a varied capacity to participate in research, but in what way and how is difficult to know before they have been involved in the process of research. Our results advocate that it is problematic to exclude frail older people a priori and that there is a potential for new perspectives and knowledge to be shaped in the encounter and in the relationship between the researcher and the frail older person. For research to be able to cater for frail older people's needs of health services, their voices need to be heard and taken into consideration.

**Keywords:** User involvement, Frailty, Person centred, Grounded theory, Ageing, Patient and public involvement, Research participation

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## Background

There are several different reasons as to why researchers may choose to involve people outside of academia in research projects. One reason is to have people outside academia to influence the design and conduct of the study and thus increase the relevance of research findings for society as a whole and to empower lay persons when collaborating with researchers [1]. Another reason is due to the problem of underrepresentation of very old or frail older people in research. However, there is a lack of knowledge and structure for how and when research could be conducted involving frail older people. Our previous research has intended to involve the target group of frail older people in the planning and implementation of research, but involving and collaborating with frail older people has not always been easy [2, 3]. Due to their health status as frail, they can be a hard-to-reach group [4]. Barriers for user involvement could be their degree of frailty, morbidity and disability.

One reason for frail older people's underrepresentation in health research could be that they are often directly excluded from participation, for example in randomised controlled trials. This exclusion could be based on notions that they would not be able to participate, or that the results would not be beneficial to them [5]. In a review, Thake & Lowry (2017) describe that 92.8% of the investigated clinical trials that had a specified upper age limit did not include any justification of why this was the case [6]. As frail older people often have several illnesses, they can also be excluded indirectly from research in the quest for a 'clean sample' in the population studied [5]. An example of indirect exclusion is how frail older people are excluded by the fact that it is a common requirement for participation in research to have cognitive abilities intact [7]. Therefore, frail older people's underrepresentation runs the risk of results from health research being irrelevant for them and that it might be difficult to organise healthcare that will be able to meet frail older people's needs.

User involvement in research is a way of involving lay people in research and thereby make it more relevant and closer to the group of users that the research aims to benefit [8]. The users can be involved in one or more of the different parts of the research process, such as contributing to the determination of research questions, project applications, data collection, analysis, compilation and dissemination of results. There is a difference between user involvement and participation in more conventional research as data sources [1]. In contrast to participating as data sources, user involvement in research provides a possibility for new knowledge spaces to be created, where knowledge can be co-created in collaboration between researchers and lay persons [9]. One consequence of the direct and indirect exclusion of frail

older people is that there is no scientific evidence on how research in collaboration with frail older people should be performed. Therefore, in order to fill the current knowledge gap about how involvement of frail older people in research could be optimised, the aim of this study was to explore frail older people's experiences of involvement in research.

## Method

### Design

A qualitative design inspired by Charmaz's [10] constructivist grounded theory was chosen for the study. This is a method suitable for studying processes and exploring actions in their context, where research and data are constructed in the interactions between researchers and participants. Constructivist grounded theory contributes with understanding rather than trying to explain the process that is studied [10]. The method was chosen in order to be able to give an increased understanding of frail older people's involvement in research based on their thoughts and experiences.

### Participants

To be able to explore frail older people's experiences of participating in research, participants were recruited among people 75 years of age or older, who all had previous experiences of participating in a randomised controlled study [11]. In that study, they had all been screened as physically frail [12]. Contact details of potential participants were given to us by the researchers responsible for the study where they all had participated previously. In that study, the participants had been assessed repeatedly with quantitative interviews and physical tests in their own homes. However, what mattered was not what they had done in the study but that they all had some experience of participating in research, which was the point of departure for our project. Initial sampling criteria were set up aiming for diversity in age, sex, cognitive status [13], living situation, dependency in activities of daily living [14] and level of education. No exclusion criteria were set up because the aim was to invite a group of frail older people as diverse as possible to participate. This was in order to give them the opportunity to choose for themselves whether or not they perceived themselves of being capable of participating. A total of 31 potential participants were contacted at the hospital, or by phone if they had been discharged. Potential participants who did not answer the phone ( $n=3$ ) were sent a letter with information about the study and contact information. In total, 14 participants could not be reached ( $n=7$ ) or declined to participate ( $n=7$ ). Thus, 17 participants aged between 76 and 95 years were included, out of which eight were women and nine were men. Participants' characteristics are shown in Table 1.

**Table 1** Participants' characteristics,  $n = 17$

Variables	Value
Age, median (range)	85 (76–95)
Men, n (%)	9 (53)
Dependency in ADL, median (range) <sup>a</sup>	3 (1–9)
Higher education, n (%) <sup>b</sup>	6 (35)
Living alone, n (%)	10 (59)
Living in a nursing home, n (%)	3 (18)
MMT, median (range) <sup>c</sup>	28 (21–30)
Screened frailty factors, median (range) <sup>d</sup>	3 (2–4)
Decreased endurance, n (%)	16 (94)
Tired (last 3 months), n (%)	12 (71)
Fall tendency/fear of falling, n (%)	9 (53)
Help with grocery shopping, n (%)	9 (53)

<sup>a</sup>Degree of dependence in Activities of Daily Living (ADL) A higher score equals higher dependency [14]. Since continence was not considered an activity, nine was the max score

<sup>b</sup>Tertiary education (university or college)

<sup>c</sup>Mini-mental test [13]

<sup>d</sup>FRESH-Screen [12]

### Data collection and analysis

The data collection and analysis were conducted in parallel in accordance with grounded theory [10]. The data was collected through intensive interviewing using an interview guide with a number of question areas. The question areas focused on the participants' experiences of involvement in research, the different parts of the research process and how their involvement in research could be influenced. For instance, they were asked about their thoughts on identifying research topics, designing studies, data collection and dissemination of findings in relation to research in general, based on their previous experiences. In line with Draucker et al. [15], the question areas were updated during the study process as a way of theoretical sampling to modify the data collection procedures to deepen the understanding of emerging concepts [15]. The interviews started with an open question: 'Can you please tell me what it was that made you choose to participate in a research study?' Follow-up questions were also used, for example 'can you please give me an example of ...' or 'how do you mean when you say ...' [10].

The interviews were conducted between February 2018 and March 2019 by three of the authors (IB ( $n = 15$ ), EB ( $n = 1$ ), SDI ( $n = 1$ )). The time and place for the interviews was chosen by the participants, and they all chose to be interviewed in their homes. Saturation was considered after 13 interviews, when the analyses did not yield any new findings on the questions studied. In the interviews that followed no new concepts emerged. The interviews lasted between 14 and 86 min, with a mean of 49 min. All the interviews were recorded

digitally and transcribed verbatim. The qualitative data analysis software NVIVO pro 12 was used to organise and manage the interview data. The methods of initial coding, focused coding, constant comparison and memo-writing were used when analysing the data.

Firstly, the interviews were read/listened to as a whole, and thereafter an initial coding started using line-by-line coding. When coding line by line, the codes stayed close to the data and were mostly expressed in terms that attempted to capture actions and their connections to emotions and feelings. Thereafter the codes were organised into tentative categories to describe the participants' different processes [10]. Secondly, focused coding was used to go through a larger amount of data, testing the meaning of the tentative categories. A constant comparison of codes/data within and between interviews using the tentative categories resulted in new categories with specific subcategories. The data was re-examined several times in an iterative process between the essence of the interviews and the meaning of the emerging categories and subcategories.

Field note memos were written soon after each interview, describing the context and setting. After the first examination of every interview, an analytical memo was written with a first impression. These memos were then used to identify different processes to examine further in coming interviews and the ongoing iterative process of analysis. Analytic memos were also written during the whole process of analysis to be able to compare codes, ideas and emerging categories both between and within the interviews [10]. In the results, quotes are used to give voice to the participants. All quotes are translated with breaks and repetitions removed for increased readability. All participants have been given pseudonyms. The numbers in brackets refer to which interview the citation is taken from.

### Ethics

This study followed the ethical principles of the World Medical Association's declaration of Helsinki [16], and was approved by the Regional Ethics Committee at the University of Gothenburg (DNR T097–18). The participants were frail older people, some of them with cognitive impairment, who could have been considered a vulnerable group, and therefore they could have been excluded from participating. In the Helsinki declaration it is stated, however, that underrepresented groups should "be provided appropriate access to participation in research" [16] and this guided the inclusion of participants in the present study. To give the participants appropriate access, the language used in the information letter was adjusted by using short sentences and a large font size. Before the start of each interview, the participants had time to read the information and get it

verbally from the interviewer. They were informed about the aim of the study, the voluntariness of participation, that they could terminate their involvement at any time without needing to give a reason, and that their involvement would not in any way affect their regular care or medical treatments. All interviews were conducted by healthcare professionals experienced in working with the target population and all participants were deemed competent to consent.

## Results

From the perspective of the participants, the experience of being involved in research was understood as a process (see Fig. 1) that started in the category of *Contributing to making a difference for oneself and others*, which gave the participants the incentive to be involved in research and place themselves on the threshold to the world of research. This is described in the following subcategories: *Getting a break from everyday life*, *Wanting to address everyday problems*, *Wanting to enrich research with one's historical perspective*, and *To do good for others*.

The participants' involvement was influenced by them being in a context where their circumstances were influenced by *Living a frail existence*. Being involved in research meant that they as participants challenged themselves by placing themselves in the unusual position of *Being on somebody else's turf*. This challenge in turn influenced whether they were content with their participation or whether they could find new incentives for involvement, which is described in the subcategories of *Doubting one's role* and *Growing as a research participant*. This process is symbolised in the core category of *Challenging oneself on the threshold to the world of research*.

### Contributing to making a difference for oneself and others

When asked to participate in research, an opportunity of *Contributing to making a difference for oneself and others* was given, which worked as an incentive or motive for participation. By contributing to research, they were given the opportunity to influence their lives, both directly by being involved but also by using the occasion as a way of giving voice to their experiences. They were thus motivated both by selfish and more altruistic ideals. Four subcategories were identified; *Getting a break from everyday life*, *Wanting to address everyday problems*, *Wanting to enrich research with one's historical perspective* and *To do good for others*.

### Getting a break from everyday life

For the participants, one motive for getting involved in research was that they could get a break from everyday life and were given the opportunity for social exchange with a researcher. This meant that by being involved in research, they were given the opportunity to get time with another person, which was something they missed in their everyday lives. That it was a research activity mattered less than the interpersonal exchange taking place and that something out of the ordinary happened. As Majken described being visited by a researcher:

'It's fun, everything that happens is fun. You know, you're so incredibly lonely when you are this old. So you welcome every break with open arms' [Interview 4]

### Wanting to address everyday problems

By being involved in research, the chance was given – or taken – to address problems close to everyday life. It was seen as an opportunity to talk about situations and

events from everyday life or life in general that they experienced might be improved by more research. This could be self-perceived problems, things that had affected others nearby but also analyses of things that they had seen or come across in their surroundings. In dialogue with researchers, who the participants generally considered to be working with social development, a space was created for the frail older persons to express their concerns, perceived problems or other things that they wished that researchers would be able to contribute towards improving. One example of this was when Bengt said at the end of the interview:

'I've got this thing ... I don't know if it has anything to do with this, but I am absolutely not happy with it, and there are many [who think] like me, and that's accessibility when it comes to primary care' [Interview 8]

### Wanting to enrich research with one's historical perspective

The participants saw themselves as an important group that should be given a greater opportunity to enrich research as they by virtue of their age have experiences and a historical perspective that no other group in society has. They described how they could make historical comparisons based both on their own personal experiences and experiences they shared with other older people. The participants experienced that society in general was bad at utilising older persons' viewpoints and that by being involved in research, they would be able to enrich research and social development. For example, Allan described how older people's involvement in research could make a difference:

'Completely different questions and different perspectives so to speak. That would be appreciated on both sides I think.' [Interview 5]

### To do good for others

Involvement in research was described as an opportunity to be of use and make a positive contribution for others. This was because research was seen as something that contributes to progress and helps society to develop for the better. The participants also wanted to contribute on an interpersonal level by helping the researcher they had personal contact with to succeed with their project. The participants considered it to be their duty to participate and contribute if they could. The most important thing was not what the research was about but that it was them as persons who had been asked. Considering themselves to be representatives for their own group added to the motivation the participants felt to do good for research that could help the whole group of frail older

people. One example can be found in how Ulla-Britt explains why she decided to be involved in research:

'No, I'm thinking why wouldn't one do it. If it helps someone in some way ... Of course one should do it.' [Interview 6]

### Living a frail existence

Living a frail existence was characterised by living with physical and social changes when everyday life is influenced by ageing. Ageing meant living with various physical limitations and illnesses that impacted on the conditions for how and where it was possible for them to be involved in research. As Göran who lived at a retirement home and used a wheelchair described the importance of the researcher making home visits:

'I have very much been stuck here ... Way too much ... So I have gotten problems with my legs. I'm handicapped' [Interview 10]

Ageing was described as a process with a changing social situation and diminishing social network as both family members and acquaintances their own age pass away. Living a frail existence was experienced as a change in the activities participants now were able to partake in compared to before. Märta, who only left her apartment once per quarter year, described this changing social network:

'Because when all old friends are gone you get so lonely. And the kids, they have their own families and jobs after all so they can't be with grandma all the time. It's not possible' [Interview 1]

There was both a carefulness and a longing to be involved in different types of activities because they had already stopped or been forced to cut back on activities in their lives. Having fewer activities and a diminished social network led to the experience that frail older people were outside of social development and that they were of lower status as a group.

### Being on someone else's turf

When meeting with the researcher, the participants experienced inequality when they compared themselves to the high status and expertise that they experienced that the researcher stood for. Being involved in research was something new and unfamiliar that was not part of the participants' everyday lives. The research topic played into the participants' sense of insecurity in various ways depending on the extent to which they felt that the research came close to their own area of expertise, namely their everyday lives. Even when the researcher visited



**Fig. 1** A figure to visualise the processes of the participants' experiences of involvement in research and how the categories interact

the participants in their everyday lives, they experienced it as though they were on somebody else's turf. This was due to the fact that the visit was characterised by it being the visiting researcher who was in charge and controlled the conditions for how and when the participants were in the research process, which information they were given and when their role as research participants was over.

Two subcategories were identified; *Doubting one's role* and *Growing as a research participant*. These were two different dynamic processes that to varying extents occurred simultaneously in the research participants and influenced how participants viewed their contribution to research and how they felt about further involvement in research.

#### ***Doubting one's role as research participant***

There was an uncertainty surrounding the expectations of what the role of a research participant would entail. The participants saw themselves as amateurs and were not sure about what they could contribute with as compared to other persons who they thought were better suited. Research was perceived as something that others do. When it was considered difficult to participate in research, the participants found comfort in the fact that a researcher had deemed them suitable to be involved in research. They dealt with their insecurities as research participants by doing as well as they could, at the same time as they tried to give the best possible answers based on what they expected that the researcher wanted to hear. Sune expressed his insecurities about what he would be able to contribute with:

Sune: No ... No so I think that I don't have much to contribute.

Interviewer: No.

Sune: No, I don't you see.

Interviewer: To ... To research or to the conversation?

Sune: To what you are after.

Interviewer: No. You say many interesting things Sune.

Sune: What?

Interviewer: You say many interesting things.

Sune: Yes. That can happen [Interview 14].

#### ***Growing in one's role as research participant***

In the process of research, as participants were affirmed by the researcher in that their experiences and thoughts were important and interesting, they also felt affirmed in being important to society and able to make a positive contribution. The respect that they felt they were given by the researcher influenced not only how the participants saw their involvement in the research process, but also how others in their surroundings were influenced in that they experienced the participants as being more respected as persons. One example of how participants thought they were being more respected by people in their surroundings can be found in Märta proudly showing a diploma that she received as a thank you for participating in another study:

"Märta: Yes, I don't know but they [home health service staff] admire me differently. [they say] - Do you have a diploma, from the university.

Interviewer: Then they are impressed?

Märta: Yes, they are impressed. So am I. It's a bit haughty to show this. They take a look, [and say] - what's that? What have you been involved in?

Interviewer: You show the home health service staff?

Märta: Sure, they get to see it. I have it out, so they all can see it." [Interview 1]

By growing as research participants, an interest and desire to be more involved could be evoked. The key to further involvement consisted of that researchers assessed them as valuable and of what would be demanded of them as participants.

#### ***Challenging oneself on the threshold to the world of research***

The core category of *Challenging oneself on the threshold to the world of research* symbolises the process that the participants went through when they reasoned with researchers based on their experiences of how they as persons could consider to be involved in a research project. The threshold to the world of research symbolises the distance they experienced between those who conduct research and those who participate in it. The way and the extent to which they wished to be involved in research ranged from standing on the threshold and being observed as an object on one end, to taking a step into the room of research and being involved as a partner on the other.

The participants' motives for challenging themselves on the threshold to the world of research were influenced by their experiences of the frail lives they were living, but also by the experiences they gained from being involved on someone else's turf and the incentives that this could give.

On the threshold, they were striving for equilibrium, and the challenge lay in balancing one's own preconditions against the expectations growing out of the contrast of living a frail life and the unfamiliarity of being on someone else's turf. This can be understood as a thought process where the participants sought to find their own role and form of involvement by assessing their capabilities in relation to what they themselves and the researchers wished for them to do.

#### **Discussion**

The aim of this study was to explore frail older people's experiences of involvement in research. The results showed that there seems to be variation in how frail older people want to and can be involved in research. This experience is shown in the core category *Challenging oneself on the threshold to the world of research* that is influenced by several different sub-processes that interact with one another. The study thereby contributes with knowledge on frail older people's experiences of and reasoning about being involved in research. Earlier studies on frail older people's view on involvement in research are scarce, if not non-existent. The little there is, is mostly written from the researcher's perspective and is mostly anecdotal [17]. In a review by Brett et al. [18] on how involvement in research can impact on users, few studies are on older people in general, with most of them presumably being younger and healthier than the participants in our study [18].

A central finding of our study pertains to how frail older peoples' experiences and reasoning about being involved in research is influenced by their experiences of power structures stemming from the contrast they experienced between their frail existence and research as something that is done on somebody else's turf. In their frail existence, the participants had experiences of how physical changes influenced life and lead to an increasingly socially isolated existence. This experience shares similarities with how Sjöberg et al. [19] describe existential loneliness for frail older people. They describe how frail older people feel trapped in their frail and deteriorated bodies, which leads to isolation. How they feel abandoned, miss having somebody to share their everyday lives with, and a feeling of a lack of meaning when they do not feel connected to their surroundings and the rest of society [19]. Our results suggest that involvement in research could be a way of alleviating frail older peoples' feelings of existential loneliness.

The fact that the participants experienced a difference in power between researchers and themselves as participants in our study could present a risk for participants experiencing their involvement as a symbolic representation (tokenism), that is to say that they experience that the researchers are not genuinely interested in what the participants contribute with. If the involvement of users in research is due to demands on the policy level, without a genuine interest on the researchers' side to conduct research with users, their involvement runs the risk of being nothing more than what Buck et al. [20] describe as 'ticking a political box' [20].

The participants of our study had different motives or incentives for participating in research. These motives are similar to the proactive motives that Cox and McDonald [21] describe in their article on motives for research participation in health research. Proactive motives refer to when participants choose to participate based on their own volition [21]. The proactive motives of the participants in our study oscillate between favouring themselves (self-orientation) and others (social orientation). This was for instance the case in the subcategory of *Getting a break from everyday life*, which was a proactive way of fulfilling one's own need of social interaction. Participants favouring themselves can, according to Cox and McDonald [21], lead to a feeling of increased empowerment. The feeling of empowerment may have been a part of how the participants in our study could *grow into the role of research participant* by way of feeling that they succeed in fulfilling their motives in the subcategories of *Wanting to address everyday problems* and *Wanting to enrich research with one's historical perspective* [21]. Similar variation of motives for participation have been found in a study by Dahlin-Ivanoff et al. [22]. Even though the Dahlin-Ivanoff study was conducted on a younger and healthier sample, described motives for participation in research ranged from self-serving to altruistic ones. In our study, the participants highlighted the social dimension of participation. That this was not described by the participants in the study by Dahlin-Ivanoff et al. [22], which could be due to the studies' different aims, or because the social dimension of participation might be more important for frail older people than the younger population in the Dahlin-Ivanoff study [22].

The participants found strength in receiving affirmation of being important and meaningful by researchers, who are a group that they perceive to be of high status. They were affirmed in that the historical perspective they could and wanted to contribute with also is of interest for society at large. The researcher's attitude towards participants and the affirmation they received influenced the way in which they could *grow as research participants*. Dudley et al. [23] write about how the researcher's attitude impacts on the experience of how

users influence research. Those with a negative attitude towards user involvement experienced that the research had not been impacted, whereas those with a positive attitude found that the research had been influenced [23]. Our study participants' experiences of how ageing had changed the conditions for what they can do and which social contexts they find themselves in may also explain why many may feel ill-suited to be research participants. At the same time, it also points to the importance of positive affirmation from a researcher that they are capable people when they are faced with the unfamiliar opportunity to be involved in research.

Our results emphasise the centrality of the relation between the researcher and the participants and the importance of the researcher's attitude towards the participants' capabilities, as the latter seems to be meaningful for how frail older people feel about the opportunity of being involved in research. Being able to cooperate and meet frail older people seem to be important skills that researchers must have in order for frail older people to be able to be involved in research. Our results point to the significance for there to be a space for variation in how frail older people can be involved based on their wishes and individual circumstances. One approach that allows for this variation can be found in Buck et al.'s [19] description of a successful research cooperation between researchers and users, where the researcher needs to be both flexible and responsive. Being responsive and flexible means that users' contribution is not pre-determined before the start of a project, but rather that it takes the form of a joined endeavour that entails a real sharing of power [19]. This may be contrasted to those who want to determine everything in advance, or are determined to do it together. One way of starting a research project between researchers and external actors is described in a case study by Barenfeld et al. [24]. Their project involved a process of finding a common ground to the problem of researchers and external actors coming from two different worlds where there is a lack of understanding for the other's perspective, situation and view of the project. The process of finding a common ground was eased by clarifying the overarching expectations, using a shared language and trying to work on equal terms to counter hierarchical conceptions of power imbalance [24].

Challenges inherent in forming an equal relationship between researchers and participants emerged in our study and have also been described in previous research [25, 26]. One could argue that there are two different ways of diminishing this perceived inequality. One is that participants are offered education in order to thereby increase their knowledge about the process of research and thus come closer to the researcher's high status [27]. The other way is to affirm the participants'

and researchers' different areas of expertise, that it is precisely because they have not been schooled within academia that they can enrich research.

In the encounter between participants and researchers in our study, there was a power relation that was influenced by the fact that the two parts had different areas of expertise. Gaby et al. [28] propose that the power relation in the relationship between the researcher and participant is influenced by them having different expectations, interests, needs and feelings regarding research based on the different contexts they come from. One way for researchers to challenge the dominant ideologies and structures that tend to reduce research participants to objects is by way of adapting a person-centred approach towards the participants. A person-centred approach in research builds on a view that everyone involved are people who are relational beings and that it is in our relationships to other people that we can grow. From this view, this is what allows new knowledge to be formed in the meeting between researchers and participants [28].

Our study was built on showing a genuine interest and attention to the participants in order to create a space for communication through dialogue, where participants with their expertise would be able to make their voices heard and where our different perspectives would be seen as a strength in our collaboration. Similar to Gaby et al. [28], our results show that being involved in research can lead to a feeling of empowerment in the participants by way of allowing them to build their capacity in collaboration with researchers. For this knowledge that is shaped in the relation between researcher and participant to be able to be understood in its context, it is necessary for the researcher to adapt a critical reflexive approach. This requires the researchers themselves to be aware of their own position and status [28]. A person-centred approach in research can be that the researcher is responsive and flexible with regards to the participants' circumstances, and contributes to optimising the participants' influence on the research process based on this.

#### Methodological limitations

According to Charmaz [10], the results of a study are dependent on its context, the situation, time, place and culture in which it is carried out. This study therefore needs to be understood within its specific context and the selection of participants. One limitation with this study is that the participants were discussing involvement in research without having any first-hand experience of it, or, for those who had experiences of it, discussing earlier experiences when their life situation was different. However, as the participants' experiences were discussed in the context of collaboration with

researchers, their experiences of participation in research as data sources with face to face contact with a researcher in the randomised controlled study they were recruited from, made them relevant for discussing involvement in research. Thus, even if our findings inform both quantitative and qualitative research, they are less applicable to research without face to face contact between frail older people and researchers, such as filling in surveys by themselves. Another limitation in our sample is that participants were recruited by people responsible for a larger population of participants in another study. That we ourselves were not entirely in charge of the process of inclusion may have influenced which people were asked to participate. For example, all our participants were Swedish-speaking. The experiences of involvement in research of frail older people who do not speak Swedish is thus something our results do not address.

One strength in our population is that we were able to include people with a range of cognitive abilities. That people with cognitive impairment are excluded from research is still common in geriatric research, often without explanation of why or any discussion on how it influences the results' representativeness of older people as a group, where cognitive impairment is common. It seems as though dementia or cognitive impairment are regarded as impacting on the possibility to participate in research [7], instead of considering all participants to be individual persons with different capabilities. In our material there are for example interviews with people with low MMT, and in spite of, or precisely because of this, these interviews could contribute to our results with important insights and experiences.

Not having the strength, will or capacity to be interviewed for a certain length of time should not be what matters for whether or not one is considered suitable for participation, but rather it is what is said that matters and that is not possible to know before the interview has been conducted. An interview lasting 14 min can contain more important pieces of a puzzle than an interview that lasts several hours. In this study, no interview had to be terminated because a participant felt tired; rather, there was a desire for more conversation and social exchange. There may be a risk when the researcher starts the interview with the view that the other is a vulnerable person that one needs to be especially careful with.

#### Conclusions

In conclusion, this study contributes with an understanding of how frail older people can and want to be involved in research, and that frail older people have a varied capacity to be involved. But in what way and how is difficult to know before they have been involved in the process of research. In collaboration with researchers,

frail older people are given the chance to assess what they want to and are able to do. Our results advocate that it is problematic to exclude frail older people a priori and that there is potential for new perspectives and knowledge to be shaped in the encounter and in the relationship between the researcher and the frail older person.

In the research relationship between the frail older person and the researcher, there are opportunities, but also obstacles based on the different worlds both come from. In research without user involvement, there are needs, perspectives and resources that run the risk of being left out. For research to be able to cater to frail older people's needs of health services, their voices need to be heard and taken into consideration. Otherwise, there is a risk that health services will continue to treat the group of frail older people based on the wishes and perspectives of other groups.

#### Abbreviations

ADL: Activities of daily living; MMT: Minimal Mental Test

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#### Authors' contributions

IB made substantial contributions to design, data collection and data analysis, and drafted the manuscript. EB made substantial contributions to design and data analysis. SDI made substantial contributions to conception, design and data analysis. MH made substantial contributions to design and interpretation. QL made substantial contributions to conception and interpretation, and was responsible for the study design. All authors revised the manuscript critically for intellectual content, gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

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#### Availability of data and materials

This is a qualitative study and the datasets generated and analysed during the current study are not publicly available due to the information provided to the participants when obtaining their informed consent, stating that all attempts would be made to maintain confidentiality. De-identified data are, however, available upon reasonable request to enable review, and will be stored for 10 years at the University of Gothenburg. All data are covered by the Public Access to Information and Secrecy act (offentlighets- och sekretesslagen) and a confidentiality assessment (sekretessprövning) will be performed at each individual request. Permission from University of Gothenburg, the Institute of Neuroscience and Physiology, has to be obtained before data can be accessed.

#### Ethics approval and consent to participate

The Regional Ethics Committee at the University of Gothenburg approved this study (DNR T097-18). Before the interviews both verbal and written information was given about the purpose of the interviews and the study, and all participants gave their written informed consent to participate. All participants were assessed by the interviewing healthcare professional experienced in working with the target population and all participants were deemed competent to consent.



**Consent for publication**

All participants gave permission to use their anonymised data for publication purposes.

**Competing interests**

The authors declare that they have no competing interests.

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## A real eye-opener: Nursing home staff experiences of co-designing nursing home health care services together with frail older persons

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### Abstract

**Introduction:** Both research and health care services seem challenged to fulfil the desires and needs of an ageing population. User involvement has been advocated for as a way to co-design health care services to increase relevance and impact of both research and clinical practice. Therefore, this study draws on a local Swedish development project based on a guide to promote user involvement through experience-based co-design of health care services, with the aim to explore nursing home staff experiences of such co-design with frail older persons.

**Method:** A focus group methodology was used. A total of 17 nursing home staff members (15 women and two men) participated in four focus groups, two at each nursing home. Both homogeneity and heterogeneity was strived for among the participants.

**Results:** The analysis is summarised in the overarching theme “Moving from object towards person” which describes the co-design process as a real eye-opener for staff in terms of realising the capability of both the frail older persons and themselves, and changing the relational dynamics between them. This is visualised in five sub-themes.

**Conclusion:** The co-design project revealed a discrepancy between the participants’ pre-understandings of the capabilities of frail older people and what they actually were able to contribute with. The co-design process was experienced to change the relational dynamics between the participants and the frail older people and reinforced their importance for each other.

### Article history:

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### Key words:

Research,  
Nursing home,  
Frailty, User  
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Personnel

### Introduction

More and more people live to experience age-related changes that manifest themselves as frailty and disability [1] and research and health care services meet challenges with fulfilling the desires and needs of an ageing population [2]. User involvement has been advocated for as a way to co-design health care services [3], and to increase relevance and impact of both research and clinical practice [4]. Co-design is an

inductive approach to innovation, actively encouraging all people involved to set priorities together and support the transition between research, policy and practice [5], especially in complex organisational settings [6] such as nursing homes. In co-design approaches, subjective experiences of health and social care services are typically explored through interviews and observations [7] to identify what needs to change and how to go about making

those changes [8]. In an attempt for Swedish nursing homes to be fit-for-purpose, Swedish Association of Local Authorities and Regions developed a guide to promote user involvement through experience-based co-design of health care services [9]. The foundation for the guide is the call for healthcare systems to be responsive to the needs of the population in order to provide quality services [10]. As described in previous research, this requires user involvement in both research and design of health and social care services [11], but there are knowledge gaps, both with regards to how to make use of frail older persons' knowledge in research [12], and on how they could be involved to influence health care services that are available to them.

Nursing homes in Sweden provide nursing and health care service to persons 65 years of age and older in a home-like environment [13]. Factors associated with transition to a nursing home are frailty, cognitive and physical impairment [14], and the level of care and support the person receives depends on professional assessments of their abilities [13]. Thus, persons who live in nursing homes are typically physically frail and live with multiple health problems [15], and they have access to direct care staff (mainly assistant nurses with upper secondary care education) round-the-clock [13, 16]. Nursing home staff are thus key actors in shaping social situations for frail older persons living in nursing homes [17]. Backhouse et al. [18] describe attitudes from nursing home staff towards the older persons as both facilitators and barriers for co-design of nursing home health care services [18]. Few attempts have been made to involve frail older persons in nursing homes in co-design of health care services, and amongst the ones that have succeeded, the older persons have mainly been part of reference groups in large research projects, or been collaborators in minor research projects [18]. It is important to understand what could facilitate or hinder co-design of nursing home health care services with and for frail older persons. As part of research programme on how to optimise user involvement in research on ageing and health [19], this study therefore draws on the previously mentioned user involvement project

in Swedish nursing homes [9] to explore nursing home staff experiences of co-designing health care services with frail older persons.

## Methods

### *Study context*

The study was conducted at two publicly run nursing homes that were part of the national co-design development project [9] that aimed to visualise the perspectives of frail older persons living in nursing homes. The goal was to identify needs for changes to care environment, and implement them to increase the older persons' well-being. This meant that older persons and staff took part in different activities together such as discussions on needs of the older persons in the nursing home environment. The intention was to involve as many of the older persons as possible in the project. The two nursing homes were located in two different suburbs of a mid-sized Swedish city, and housed 70 and 100 persons respectively. About 80% of the persons living in the nursing homes had a dementia diagnosis.

### *Design*

Focus groups were conducted to generate qualitative data on nursing home staff experiences and views from different perspectives. Based on social constructivism, the focus group methodology builds on interaction between participants to clarify their views and experiences, and provide them with opportunities to stimulate each other in discussions to explore new issues that arise [20, 21]. In this study, this meant that nursing home staff participated in focus group discussions to generate data on their experiences of co-designing nursing home care with frail older persons. Joint experiences and views of co-design with frail older persons were clarified and discussed through group interaction.

### *Participants*

A total of 17 staff members (15 women and two men) participated in four focus groups, two at each nursing home, with between three and five participants per group. Homogeneity among the participants was strived for in terms of shared experiences of being part of the same project and caring for frail older persons in a nursing home. Heterogeneity was also strived

for in order to capture a diversity of experiences and to broaden the discussions [20, 21]. In this study, this meant that the participants' age ranged from 34 to 65 years, their work experience ranged from four to 30 years and four of the participants had another mother tongue than Swedish. One participant was employed as service developer at one of the nursing homes and the rest of the participants were employed as assistant nurses.

### *Procedure*

Participants were invited to participate through nursing home managers who provided them with written information on the study aim and what it would require of them who chose to participate. Interested participants were scheduled in for a focus group discussion at the nursing home, which started with an opportunity for participants to ask questions about the study before signing informed consent. The researchers also informed the participants about the voluntariness of participation, and emphasised that they could interrupt their participation at any stage without negative consequences for them professionally or personally. They were also ensured that they would be kept confidential in all reports on the study. All participants gave their written consent to participate before commencement of the discussions.

The focus groups were conducted during the participants' work hours and lasted between 65 to 74 minutes, starting with a description of the study aim and the structure for the focus group. Researchers put emphasis on the importance of the participants to share their experiences freely, and the moderator opened up the discussion with a question about the participants' work with the older persons at the nursing home, followed up by questions to deepen the discussion on the co-design process. The first author moderated three focus groups and observed one and last author moderated one focus group and observed three. The moderator had responsibility to make sure that everyone had the opportunity to make their voices heard, and to stimulate interaction. The observer took notes on non-verbal situations and interruptions. All focus groups were recorded digitally and transcribed for analysis.

### *Data analysis*

The analysis was based on the method for focus groups described by Krueger and Casey [22]. The analysis was made in Swedish and stayed close to the data not to lose content and meaning. First, the focus groups were listened to repeatedly by the first author, who also read the transcripts and field notes carefully. This step resulted in preliminary themes that were discussed with the second and last author. Secondly, the first author sorted the data according to analytical questions on what had been done during the co-design process, how it was done and why. The sorted data were condensed to describe the content of the focus groups and discussed in depth with the second author. The meanings of the condensations were compared to the preliminary themes that were revised through discussions between the first and second author. Finally, the revised themes were discussed among all authors to reach a final interpretation of the abstract understanding of the meaning of the focus group discussions.

## Results

The analysis resulted in the overarching theme; *"Moving from object towards person"*, which describes how the co-design process became an eye-opener, involving a change in how the participants perceived the frail older persons, as well as themselves. When working together in a joint project, the participants became aware of the frail older persons' personal characteristics, and discovered abilities that had previously been hidden by the staff-resident role. The co-design process changed the dynamic between the participants and the frail older persons, from being staff who care for residents in a rather objective manner, to becoming persons who work actively together in a joint project. This change was interpreted to start with the participants discovering the frail older persons' unexpected abilities, which meant that they could meet each person where they were. This, in turn, gave the participants new insights and perspectives that made them realise that they needed to become more of a person in their professional role to become true advocates for the frail older persons' needs. This process is described in detail below in five sub-themes.

#### *Discovering frail older persons' unexpected abilities*

This sub-theme illustrates the co-design process as a means for the participants to interact with the older persons in a different way than before. Opening up for collaboration with all persons at the nursing home, the co-design project provided them with tools to discover frail older persons' abilities that had previously been hidden by physical frailty and disability. Contrary to the participant's professional experiences of frail older persons being in need of extensive support, the frail older persons' abilities to co-design came as a surprise to the participants. The co-design thus facilitated interaction that made it possible for them to discover new sides of the frail older persons, sides that had not been visible in daily care relations. When talking to the frail older persons, the participants became aware that even the frailest persons had resources and expertise of relevance for the co-design process. For instance, the participants described that when being encouraged to ask all the frail older persons questions, regardless of their functional and cognitive abilities, they got responses that they did not expect. An example of this was given in focus group two.

*"P1: I was very surprised by the answers we got from the residents. That they had so many thoughts and ideas, sort of experiences they shared, you didn't think so, that they would answer like that. So they, many of them were quite quiet and sort of cautious ladies. One, she was postured like this, shrunken down, "you're welcome to come in, and so", for every question I asked her, the more she sort of stretched out. In the end, she kind of spoke freely. There was no need for me to ask questions, she had become so proud that she was able to answer, that she participated.*

*M: Is this something you all experienced when working with these questions?*

*P2: First and foremost it was so amusing that they who we didn't thought would answer, that they did answer and the ones we thought maybe were more alert, no they didn't want to answer. But the ones who didn't, if you gave them some time, then a lot came, and "we can do like this..."*

*P1: Definitely.*

*P3: I think it's about participation, that we are listening.*

*P2: That we are listening, the most difficult thing has been to wait for the answer, but that it has come. The ones we didn't though was going to be able to answer have answered."*

#### *Meeting each person where they are*

Through discovering, and acknowledging, the frail older persons' unexpected abilities in the co-design process, the participants described that they could meet each person where they were. This meant that they combined their professional knowledge on frailty and daily care with their personal understanding of each frail older person. Through a flexible approach, the participants could adapt to each person and act differently depending on the frail older person's daily mood and functioning. To compensate for such variation, the co-design process was not limited to one chance or one meeting between a participant and a frail older person. Rather, it was seen as a continuous process that took place in different situations and in different spaces, as well as during different times and between different persons. The co-design was also facilitated by trying out different approaches, and by prompting discussions with the older persons using probe questions. This was described as a balancing act, which sometimes could move towards persuasion through suggesting things that the participants themselves perceived as needs of the older persons. Participants in focus group four gave examples on the flexible approach when co-designing.

*"P1: Like I scheduled time with some of mine and came with papers and sat and wrote and such. They thought it was fun, that they were needed. They kind of can do something good. But some, "No, I don't quite know if I want to" like that. So, then you had to go in and just talk a little while you perhaps made the bed and such. So, it's a little different but a lot was; "How is a good day for you?" and "What would it look like if it wasn't good?", "How would you, if you can think freely? How would it look?", or ah but you know so. But they are shy, so you have had to pull a lot, and gently persuade and kind of walk around and so on. Imagine how practical it would be to just sit and just turn on the light*

*or something with a button. "No, no it's all right as it is now." Sort of little like that, "yes, yes, but when you say that, maybe it would not be such a bad idea anyway"."*

#### *Gaining new insights and perspectives*

Gaining new insights and perspectives meant learning from the frail older persons' narrations on their abilities, and from reflection over one's own work when meeting each frail older person where they were. By putting themselves in the frail older person's shoes, the co-design process contributed with new insights and perspectives for the participants, on what it may mean to live and work in a nursing home. It also brought with it changes to how the participants perceived and treated both themselves and the frail older persons. The frail older persons' abilities to co-design were a contrast to the participants pre-understanding of the abilities of frail older persons who are granted an apartment in a nursing home. Before the co-design project, the participants had based their understanding of the frail older persons on their disabilities rather than on their abilities, and on their extensive needs of help and support with daily care. In the co-design project, all people were regarded as capable persons, a new perspective, reflected both in how the participants perceived the frail older persons and themselves. This involved a positive change to the relationship between the participants and the frail older persons, through the new insight of how important they were for the older persons. Below is an example from focus group two how the co-design process had given them a new perspective on what it meant to be living in a nursing home by putting themselves in the frail older person's shoes.

*"P3: I'm scared to death.*

*P4: But do you know what?*

*P3: Scared to death to end up here and have a door that's locked and have someone that just pours this much wine to me a Friday night.*

*Whole group: Laughter*

*P3: Or something, when it exists boxes (of wine) that I can just push. And when I have forgotten how, that they*

*teach me. No but honestly god, give them a glass of wine, they take so much medicine, but come on!*

*P4: Yeah, what difference does it make?"*

#### *Becoming more of a person in one's professional role*

Contrasting the general view of nursing home staff as executors of tasks, the co-design process made it possible for the participants to become more of a person in their professional role. This meant that they could make use of both professional and personal knowledge and expertise in their work. Providing time to really listen to the frail older persons' narratives, the co-design process represented a different way of working compared to usual practice. It gave the participants an opportunity to develop their relationships with the frail older persons through exchange of expertise between two persons. This contributed to a deeper and more personal understanding of the frail older persons, and the participants felt acknowledged as important for the frail older persons. They became positively surprised by the frail older persons' narrations of the significance of staff being persons who care for them and for one another, as compared to the role of being staff member and residents who are in a professional relationship built on one-sided physical dependence. In focus group one the participants described how the co-design process illuminated their importance as persons for the older persons.

*"P2: But the questionnaire that we had for the old, it wasn't so easy to ask questions to demented people. But we managed quite good in this house, to ask questions. But what came was fascinating and brought to our attention. We wrote a lot down on post-it notes. We made them with answers about relatives, staff and such and the overwhelming majority of post-it notes was about us, the staff, what they said about us, how they expressed themselves, that was very fascinating actually.*

*M: And what could that be?*

*P2: It could be a resident for example who doesn't say so much... she kind of started to talk, at least a little, and we understood each other and I asked; "What makes you happy?" We tried to have some easy questions, kind of general, that we asked when the opportunity came. And she was quite for a long time, so*

*I began to think that it didn't go so well, "Hey you" she said, and we got, we discovered a lot of such things like; "When I see you", so it was really fascinating actually, to hear how important we are. It isn't this that we organise like activities. Yeah, of course, some of them mentioned this with activities and such but it wasn't the majority actually. It was more like; "I feel good when you are here", very I have to say, a very strong message.*

*Becoming a true advocate for the older persons' needs*  
Going through the process of co-designing with frail older persons in the nursing home, the participants described that they became true advocates for the frail older persons' needs. This meant that the personal relationships that they developed as a result of the co-design process made it possible for the participants to become the frail older persons' voices in relation to the desires and needs of relatives and management. The co-design facilitated dialogues on the older persons' desires and needs, and allowed the participants to be innovative and come up with new ideas together with the frail older persons. Some of the ideas were actualised as part of the project, allowing the participants to advocate for the frail older persons' own perspectives of what their needs were. The participants felt strengthened to attend to the frail older persons' actual needs in their daily work, and the collaboration between them and the frail older persons gave the participants mandate to stand up for what they did or did not do when relatives came to question them. It also meant that they got opportunities to implement changes that management had previously rejected. The participants gave an example in focus group one of how they acted as true advocates for the older persons' needs.

*"P2: This closeness, that's what they need, because they are so lost in themselves and their activities... they want to be where we are. I think that and it was actually what was really nice that it came out so clearly. Because we already know this. We have known this for all these years, but no one has been interested in it. Because everyone needs to go out, everyone must do that and everyone should do that, well that is not the case at all.*

*M: Then you kind of got some support for it, your experience that it was so?*

*P4: Who see them most then? We who work with them or someone who stands outside. It's like that you know. No need to go further than to relatives who say that, "Mum wants to go out for a walk." but she has not done that for the last five years perhaps. But then the daughter or son thinks that the mum... she wants to go out for a walk but she does not want to, she wants to sit with us and have a cup of coffee instead.*

*P3: Or read the newspaper.*

## Discussion

This study was conducted with the aim to explore nursing home staff experiences of co-designing health care services with frail older persons. The major finding is the visualisation of co-design as an eye-opener for the participants, which involved a process of realising the actual capability of both the older persons and themselves, described in the overarching theme "Moving from object towards person". This contributes with knowledge on how co-design processes could challenge preconceptions about ageing and frailty in general, and nursing home health care services specifically, and also how it could influence the relationship between frail older persons and staff in nursing homes. Previous research about involvement of frail older persons living in nursing homes in research has applied collaborative or consultative approaches [23], but to the best of our knowledge, no previous studies have explored the experiences of such approaches.

Another important interpretation of the present findings is an underlying criticism towards the task-oriented culture of many nursing homes. When tasks need to be completed in a similar way for all persons, without attending to each person's opportunities and prerequisites, staff may feel like they care for an object rather than a person. According to Beck et al [24], a task-oriented culture could create a dilemma for nursing home staff, as they may feel that the relational needs of the frail older people are not prioritised over the expectations of relatives, managers and registered nurses [24]. The sub-theme "Becoming a true advocate for the older persons' needs", describes how the participants' experienced a strengthened role in relation to

managers and relatives when co-designing with the frail older persons and this can be interpreted as how the participants took a step towards higher prioritising of being with the older persons rather than simply doing things for them.

To co-design gave the participants in the present study an opportunity to have different kinds of conversations with the frail older persons than they perceived that they usually had. The conversations were characterised by listening to the narratives of the frail older persons in order to discover their individual experiences, resources and needs. This enriched the image of the people living in the nursing home as persons, rather than just belonging to the group of frail nursing home residents. This is reminiscent of a person-centred conversation which is based on how Ricoeur [25] describes that a person consists of both a who, or ipse which is the person's unique personality, and a what, or idem, that refers to the elements that are shared with others [25]. The person-centred type of conversations the participants had with the frail older persons created an opportunity for new experiences to emerge, complementing previous research that has not given voice to frail older persons. Fricker [26] describes how epistemic injustice arises when persons who have legitimate reasons to be involved in creating new knowledge do not get to contribute in their capacity as a knower. According to Fricker [26], there are two different ways in which epistemic injustice occurs, through testimonial injustice and through hermeneutical injustice [26]. For frail older persons, testimonial injustice could take place when prejudices that the listener has does not give credibility to the frail older persons' statements, which indicates that they are not credible sources of new knowledge. Fricker [26] further describes how hermeneutical injustice could take place on a higher level when there are societal gaps in knowledge on how people understand their social experiences [26]. In relation to frail older persons in nursing homes, the gap of societal knowledge on the meaning of living in a nursing home could be a result the societal view that a nursing home is a place for bodily decline and death [27] rather than a place for growth and meaningful life.

In this study, the participants perceived themselves as the ones most suitable to advocate for the frail older persons, and when meeting each person where they were, they applied different techniques to carefully persuade or lure answers from the frail older persons. This raises important questions regarding co-design or other forms of collaboration with frail older people. To carefully persuade or to lure answers from the older persons might be necessary to initiate a co-design process, however this comes with the risk that the collaboration does not become genuine and that the frail older persons do not have real influence on the processes. Frail older persons' involvement thus risks to be of a symbolic character and their involvement might become a way for the responsible for the project to just tick a political box [28]. The co-design approaches in the present study may have led to the participants' views being put on the older persons, with the participants mediating their own views as if they were the older persons' views. The older persons' views might then have been taken in hostage by the participants and the older persons' part in the co-design process been reduced to a symbolic representation without real influence.

An interesting aspect of the present result is the tension between the subthemes "Meeting each person where they are", and "Discovering the unexpected abilities of frail older people". The participants described that their previous experiences of working with frail persons made it possible to adapt to where each person were at the time of collaboration. At the same, the project became an eye-opener with regards to the understanding of frail older persons as capable to co-design. Despite their knowledge and expertise, the participants were surprised that the frail older persons could contribute to the co-design process. The contradiction in how the participants understood frailty and how they understood capability was grounded in the older persons' need for health and social care, and could be interpreted as being influenced by ageism as described by Nelson [29]. Moreover, supported by the review by Backhouse et al. [23], the sub-theme "Discovering frail older persons' unexpected abilities" highlights the

impact of staff attitudes and roles for collaboration with frail older people in nursing homes. The initial scepticism expressed by the participants may have hindered some of the frail older persons to be involved in the co-design project, even though they may have been fully capable to do so. This supports previous research findings [30] that put emphasis on the importance of providing opportunities for frail older people to be involved in research according to their desires and abilities [30]. When the frail older persons got the chance to be involved in the co-design project under exploration in the present study, they surprised the participants in showing that they were capable of contributing. This gave the participants a new perception of what was possible to do with and for frail older persons in nursing homes.

#### Methodological limitations

Focus groups are based on a collective understanding of participants' views [20] and one crucial feature is to stimulate interaction between the participants in order to create discussion [22]. In this study, the participants provided each other with opportunities to comment, question and develop each other's answers, so that the interaction lead to development of the collective understanding experiences of co-designing health care services with frail older people. There were between three and five participants per focus group, and some authors claim that there should be six to 12 participants in each group [31], others claim that the ideal number of participants is between four and eight [32]. One question to discuss when it comes to this study can thus be the limited number of participants in each group. However, small groups of three to five participants have been shown to be more about the involvement of the participants than on the number of participants [20]. In this study we found that the discussions were very dynamic, and the outcome of the discussions depended more on the involvement of the participants in each group than on the actual number of participants. The dynamic discussions might have been influenced by that the participants all knew each other, and they took the opportunity to reflect in group over the whole co-designing process that they felt have had an impact on

their daily working behaviour. This relates to the advantage with focus group methodology described as creating awareness [21, 31, 33].

#### Conclusions

The findings of this study indicate that there seem to be a discrepancy between nursing home staff preunderstanding of the capabilities of frail older people and their experience of how it can change during and after a co-designing development project. To involve both staff and frail older persons in a co-designing project created values that went beyond the project itself, such as changing the relational dynamic between them, and reinforcing the capability and importance of each person. This could be used to support health care services to meet the needs of the heterogeneous group of frail older persons, and empower nursing home staff to see the value of their role in the daily work. While this study was made in a nursing home context, we argue that the findings could be useful in other co-design projects, both for research and development purposes, with and for frail older persons.

#### Ethics

The study was approved by the Regional ethics board in Gothenburg (ref no. 813-18). Before the focus groups were initiated, the participants were informed about the aim and design of the study. They were also informed about the voluntariness of participation, and that they could withdraw their participation at any time without negative consequences for them professionally or personally. They were also informed that they would not be able to identify in any reports of the study. All participants gave informed written consent to participation.

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#### Availability of data and materials

This is a qualitative study and the datasets generated and analysed during the current study are not publicly available due to the information provided to the participants when obtaining their informed consent, stating that all attempts would be made to maintain confidentiality. De-identified data are, however, available upon reasonable request to enable review, and will be stored for 10 years at the University of Gothenburg. All data are covered by the Public Access to Information and Secrecy act (offentlighets- och sekretesslagen) and a confidentiality assessment (sekretessprövning) will be performed at each individual request. Permission from University of Gothenburg, the Institute of Neuroscience and Physiology, has to be obtained before data can be accessed.

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