Teaming Up to Traverse Loneliness: a Co-creative Journey Toward a Home Care Work Model for Supporting Social Participation Among Older Adults

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Abstract

Background: There is a disparity between what is known about the benefits of social participation and home care's responsibility to provide conditions amenable to older adults' social participation, and what is accomplished in home care practice. Home care workers are a large, low-power group, working in a complex environment, whose competences should be better harnessed. We carried out a participatory action research (PAR) project with the goal of generating an improved structure for identifying and alleviating loneliness. This article aims to explore the co-creative process of designing a work model that guides home care workers in supporting social participation among older care recipients.

Methods: Multimodal data from 16 PAR workshops with 14 homecare workers were described and explored through the 'recursive PAR process' and the 'framework for occupational enablement for change in community practice".

Results: The PAR process is outlined through the objectives, activities, and work model, as well as enablement strategies employed throughout the PAR process; as are its opportunities, challenges and implications. The work model describes how care workers can act as discoverers of care recipients' unmet social needs, employ intentional communication, and link to relevant professions or community services to alleviate loneliness among older home care recipients.

Conclusions: This research process included opportunities of collaborating with enthusiastic and competent home care workers, but also challenges of moving between theory and practice and maintaining active participation between workshops. The resulting work model is in step with the requirements of elderly care and is unique in its field. This research could comprise a first step toward a more systematic approach of assessing and addressing loneliness and moving home care towards its legislated goals of person-centered care that supports older adults' rights to a meaningful life with others in the community.

Background

Loneliness and social isolation have been increasingly acknowledged as a cause of ill health (1–5), and older adults are more likely to face reduced opportunities for leisure activities (6) and shrinking social networks, and, consequently, to experience loneliness (7). The opportunity to participate in society and to maintain individually-relevant relationships; i.e. 'social participation', is a key component in better health and wellbeing (8–10) and in healthy aging (11). However, loneliness and social participation are complex and intertwined experiences which are situated in day-to-day life, and with the need for assistance in daily activities the situation becomes even more multifaceted.

In Sweden today, like in many other countries, home care is the most common form of elderly care (12), and more than half of Swedish homecare recipients report feeling lonely 'sometimes' or 'often, (13) which has remained fairly constant over recent years. Qualitative research has shown that older home care recipients perceives the endorsement of their agency, interests, and valued relationships as important in satisfactory social participation (14), and yet other research has indicated that homecare recipients feel that homecare workers can both facilitate and hinder their sense of agency (15). Although the Social Services Act (16) which regulates home care stipulates that older adults have a right to assistance in engaging in a meaningful life with others, systematic approaches for assessing and adressing social needs are lacking (17). Evidently, there seems to be a gap

between what is known about the benefits of social participation and homecare's responsibility to provide conditions amenable for recipients to engage in a meaningful life with others, and what is accomplished in practice: a so-called "know-do gap" (18).

All Swedish homecare services are financed with public funding, but are carried out by either municipal or private organizations. Needs are granted by municipal homecare assessors, and if the municipality also has private options available, the care recipient may choose their provider. While the time slot and formal content is strictly delineated in service grants, the individual care worker is rather alone in deciding *how* to carry out the service. Delivering homecare support is complex (19), marked by restraints on time, working alone, and balancing conflicting values (20, 21). This demanding work situation has been described as one of low control, affecting care workers' health, quality of work life, and their output quality of care (22). But while stress of conscience and exhaustion are common, homecare workers often describe their jobs as meaningful and morally fulfilling (23). And while the profession is known for its complexity, homecare workers have low levels of education; usually assistant nurse training (training at a high school level), but a lack of formal care training is also common. This contributes to the profession's low status, low salary levels and low power. Employment in the elderly care sector (home care, care homes and home health care) comprises the largest employment sector in Sweden, and 90% of care workers are women(24).

Research examining Swedish homecare workers' perspectives on supporting social needs is sparse. A discourse analysis showed that homecare workers value social support for care recipients and that their obligations and opportunities could involve both strengthening their current procedures or developing structures to better fit the social needs of older homecare recipients(25). Research from other countries shows that care workers can have a positive attitude towards supporting meaningful and social activities (26), but that physical care is often seen as homecare's main concern and the lack of time, knowledge and awareness of such issues remain barriers (27). Therefore, it has been argued that addressing organizational factors might be crucial in shaping conditions to enhance a socially-oriented and person-centered approach to elderly care (20).

Participatory research has been suggested to be particularly suitable in adressing know-do gaps in health systems (18), and for including and addressing issues relevant to women (28). Participatory action research (PAR) is a style of research that acts within a specific context, with a focus on social action and change (29). In PAR, scientists and stakeholders work together in order to examine problems and generate context-specific solutions, even when stakeholders have little or no experience in research or organizatitional development (30). This collaborative generation of knowledge, where stakeholders and academics join forces to develop services, is often called 'co-creation' (31). Central to co-creative and participatory processes are fostering mutual respect, capacity-building and empowerment (30), and aiding in uncovering tacit knowledge and competencies. Researchers and participants often utilize various creative methods such as role playing, storyboarding, and futures workshops (29, 32).

To address this know-do gap, situated in a complex context with workers with lower levels of formal education but vast practical knowledge, we carried out a participatory action research project with the goal of generating an improved structure for identifying and alleviating loneliness. This article aims to explore the co-creative process of designing a work model that guides homecare workers in supporting social participation among older care recipients.

Methods

Study design

This project had a Participatory Action Research approach (29), focusing on co-creating knowledge with homecare organizations in an attempt to improve support for social participation among homecare recipients. The PAR approach (29) was chosen for its recursive orientation towards action and change in practice. Furthermore, the study was also inspired by 'participatory design' (32) and 'futures methodology' (33, 34) for their respective focuses on designing prototypes and providing a concrete structure for people without design experience to examine a problem, envision a goal, and construct a model for change.

Roles in the collaborative PAR-process

Concurrent with a participatory ontology (35), participants were viewed as situational experts providing knowledge on home care and on work model content. The researchers' role included creating space for collaboration and design, breaking down the end goal into manageable steps, providing evidence-based knowledge on loneliness and social participation, and supporting operationalization of homecare workers' competencies. Homecare workers that co-designed the model are, in this article, called "participants", and the occupational therapy scientists who initiated the project and led the workshops are referred to as "the researchers".

Reflexivity and researcher-as-instrument

The on-going collaboration between researchers and participants in PAR requires an active and reflexive researcher; the researcher-as-instrument (36). We attempted to consciously use ourselves (37) to balance power and facilitate a collaborative space; for example through purposive adaptability in verbal, emotive, written, spatial and material communication. This endeavor requires awareness of, for example, our backgrounds and preconceptions throughout the research process and transparency in the report (36). The first and last authors, who led the workshops, have a background in occupational therapy, and the second author, who functioned as PAR methodology expert, is a sociologist. Whereas second and third authors are experienced researchers with PhD degrees, first author was a doctoral student. The occupational therapy background follows philosophical assumptions (38) regarding, for example, viewing people as autonomous and with the potential for participation and as the driving force of their own change, which guided our facilitation of the PAR process. Additionally, all authors has previous work experience in elderly care and rehabilitation prior to entering academia.

Context

This research project, "Stay In Touch", is part of a multi-disciplinary research program, "Future Care" (39), where three universities are collaborating with healthcare providers in contributing "*to the development of knowledge-based care for older adults that improves opportunities for participation and the feeling of being socially included*". The Stay In Touch project is generating knowledge about loneliness among older adults in a home care context (14, 25).

Umea University is a comprehensive university in northern Sweden, located in proximity to the participating homecare organizations. The home care organizations were municipality-operated, and were the only homecare

option in these municipalities, which were relatively small and semi-rural. The home care organization thus covered homes located both in town and in the countryside.

Recruitment and participants

Based on a shared interest in the challenge of loneliness among older adults in the home care context, two managers of municipal home care organizations volunteered to participate in the research project. The researchers (IN and TN) invited care workers to volunteer for participatory workshops at staff meetings. We strived for a variation in participants' backgrounds by verbally emphasizing that we were seeking all ages, genders, and levels of professional experience. All care workers that wished to participate were included in the study. Oral and written information about participation in the study were provided, and all participants provided informed consent.

We first recruited participants for four workshops in each home care organization, and 11 homecare workers chose to participate. Those participants were later invited to a second round of four workshops, in which seven participants decided to extend their participation, and three new participants joined the project. In total, 14 homecare workers (equally distributed from care organizations A and B) participated in the study (Fig. 1). The two groups of participants covered a wide range of ages (23–58) and years of experience in home care (5–30). Most participants were women, and most had a high school education, with additional courses at high school or college level. Three participants decided to adjourn their participation before the end of a round, and expressed a heavy workload, that they were not interested in engaging in the development process, or gave no explanation as to their withdrawal.

Data generation and analysis

After establishing collaboration with the care organizations (prior to staff recruitment for workshops), we shadowed homecare workers for four days, where IN and TN each accompanied a care worker in their daily work to gain an understanding of their work situation.

The co-creation process consisted of a total of 16 workshops with two groups, A and B, of home care workers from two municipal home care organizations. The workshops were partitioned into clusters of four: first a consecutive setup where group A had four workshops (sub-cycle 1); followed by four workshops with group B (sub-cycle 2). Afterwards, group A and B had four workshops each that were parallel in time (sub-cycle 3), which also allowed cross-group communication. Together, the three sub-cycles amounted to one over-arching PAR cycle. Each workshop took place about once per month, for 2.5 hours, at an assigned conference room in the home care organizations' respective office buildings. Initially, eight workshops were planned (first round), and the latter eight workshops (second round) were added as it became clear that additional time was required to refine and test the model.

The analysis proceeded in two phases. The first analytic phase was a hands-on process where, in line with PAR methodology, data generation and analysis proceeded in parallel activities of continuously reviewing and reflecting upon data to direct the next action. In practice, researchers discussed and summarized audio and written data, which the participants then discussed and used to further develop the content of the work model. The overall goal was to create an improved structure for identifying and alleviating loneliness generated questions; for example "what can loneliness and social activities encompass?" Such questions led to the

emergence of new questions and were examined as they emerged through action-oriented modalities like mind-mapping, drawing, collaging, writing and filming. In the beginning, questions were primarily introduced by researchers, and as the groups and the project matured, research questions became more participant-driven. The on-going analytical process also encompassed monitoring and facilitating a fruitful group climate. The process generated a vast amount of data, including summaries, field notes, mind maps, textual and graphical drafts, audio recordings (~ 12 hours) and videos. A list of workshop topics, action-oriented research questions, and data is provided in appendix 1. The final Stay In Touch model included a five-step figure and chart describing the work process from identifying to alleviating loneliness. After the workshops ended, researchers prepared material for further testing for a pilot study (a website, mobile application and introductory material) which was reviewed and verified by two volunteering participants.

The second phase of analysis consisted of scrutinizing data to explore the co-creative process. First, all data (for example workshop plans, audio files, sketches, field notes) were reviewed and sorted in chronological order. Through iterative examination of the data (appendix 1), objectives and activtivities of each workshop were extracted and descriptive text for each sub-cycle (Fig. 3) was formulated. These descriptions were then related to McIntyres “recursive process of PAR” (29) and Rensburgs “framework for occupational enablement” (40) (Fig. 2), for the purpose of highlighting and interpreting the group process, researchers’ enabling strategies, and obstacles and opportunities. This analysis was mainly performed by TN, and intersperesed with extensive reflection among all authors throughout the analysis process.

Results

In line with PAR methodology, the process is a part of the result and is therefore described in this section, addressing (in chronological order) the three PAR sub-cycles that together made up one over-arching PAR cycle (see Figure 3), and lastly describing the created work model. All of the *enablement foundations* and *facilitators of enablement* described by Rensburg (40) were utilized in the overarching par-cycle, but they varied in pertinence over the course of the PAR process.

At the beginning of each sub-cycle, all participants were provided a folder with information and writing material, to use as they liked. All workshops were structured to include a warm-up phase, a working phase, and an ending phase, and ongoing engagement was expected between workshops. Participants were encouraged to reflect on a specific part of the design process in light of their daily work, and researchers reviewed the previous workshop(s) and prepared material for the next. In the first round, researchers provided more structured tasks, and in the second round, the participants were encouraged to take on a more active role.

First round: two sequential sub-cycles of questioning, reflecting, and prototype development

This round consisted of two sequential sub-cycles with similar layouts. The structure of both sub-cycles was inspired by Futures methodology (33), beginning with reflecting upon loneliness among care recipients, envisioning a “social future” for older care recipients and modeling a concrete plan for change. The creative assignments used to explore topics and questions were inspired by creative group work and process mapping (41), used to stimulate reflection and operationalization.

Since researchers and participants were new to each other and the project was in its initial stages, two of the “enablement foundations”(40) were of particular relevance: creating a ‘shared vision of possibilities’ and

exploring how ‘change, transformation, liberation, and actualization’ could come about. In addition, two “facilitators of enablement”(40) were highly relevant in the first round: using intentional ‘communication’ and ‘fostering relationships’. In the interdependent relationship between researchers and participants, researchers took on a relatively active role in introducing objectives and activities.

Sub-cycle 1 with group A

This sub-cycle corresponded to the first phase of the overarching PAR cycle: reflecting upon loneliness among care recipients and investigating how social participation could be supported within the existing organization of home care services. The sub-cycle also included the initial steps of development of an action plan and the “implementation” of this plan into a first model draft.

Objectives and activities

The objective of group A’s four workshops was to generate a work model draft. The very first warm-up assignment invited participants to reflect on their own social lives through a mind-mapping exercise discussing the activities and relationships they valued. After a miniature lecture about research on loneliness among older adults, participants explored their perceptions of older care recipients’ loneliness and social needs. To spark creative and visionary thinking, the group drew an “avatar”: a fictive care recipient for whom they formulated a vision of a rich social life. Thereafter, the participants examined how they work today and how they could, within the boundaries of their role, enhance their work to identify, address, and evaluate social needs. They noted specific work-tasks and ranked them from easy to difficult to accomplish. Participants discussed different structures that could visualize their described work-tasks in a process, and chose a pie-chart design, into which they fitted their work tasks. The researchers prepared a clean copy of this draft, which the participants used as a base for discussion and changes. They also wrote a short description and a fictive case example for each step in the model prototype. Finally, the participants made a video presenting their prototype and wrote down questions for the next group about aspects they thought needed further development in their prototype.

Facilitators of enablement and group climate

The assignments for group A were intentionally partitioned and concrete, intending to break down the investigative process into manageable pieces. The researchers were deliberate in using constructive and encouraging communication, aiming to foster positive relationships within the group and to generate an open-minded and creative atmosphere. The participants seemed comfortable with each other, showed enthusiasm toward the matters at hand, and were able to work independently during the workshops’ work-phases. Although discussions sometimes became tangential, they also managed to pull themselves back on topic and appeared engaged and goal-oriented. The researchers’ impression was that their suggested questions and assignments fitted the participants’ competencies well and successfully contributed to the positive and creative climate.

Beginning by reflecting upon one’s own social preferences seemed to accentuate the idea of social needs as being universal in essence but also highlighted individual differences, which produced subsequent discussions on care recipients’ variations in social needs. Creating an ‘avatar’ seemed to spark imagination and concretize the visionary discussion, which has been previously described as a fruitful method in participatory processes (42). Participants were both confident and competent in discussing the concrete details of social support for care recipients, whereas mapping and abstracting these competences proved more challenging, which was reflected

when discussions drifted away and their progress slowed down. However, the group did reach a model prototype that delineated their work process from identification to alleviation of loneliness.

Sub-cycle 2 with group B

This round corresponded with the middle phases of the overarching PAR cycle: continuing with developing the plan and initializing implementation and refinement.

Objectives and activities

The objective of group B's four workshops was to refine the preliminary model draft proposed by group A and testing it (informally) in practice. This group began with examining their perceptions of older care recipients' social situation and envisioning a positive future through a brainstorming and collaging exercise. Afterwards, they reviewed group A's problem and vision formulations, model draft and video, and discussed similarities and differences to their own previous discussion. Group B then investigated the model's phases and reflected on challenging and supportive preconditions around each phase, and the model's overall feasibility. They also discussed which other professions might be relevant to the work process. They elaborated the graphical elements of group A's model draft, aiming to add visual appeal and relevant aspects to the process. Changes included incorporating a symbolic color scheme, changing the pie-chart design into a circle of action points, adding a quick-route, and emphasizing person-centeredness. Based on discussions and sketches, the researchers prepared concrete design examples that depicted the suggested design elements in various ways that the participants used as base for further discussion. The participants also attempted to plan informal testing by individually identifying a care recipient and trying to follow some (or all, if possible) model phases between the third and fourth workshop. Last, the group discussed conditions important for testing the model on a larger scale, such as organizational preconditions, language use, and documentation (Table 1), and prepared a video presenting their refined model.

Facilitators of enablement and group climate

It quickly became clear that the sequential setup of this round (i.e. taking over another group's work) gave group B different preconditions than the first. Simultaneously investigating their own perceptions while also relating the result to another group's work process was not ideal and gave them a more challenging start. Another hampering aspect was that two out of the five participants did not have the opportunity to attend the first workshop, which prolonged the group's formation phase. Participants showed engagement and competence, but independent work proved more challenging in this sub-cycle, especially regarding abstraction of their practice-based knowledge. To adapt to this situation, the researchers altered their approach towards more hands-on discussions and collaborative work: interdependence and collaborative planning and doing became the prominent strategies. A successful approach became the preparation of visual concretizations; i.e. making several design examples that captured the participants' previous discussions. These concrete examples seemed to spark creative thinking and critical reflection upon how they did or did not want the model to be characterized. In practice, this collaborative work often consisted of scribbling together on printed copies of the prepared design examples while discussing possible improvements, and the researchers prepared clean copies with refined examples/questions (based on previous discussions) for the next workshop.

Initially, the researchers had hoped that sub-cycle 2 would encompass informal testing of the model in the participants' daily work, but the participants needed all four workshops to reach a model they were comfortable with. The researchers' suggestion to prepare a small individual plan for testing between third and fourth workshop was received with caution. Although participants did not refuse, they expressed hesitance and insecurity as to how to do it, and ultimately, little testing was carried out. Researchers concluded that testing was likely too difficult under present circumstances, and would require more preparation than had been available. Therefore, the researchers decided to invite both groups to another round of workshops, and to make arrangements to avoid the uneven preconditions produced by the sequential setup.

Table 1: Important conditions when testing the model in a larger scale, as identified by participants.

Important for future testing
➢ Managers' involvement in the decision to implement is crucial ➢ Some extra time is needed in the beginning, to develop the frame of mind [få in tänket] ➢ Try to integrate the work with existing structures and tools, such as recurrent quality of care-meetings ➢ Potentially using the work phone to increase the model's accessibility in daily work ➢ Collegial discussions in small groups, about how to do it in practice, and preferably using case examples that sparks imagination and comprehension ➢ Documentation of actions done in the Stay In Touch process are crucial ➢ Language matters; wordings in the model, in case manager grants [biståndsbeslut] and in direct communication with care recipients. Loneliness can be a sensitive issue that requires a delicate approach, and the standardised wording of case manager grants can be difficult to understand for care recipients.

Second round: a sub-cycle of parallel testing and refining the model

In the over-arching PAR cycle, this round corresponded with the last phase: implementing and refining the plan. Although 'communication' and 'fostering relationships' remained important in this round, the groups stayed fairly intact since the first round and the relationships between researchers and participants felt relatively established. In this round, the researchers increased encouragement for participants to take on a more active role in the interdependent relationship. 'Collaborative planning' and 'monitoring the process' became more pertinent facilitators of enablement, and towards the end of the round we also developed 'strategies for sustainability and handover'.

Sub-cycle 3: groups A and B

In this cycle, researchers increased focused on fortifying active participation and participant ownership (29) of the process and work model. The two groups worked simultaneously and transferred suggestions, questions, and changes through the researchers, to align the groups' preconditions and to enable a sense of community and shared ownership. The work model was tested in everyday homecare work between workshops. During workshops, participants reported their experiences from testing the work model and suggested ways to refine the depiction and description of this process. In attempt to increase participants' feelings of ownership, researchers suggested that one (voluntary) participant would moderate the report phase in each workshop. Thus, a typical round 2 workshop began (after recap and small talk) with a test reporting with a participant as chair, and then continued with refining details in the work model according to needs discovered during testing.

Objectives and activities

The objective of this round was to test the model and to produce case examples. Both groups' initial tasks encompassed deciding how to use the coming workshops to test the model and create case examples. Group A decided to focus their testing on the quick-route ('here and now'), due to their restrained work situation. Group B decided to aim for at least three case examples of the long route and one of the quick-route of the model, and to maintain the structure of group member–moderators while reporting their testing. The participants in both groups also wished to receive text-messages from researchers each week to be reminded to test the model and note reflections. During workshops groups discussed what they felt was important to add or change in the model, and researchers prepared printed clean copies of their suggestions placed next to the previous version for comparison. Additions concerned, for example, person-centeredness, care recipient agency, assigning a staff member to monitor the process, and tying the Stay In Touch process to existing structures in everyday homecare work (such as care meetings and the 'contact care worker'). They also formulated questions for identifying loneliness and wishes for specific support, need for documentation, and discussed and determined a Swedish name for the work model ["Håll kontakten"]. Transfers between groups concerned problematic areas meriting further discussion and/or suggestions for changes to text and graphics.

Facilitators of enablement and group climate

In this round, one of the groups had a new manager, which seemed to alter the atmosphere in the group: participants appeared down-hearted, but were nonetheless engaged in the project. In both groups, testing still seemed somewhat difficult to grasp. Therefore, researchers prepared note-taking booklets for each participant in order to make the testing more concrete. The booklets contained headlines and spaces for notes, and covered phases of concern, what had been done, and challenges and opportunities experienced during testing. Our attempt to encourage the groups to take a stronger lead in planning and managing the work seemed to sometimes generate insecurities rather than empowerment. The participants' roles as moderators during reporting worked unevenly: while some participants adopted the task with confidence, others seemed uncomfortable and insecure. To meet these insecurities without decreasing participant influence, researchers strived to convey availability and support without officially taking over. In practice, this could mean sitting next to the participant–moderator, answering their questions about how to moderate, or help by asking follow-up questions to the group. The preparation of concrete summaries and design alternatives continued to be successful strategies for enabling creative and critical thinking. Weekly text messages were described as helpful for following through with testing, as participants found it difficult to remember and prioritize testing among their regular work tasks.

The Stay In Touch work model

The over-arching PAR cycle, consisting of three sub-cycles, resulted in a work model called 'Stay In Touch'. The model describes how home care workers can, within the boundaries of their role, act as discoverers of unmet social needs, employ intentional communication, and link to other professions in order to facilitate more person-centered support for social participation among older care recipients. The model can, in a way, be seen as a frame of mind, which illuminates loneliness and social support within in the regular organization of home care and provides guidance in day-to-day contact with care recipients.

The Stay In Touch model consists of a process divided into five phases, depicted as a large circle with an additional inner circle (Figure 4) and a chart describing each phase (Figure 5). Symbols were carefully chosen by participants to convey, for example, iteration, early withdrawal and person-centeredness, and the traffic-light color scheme symbolizes the process moving from a bad to a good situation. Being attentive, responsive, encouraging, adaptive, and exercising professional judgement are strategies emphasized in the participants' description of how to employ the Stay In Touch process. And although the model describes actions from the care worker's position, participants were adamant about the care recipient´s agency and control in every step.

The model begins with phase *Present situation,* and conveys importance of being attentive to signs of loneliness and using ordinary small talk to learn if the person experiences problems with loneliness (or referring this task to another care worker). If the person confirms loneliness, phase *Analyze* follows. The inquiry continues by asking what the care recipient enjoys doing, which relationships they value, and if they think home care could provide support. The care worker can also, with the care recipient's approval, discuss potential support with colleagues or the person's next of kin. One care worker will be assigned to monitor the process, preferably the 'contact staff member'. Phase *Plan* includes examining potential support to suggest to the care recipient. In this phase, colleagues or other relevant professions can be involved with the care recipient's approval. The phase might require application for additional service grants, in which case, a social service case manager will perform planning. However, it is also possible that the care recipient's aspirations fit within existing grants (such as social stimulation, meal company, or walks), and planning can be done informally or via structures for individual care planning. Lack of clear communication between different professions, and between lay-language and formal language were identified as potential barriers, and careful communication was therefore emphasized in the descriptive text. In phase *Implement*, the care worker's role depends largely on the result of previous phase, but emphasizes the need to remain attentive to signs that care recipients require additional support and using judgement and showing that the person's chosen activities are valued and prioritized is highlighted. The last phase, *Evaluate,* encompasses dialogue with the care recipient and home care colleagues about whether the plan worked well or needs changing, and distinguishes four aspects to determine whether the process has been successful. The process can start over at a suitable phase if it has not been subjectively satisfactory for the care recipient.

The model also contains an inner circle, *Here & Now*, which represents a shorter series of (informal) actions that reflects a small scale Stay In Touch process that can be done immediately. For example: a person expresses feeling lonely (present situation) and longing for a relative (analyze), the home care worker asks/suggests a telephone call (plan) and help finding and dialing the number (implement) and the person seems satisfied for the moment (evaluate).

Discussion

The activities in this project led to achieving the project's objective: to co-create a scalable, practice-based work model for supporting social participation among home care recipients. Participants identified how to support social participation by utilizing the existing structures of care planning and execution, and the model corresponds well with Swedish social services' foundational values for elderly care; for example, emphasizing care recipients' rights to a meaningful existence with others, respect for care recipient's autonomy, and capitalizing on the care recipient's own social resources (16). It also fits well with the required competencies for staff in elderly care (43), which emphasizes, for example, supporting social participation, adaptive

communication with care recipients, their relatives, and relevant professions, and documentation in the patient journal. Interestingly, participants identified communication with other professions as a potential barrier, particularly that a difference between the lay-language used when talking about a care recipient's needs and the formal wording of written home care grants sometimes caused care recipients to decline granted support, which is why the participants' model outlines the need for clear (oral and written) communication, especially when collaborating with other professions. Participants also identified care recipients' insecurities as possible hindrances during the implementation phase, and they accentuated the importance of care workers conveying that they value and prioritize the care recipients' chosen activities. Another interesting trait of the participants' model is their explication of tacit knowledge in general and the small-scale process *Here and Now* in particular. This quick route positions the smaller, "extra" tasks, done while doing other tasks, as an important part of meeting social needs.

Although the main objective was reached, this co-creation process was not without its challenges. PAR is well known for being an unpredictable and time-consuming research style (29), and reaching a final version that participants were satisfied with, required an additional round of eight workshops. Participants struggled with both abstracting their knowledge, and putting their abstraction back into practice. The researchers' strategies to meet these struggles and facilitate an affirmative and progressive group climate were illuminated through the 'enablement foundations' and 'facilitators of enablement; (40) in the secondary data analysis of this article. This framework has, to our knowledge, never been used to guide or analyze a PAR process before, and proved useful in supporting understanding of our enabling process.

One downside was an inability to complete testing to the extent that the researchers had hoped. The testing phase required extensive reminding and encouraging of participants to keep the project in mind between workshops and to prioritize their planned testing. Similar experiences have been described in other PAR research projects (29). A possible explanation for this engagement-drop between workshops might be the well-known precursors in home care contexts: stress (20, 21) and low focus on social issues (17, 27). It is likely that such preconditions will hamper engagement in adding tasks to address social needs (even when innately valued) when they are competing with more strongly incited tasks and values. Therefore, creating preconditions where care recipients' social well-being is formally acknowledged as a home care concern, is likely an important aspect of successful implementation of the Stay In Touch model.

Manager involvement is another aspect that might have impacted participant engagement. In the second round, one of the groups had a new manager, which gave us an opportunity to meet the same participants under two leaderships. The former manager had initiated participation in the project, whereas the latter expressed lower priority of the same. In this shift, the group's atmosphere changed visibly from strongly enthusiastic to more muted engagement, and two participants in this group also decided to end their participation before the end of the round. Leadership involvement and support have been identified as crucial for engagement and change when care workers participate in research, both by current participants (Fig. 3) and in other research (44). The possibility of increasing manager involvement was repeatedly discussed among researchers during the co-creation process, which is why we held verification meetings with the managers before and after each round. However, in retrospect, it might have been beneficial if managers had also been involved during workshops, in order to support empowerment of the participants within the power dynamics of their own organizations. Rensburg describes the importance of involving all relevant stakeholders, which became clear in the current project, but it is also evident that effectively applying this in practice is a challenge. One way to support

identification of stakeholders, power structures, and change-relevant positioning, might be to perform a power analysis of the organization (45, 46) prior to the project or in collaboration with participants.

All PAR collaborations are, of course, susceptible to power imbalances (29), which can decrease the participant's feelings of meaningfulness and active participation (40). Power sharing is one of the central foundations in the enablement model (40), and throughout the project, we strived to flatten the power balance and empower participants to feel ownership of their progress in designing a work model. This was, however, rather challenging, which became especially evident when participants were encouraged to plan and lead testing and reporting. When the researchers attempted to move themselves to the background, participants often expressed anxiety. Similar dilemmas about balancing activeness/passiveness in the researcher's role have been previously described in other PAR research (29, 47), and depict the need for a fluid shift between participants' and researchers' 'expert' perspectives, and that a more active researcher stance can be needed (47). McIntyre (29) describes how expectance to reflect and take responsibility often generates anxiety, and that reaching active involvement and joint responsibility can require extended encouragement, support and time. Although this project was extended for a relatively long period of time, an even larger (or unlimited) time frame might have contributed to enhanced preconditions for additional empowerment, by allowing silences and frustration to a larger extent (which are a natural part of participatory group processes) and eventually resolve into consensus and empowerment. Rensburg (40) describes how power sharing and participant responsibility can be facilitated through participants' opportunities to independently define objectives and activities, and to evaluate their own engagement and intervention. We strived to utilize these values within the inevitable boundaries of the project and our suggested activities and objectives aimed to crystallize the participants' views *within* the over-arching frame. But although this orchestration contributed to the model progress, it might not have provided optimal fuel for feelings of ownership. In this case, it was not possible to extend the time frame beyond what we already had done, but the importance of a large and flexible time frame should be considered for future research.

To our knowledge, this model is the first co-created work model to support social participation in a home care context. It must, of course, be tested and validated on a larger scale, but it offers a first step toward increasing systematic approaches in assessing loneliness and addressing social needs within the vast and complex context of home care. Likely, such testing would identify opportunities for further refinement, which is an expected and positive continuation of participatory action research.

Methodological discussion

This paper attempted to provide vivid descriptions of the PAR process, both smooth and gritty aspects, our facilitative approaches, and the opportunities and challenges met during the journey. Homecare workers match the type of vulnerable and low-power populations that PAR was developed to reach, but paradoxically, low power also brings challenges in the research process and might limit the potential for change (29). Throughout the collaboration, the researchers strived to flatten power and express willingness to learn about the context, through for example auscultations, keeping mini-lectures brief, and engaging in casual conversation during work-shop snack breaks. The researchers' summaries and examples nourished critical reflection among participants and sparked both rejection and elaboration of elements in the work model, as did the testing in practice. Reflexivity between the researchers was cultivated through de-briefing sessions where facilitating approaches were scrutinized (for example about how to arrange the room, carry ourselves, and manage stepping back or stepping

forward). These discussions were immensely valuable, and in hindsight they could have been audio-recorded to provide further insights for secondary analysis.

There were relatively few drop outs, but altogether, three participants left the collaboration before the end of a round, which could be considered a limitation. The researchers' impression was, however, that their adjournment was met with understanding by the remaining participants and did not cause (or was caused by) friction in the groups. The groups' constellations also changed to some degree between first and second rounds, which could be viewed both as a limitation and a strength. The majority remained, which allowed a continuation in group development, while the few newcomers provided appreciated perspectives. The homecare managers who initiated collaboration with the university expressed interest in improving social support for care recipients, as did the individual care workers that chose to participate.

The resulting model was based on the present preconditions and process of home care and reflected participants' values and beliefs, which likely augments the models' usability in practice. It has, however, to date not been tested in a larger scale, as its trustworthiness needs to be assessed further. Such testing and assessment will likely produce further refinement of this model. A feasibility study was planned to take place after this participatory process, but has (to date) been postponed because of the world-encompassing pandemic (COVID-19), which brought about social restrictions and left an immensely strained situation in homecare in its wake.

Conclusions

This paper describes a participatory action research project, where homecare workers and researchers collaboratively created a work model that guides home care workers in supporting social participation among older care recipients. This paper explores the research process's intrinsic objectives, activities, and facilitators of enablement, and discusses opportunities and challenges.

The Stay In Touch work model contains five phases that strive to facilitate person-centered support for social participation in day-to-day home care work. The model highlights how care workers can act as discoverers of care recipients' unmet social needs, employ intentional communication, and link to other professions or community services when needed. This model resonates well with the foundational values and skills required in elderly care, is unique in its kind, and could comprise a first step toward a more systematic approach to assessing and addressing loneliness in the home care context.

This project met challenges including maintaining active participation between workshops and participants struggling with moving between theory and practice, and empowerment where participants felt ownership of the process and the model seemed unfulfilled. Nonetheless, the project also contained opportunities for engaging home care workers who demonstrated competence in their field and provided opportunities to highlight their tacit knowledge, describe ways to traverse care recipients' loneliness and support social participation within the boundaries of the homecare worker's roles. The produced work model could provide a means for moving toward the legislated goals of person-centered care and supporting older adults' rights for meaningful lives with others in the community (16).

Abbreviations

PAR Participatory Action Research

Declarations

Ethics approval and consent to participate

Ethical approval was granted by the ethical board of Umeå University: 'Regional Ethical Review Board in Umeå' (Dnr. 2016-07089). Written informed consent was obtained from all participants. All methods were carried out in accordance with relevant guidelines and regulations.

Consent for publication

Not applicable due to the manuscript not containing data from any individual person

Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available, because the data includes information that could compromise research participants' privacy and consent but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

I.N. and T.N. planned and designed the study and A-B.C. functioned as method expert. I.N. and T.N. participated in the workshops and the primary action-oriented analysis. All authors contributed to the secondary analysis for this article, while T.N. wrote the manuscript draft and prepared figures and tables. All authors provided critical revision of the manuscript, all additional material and read and approved the final manuscript.

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Figures

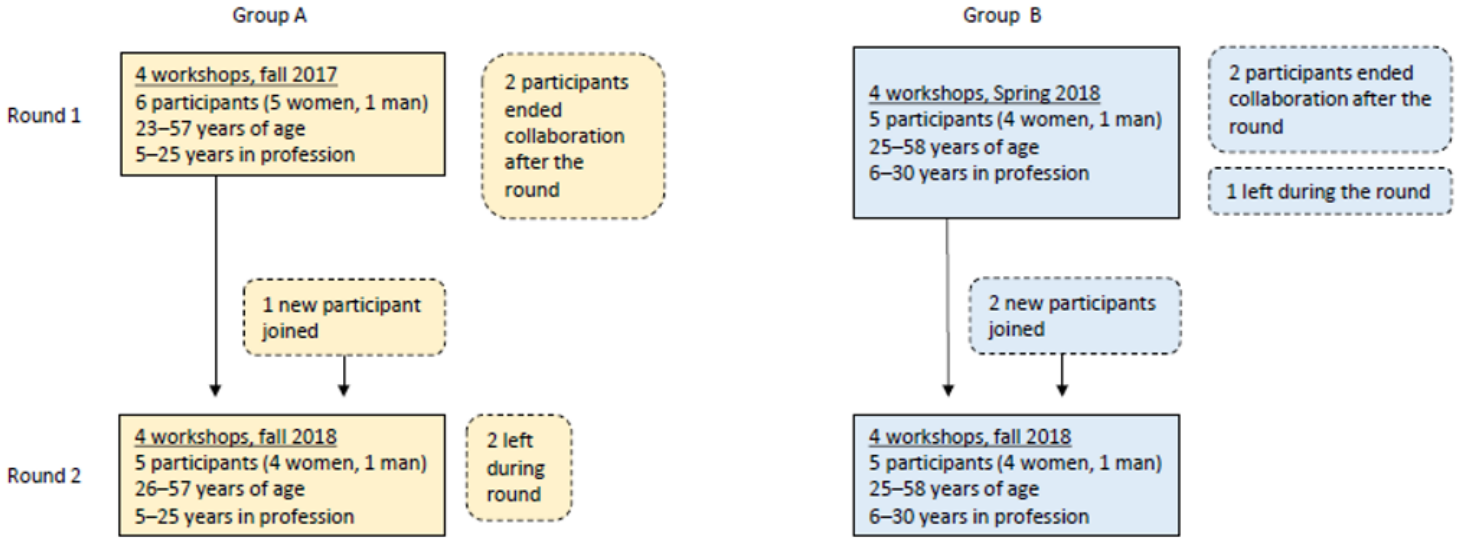

Figure 1

flow chart of recruitment and participants

Figure 2

The Recursive Process of PAR and Enablement Foundations and Strategies for social change in community practice.

The circle represents McIntyres PAR model (29) and the boxes represents Rensburgs Enablement Foundations and Strategies for social change in community practice (40) that was used to illuminate the co-creation process in the second phase of analysis

Figure 3

The process of PAR workshops

Each circle represents a sub-cycle, and all together they make up the over-arching PAR cycle. Yellow represents group A and blue represents group B. Each box represents a workshop (WS)

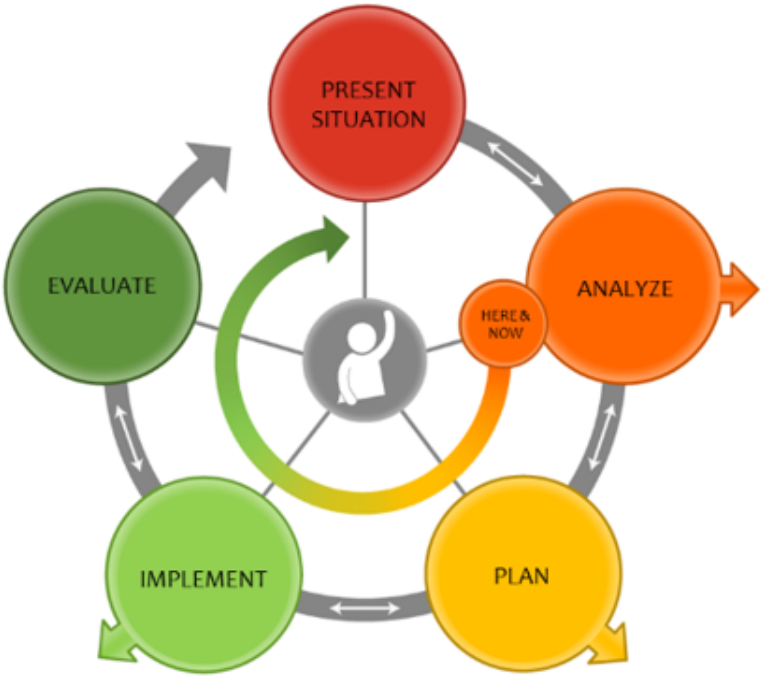

Figure 4

Stay In Touch Circle

PRESENT SITUATION	ANALYZE	PLAN	IMPLEMENT	EVALUATE
How is the person feeling?	**How can we help?**	**How will the support be performed, and by whom?**	**The plan is performed!**	**How did it turn out?**
You visit the person and notice symptoms of loneliness ➢ For example, the person expresses feeling lonely, or seems o depressed, listless, or sad? o to have difficulty getting out? o spend much time alone? o eat unusually much or little? o have cognitive problems? o sleep a lot? o anxious about getting out and doing things? o to have difficulty asking for help or afraid bother others? o want you to stay, maybe come up with new tasks to ask for help with. ➢ You or a colleague who has a good relationship with the person, talks to them about how they perceive their situation ➢ Remember to document!	HERE AND NOW First aid: what can be done immediately **Obtain information about interests and aspirations** ➢ Ask the person what they enjoy doing and what they would like to be supported to do ➢ If needed, and the person allows it, you might also: o consult the home care contact person or other colleagues. o talk to the person's relatives or other next of kin ➢ Appoint a care worker to supervise the following process (for example the contact person) ➢ Remember to document!	**Summarize previous information and individualize the activities** ➢ Gather information about which support might fit the person's interests and aspirations ➢ Present the suggestions to the person. Plan implementation and evaluation together with the person: when, how, where, whom? ➢ Other professions are contacted if needed. All communication of needs and plans must be clear and concrete. ➢ Remember to document!	**Support the person to do their planned activities** ➢ Keep attentive for needs of support ➢ Convey that both the person and the activities are valued and prioritized ➢ Offer support when you perceive it needed ➢ Keep attentive to weather the plan needs alteration – in this case, notify the supervising care worker ➢ Remember to document!	**Relative to the beginning of the process, have there been change?** ➢ The supervising care worker initiates dialogue with the person and colleagues to determine weather o the activities have been carried out as planned? o the person feels satisfied with the activities/ support? o the person's loneliness has diminished? o the person is more socially active? ➢ If something needs to be adjusted, the process starts over. ➢ Remember to document!

Figure 5

Stay-In-Touch Chart

This chart is a detailed description of the content of each phase in the Stay In Touch Process, formulated by the participants. The original chart was done in Swedish and translation to English was done for this article with the support of a professional language editor.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- SupplementarymaterialAppendixTopicsofworkshopsactionorientedresearchquestionsandproduceddata.docx