

Chapter 12

Nursing Home Residents Versus Researcher: Establishing Their Needs While Finding Your Way

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Abstract Residents at nursing homes need to exercise to retain self-efficacy. But all the while, many do not seem to want to prioritize exercise routines over leisure activities. The first part of this chapter analyzes the potential reasons for this lack of exercise commitment at a nursing home in Copenhagen, Denmark, and show a solution to overcome such obstacles, by augmenting the exercise routine with the accompaniment of recreational virtual environments. The second part of the chapter shares insights from the experiences from spending 3 years with the unique challenges and complex conditions that researchers face, when operating and navigating the specific field of nursing homes, due to the inherent characteristics of its context and users.

Keywords Older adults • Rehabilitation • Exercise • Nursing home • Virtual environments • Intrinsic motivation • Trust

12.1 Introduction

This chapter bases itself on a couple of studies performed in relation to a PhD project, which has been running over the course of three years. The project has investigated the background behind the problem of inactivity with regards to nursing home residents routinely exercise at a Danish nursing home, Akaciegården, in the Copenhagen area. From the research, it has been possible to map various aspects to nursing home life, which seem to oppose a desire to maintain a regular exercise routine for many residents. It has also been possible to implement and test a solution, which has positively affected some of these aspects, by using virtual environments to augment the exercise into a different type of experience. Last but not least, it has been possible to experience the (possibly) deceptive complexity of

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245

working as a contemporary media technologist researcher, within the very specific context of older adult nursing home residents as the users. Primarily concentrated around the context of two individual studies performed for the project, this chapter provides an elaborated insight into the process of problem identification, solution design and results throughout the two studies, and afterwards discusses the implications of performing such research.

The initial incentive for engaging this specific area of research was a desire to combine an exercise routine for elderly users with an augmentation design using virtual audiovisual technology. The applications of virtual reality technology have been investigated for some years now, but as this project has come to realize, the field seems to yet lack the maturity of covering requirements and best practice frameworks for user demographics such as older adults. From a societal perspective, the elderly demographic will be growing rapidly over the next decades [1], and there is a need for methods to help maximize the longitude degree of independence for older adults. Exercise is one such method, but while research with the elderly segment and commercial entertainment technology has been given some attention for a period, such as with the Nintendo's Wii console or Konami's Dance Revolution game [2, 3, 4], the body of research on tailored technology and content, designed specifically for exercise purposes for nursing home residents is both sparse and necessary [5]. It is imperative that the sense of meaningful purpose of a newly applied technology such age group demographic is considered [6], and what motivates physical activity behavior between age groups is very different [7].

Throughout its duration, the project has been fortunate to gain close access to the daily-living nursing home residents and their routines, which has facilitated iterations of observation sessions, interviews, private visits and social interactions with residents and staff. The resulting outcome has a variety of insights into what constitutes the nursing home life, as well as an understanding of residents' ability, approach, opinions and practices related to daily physical exercise. This has enabled the project to positively touch upon the somewhat untouched potential of virtual technology and media, specifically for nursing home exercise activities. And it has given an important understanding of what constitutes constructive procedures and necessary precautions to consider, when working scientifically with this type of technological development, with this type of user group.

The first part of the chapter (Sects. 12.1–12.4) takes a closer look at the aspects that form the exercise reluctance problem in the context of the nursing home. Thereby the reasoning behind the solution design is also detailed, leading to a description of both the solution design itself and the results from two studies using the solution; one study which initially validates the solution design [8], and another study which evaluates the motivational implications on its implementation at the nursing home over an extended period of time [9]. The second part of the chapter (Sect. 12.5) addresses a seemingly overlooked aspect to such research, which is the inherent challenges of working as a researcher in the context of a nursing home, with nursing home residents as the target user group. While these considerations are not explicitly detailed in the first part of the chapter, they have been a necessary part

of the research approach throughout the project. The second part of the chapter thereby contributes insights to research practices, which is believed by this author to be essential for any future endeavor within this field of research.

12.2 Physical Therapy and the Manuped

When moving from their original home to a nursing home, many facets of everyday life are made easier for new-coming residents compared to their previous living. This is partly due to the now closely available assistance from personnel, the optimized demographics of the nursing home increases independence, relating to daily activities such as toilet visits or overall indoor mobility, which increases overall life quality [10].

Rehabilitation is another area where nursing homes often have much to offer residents, in terms of attendance flexibility, availability and variance of activities. In Denmark, many nursing homes encourage physical therapy as part of the everyday activities at the home. The level of independent living and health status is an important factor of the quality of life for any person, and especially for these elderly segments [11]. Physical activity on a regular basis is found to improve sarcopenia, physical function, cognitive performance and mood in elderly adults [12], in addition to being able to maintain independence and retain self-efficacy [13]. Exercise makes a difference in everyday life for residents, as it fundamentally enables other activities. Examples of everyday situations where lacking self-efficacy can influence quality of life, are getting dressed, walking, or even controlling one's own drinking glass and eating utensils.

At Akaciegården, exercise and physical independence is a central part of the nursing home philosophy, but personnel are facing difficulties inspiring a portion of residents to maintain regular exercise routines [8]. Factors such as *independence* and *self-efficacy* could be regarded as rational, reasonable, and qualify as motivational reasons why exercise should be an attractive activity. Meanwhile, studies suggest that it does not reflect the engagement of many nursing home residents [8, 9].

Many residents who do not exercise regularly do not seem overly concerned with their lack of commitment, despite being well aware on the positive effects it could bring to various physical deficiencies. When asked into the reason for not exercising, many residents choose to deprioritize exercise because (a) they don't like it for one or several reasons, (b) they had been exercising regularly at one point, but couldn't find the motivation to return, (c) they feel that exercising too often interferes with other types of leisure-based activities overlapping physical therapy sessions, or d) they are simply too lazy [9].

The physical therapy center at the Akaciegården nursing home is open in two separate 2.5 h sessions a day, four times a week, with two physical therapists present in each session. Average resident participation is 10–15 during morning session, and 6–12 in the afternoon depending on the weekday due to weekly social



Fig. 12.1 The Manuped exercise device

activities on certain days. Therapists are very attentive and social towards the present residents in general, but certain exercises (any walking or standing related exercises) need the complete and attentive presence of either one or both therapists. Physical therapy sessions are therefore a race on resources, in terms of therapists' capability of placing appropriate personal attention to all residents who need it. It also means that exercise activities that residents can perform unassistedly have high value for the daily exercise routine. The most essential exercise activity for unassisted is a machine called a manuped; a chair-based bike device for arms and legs (see Fig. 12.1). In the context of the nursing home, the manuped is an all-round exercise device.

A manuped activates most parts of the body to varying degrees, and affords exercise with a high variance of intensity. Residents can use it unassistedly, as it requires no active balancing, or strength comparable to standing up independently. Nor does it demand sudden reactions or swift coordination changes (anything demanding dynamic muscle activity or quick coordination and balance). This combination of traits makes it safe for the physical therapist to leave a resident alone while using the device. Devices such as the manuped become essential, due to the resource limitations for the two therapists, as they can have more residents exercising at the same time, without having to actively attend all of them.

The manuped exercise is a single-person activity. Practicing residents are facing a wall while exercising, mainly because of the logistics placing them by the device, from e.g. their wheelchair. It does, however mean that once they are in place and start using it, residents are practically left alone for the duration of the exercise (10 min for the weakest, and approx. one hour for the few strongest). From both early interviews and casual conversations with residents, they generally really like the physical therapists. Much of what was appreciated about the physical therapy center had to do with the two therapists. Another very clear opinion among residents was that although using the manuped is good for the body, such activities are extremely boring, and difficult to want to do.

12.2.1 Why Residents Dislike Exercise

Many residents struggle with obstacles such as balance issues, pronounced lack of muscle strength (a combination of lack of exercise and sarcopenia), coordination difficulties, arthritis, or other chronic conditions [14]. Besides these, regular disease generally hit harder and last longer at this age. The effects of this were partly the reason why many residents expressed reluctance to make the effort to go exercise. When thinking about the physical therapy, they were thinking in parallel about the pain and discomfort affiliated with the activities. Of course, the impact of this varied between individuals, partly due to differences in physical performance/limitation, partly due to personal distaste for the associated pain, and partly due to their individual desire to overcome it. The last point is important, as almost all residents experience pain or physical issues to some degree, while exercising. So while the perspective of pain during exercise is a fact for most, it depends on the individual if it holds them back, is not important, or perhaps serves as a reminder to go exercise, as the sensation will only worsen if they do not. All scenarios were met during conversations with residents during visits.

12.2.2 Returning from Illness

Periods of illness are a big part of everyday life at a nursing home, which is why periodical absence from an exercise routine does not equal a lack of motivation. However, the two are potentially linked, as, physical conditioning from exercising decays much faster than at younger ages, during periods of illness. When the illness has worn off, residents are often left with the sensation of having to start all over again. For some nursing home residents, this can mean reestablishing the ability to walk. If a resident has not been able to maintain a regular exercise routine, physical therapy activities can be very physically demanding. Exercises are painful, and the residents cannot help but observe, compare and acknowledge their own inadequacies, when they for example with a physical therapist under each arm to aid the

ascent, as they try to simply practice standing up from a chair. In addition, performing (relatively speaking) intensive exercise, affects their body substantially the rest of the day, perhaps even more. Especially if they have not been maintaining a regular routine, many residents are fatigued after a physical therapy session, to the extent that it sometimes means that they cannot engage in much else for the remainder of the day. Residents therefore go into a cycle of training, where they hit a barrier, and then struggle for an extended period of time to get back into a shape where they are actually able to perform simple tasks (such as standing up).

Exercising for the pure sake of long-term physical improvements can thus be regarded a substantial, and unstable investment. Observing a resident return to exercising after a longer break, give several impressions. One is clear happiness about being able to return to exercising and to the nice environment of the physical therapy center. Another is sadness and irritation concerning the lost long-time effort from before the break. It is a cycle that repeats itself for many residents, which has been evident from many conversations along the project. And it has shown to be a factor that makes it difficult for residents to prioritize physical therapy. Some residents do return to their exercise routine after longer periods of illness, however. This has especially been pronounced for residents who from previous occasions have gained personal experience with the physical difference between returning to exercise and staying away from exercise.

12.2.3 The Alternative

Most residents at Akaciegården are physically or mentally unable to leave the nursing home at their own initiative. If they do, they require personnel (or family) assistance, which is often not possible within the in-house resources, on any general scale. This means that social and/or entertaining leisure activities are hugely important for the residents, as most residents are almost completely limited to the experiences that are offered inside the walls of the nursing home. The nursing home arranges a large number of such in-house activities per week, where residents gather with a group of personnel, who deliver or conduct the event. Events are typically quite casual, for example rhythmic and singing gatherings, a movie, coffee and cake in the yard, card or board games, etc. As it is an important priority for the events that any resident should be able to participate, the events have a minimum of physical activity required (such as crossing squares on a paper, eating biscuits or drinking coffee while sitting on a chair or wheelchair). The leisure activities at Akaciegården are enjoyed by residents, and for many reasons. They increase personal bonds between and within personnel and residents, fill the residents' days with enjoyable content and experiences, and activate (or reactivate) residents socially. Meanwhile, with a fixed perspective on increasing the desire to exercise, leisure events can be seen as a diversion, which leads residents away from regular exercise routines. And while these authors would never encourage less leisure

activities at Akaciegården, they do represent a challenge for the physical therapy personnel, in terms of keeping residents with their programs.

12.2.4 Laziness?

As mentioned earlier, a fair amount of residents who did not exercise a lot, claimed to be simply too lazy to exercise regularly. When asked into the reason behind their laziness, many residents described that it came from a combination of the areas just described; from pain, physical difficulty and boredom of sitting alone facing a wall while exercising, to the lack of any leisure entertainment during exercise sessions, the knowledge of the potentially lost effort if hitting a barrier, to the calm, relaxing and entertaining activities offered other places at the nursing home. From this outset, it seems that while some residents find themselves to be too lazy to exercise, they have a background of understandable reasons to simply not feel very positive about the activity itself.

12.3 The Conventional Manuped Exercise Experience

From observations of the daily routines in the physical therapy, the manuped exercise was by far the most shared and commonly used. It was the most resource relieving exercise form for the physical therapists, but evidently also the most repetitive and socially isolating exercise experience in the room. Over the years visiting the nursing home, numerous conversations were had with residents, concerning the manuped experience. Two iterations of interview rounds were done as well with residents in relation to the studies, where residents were asked to describe their opinions on the conventional manuped exercise [8, 9]. Interview asked into the positive and negative aspects of the (conventional) exercise, as well as opinions about possible improvements [9].

Positive aspects predominantly related to the function and usefulness of the manuped, as a facilitator of physical conditioning. Positive responses were, for example *getting the legs working, doing an effort to stay functional, to be able to do things, or physical improvement*. Negative sentiments referred more to the actual experience of the exercise, in terms of how it was *trivial, uninteresting, boring, repetitive, demanding, and hurtful*, describing the opinion about the activity, as e.g. *“you have to pull yourself there”* or *“you are caught once you enter that place”* [9].

An interesting situation happened when subjects were asked about possible improvements to the experience. Most subjects could not imagine any possible alternative. This was eventually found this to be characteristic for the user group. Nursing home personnel explained that many do not want to seem ungrateful of the offerings placed at their disposal, and have a tendency to humbly accept things as they are at the nursing home without thinking about questioning it.

Some responses did however encourage changes; by e.g. simply needing a *routine shift* or a *diversion*, while others again suggested the same, but coining it *entertainment*. A few had the imagination to associate to “*a real bike ride outside, alone, on your own, peace, and the smell of summer*” or “*to bike to Brighton*” (where she was originally from). The pattern is that positive responses about the manipulated exercise were health oriented and rational, while negative responses related to the experience of the actual exercise activity, Potential-improvement responses related to the experience by removing the boredom and repetitiveness from the exercise form.

12.3.1 VE Augmentation: An Extra Layer

Based on the responses, it was decided to augment the exercise experience, to bring a new layer to the manipulated, so the exercise activity would be accompanied by an audiovisual experience. A virtual environment (VE) was set up in connection to the manipulated, to react to the residents’ press on the manipulated pedals. When they pressed the pedals, the VE moved forward and gave a sensation of a bike moving forward in space inside the VE. As such, a manipulated exercise would (to a certain extent) reflect a bike ride through a (virtual) landscape.

This implementation was based on the following parameters. A fundamental part of the setup was to not change the form and function of the exercise. On the perspective in interaction design, and possible gameplay oriented elements, it was decided to keep the interaction with the system based on the normal input scheme of the conventional exercise. This would make the augmentation simple and easy to transfer to the users. The background for this decision came from an intermediate focus group session performed with a Nintendo Wii (using Wii Sports), which attempted to establish and evaluate the residents interaction abilities and preferences, in terms of interaction possibilities to perform while exercising.

The focus group experience led to two conclusions:

- (a) The residents in the focus group were practically unable to interact with the simple Nintendo Wii gameplay, due to cognitive and motor-based deficiencies,
- (b) Aiming, from a developer’s perspective, for a gradual improvement of interaction skills along a hypothetical timeline seemed dangerous. It was clear that the residents (all besides one) who were unable to perform the required actions within the Wii Sports game experienced a personal defeat and embarrassment, not a personal encouragement to learn a new skill. The rationale was that if even remotely more demanding interaction requirements were included, a substantial portion of the users might be alienated before they even started.

Even without changing the interaction significantly, it was expected that such augmentation could redeem some of the cardinal complaints of the conventional

manuped experience. On a very basic level, the augmentation would change repetitive experience of looking into a blank wall during every single exercise, looking into a dynamic, constantly changing landscape view in motion. Instead of simply performing trivial pedaling, an augmentation would give the effort of pushing the pedals an immediate feedback reaction and possibly an immediately valuable payoff. Another possible result could be that the attention to pain and physical inability, could be changed to the augmented exercise which could provide a diversion of attention, distracting the resident's focus from the activity related pain, as also suggested by de Bruin et al. [15].

An aspect to the VE augmentation that could have a strong impact is the ability to transform the indoor manuped bike ride to an "outdoor" bike ride. In addition, supposing that the link between actions and system response would feel natural, and that the VEs would be able to provide a convincing experience, residents might be given an option, which they might have thought to be lost - the ability to unassistedly travel to other places outside the nursing home. By that hypothesis, instead of being a lonely, uneventful and trivial single-person experience performed as rationally forced chore, the manuped exercise could suddenly be facilitating a unique, enjoyable and perhaps even personally valuable experience.

With the conventional manuped exercise, the only reward of the exercise actions is the long-term goal of better fitness, leading to gradually higher independence and self-efficacy. This long-term goal would now be supported by a short-term value from the daily ventures inside the virtual landscape.

As such, a hypothesis about the augmentation was that the hard work might transform into something more resembling leisure time—something that was previously suggested to be of high contrast to the manuped exercise. All in all, the goal for the manuped exercise would be a place where residents would want to be, instead of a place "you cannot wait to get away from".

12.4 Solution Design

As explained in more detail in [8], the first study of the concept was done through a small-scale, summer countryside VE, with 10 participants trying out a single exercise run. Results suggested definite promise, with user responses relating to the previously mentioned expectations for the augmentation. The system implementation can be seen in Fig. 12.2. To be able to track the user input actions, magnets and Hall Effect magnet sensors was attached to respectively the manuped pedal arm and manuped frame exterior, one for each side of the manuped to track each pedal push. The sensor was wired to an Arduino UNO microcontroller, which forwarded the sensor output to a desktop PC (Intel Core i5, 8 GB DDR3 RAM, ASUS GTX760 graphics card). The PC then was running a Unity 4.6 based build of the VE, which was visually displayed (running an average of 45 fps in 1080p resolution) on a Samsung 46" LCD TV. In the first study, a pair of Sennheiser HD650

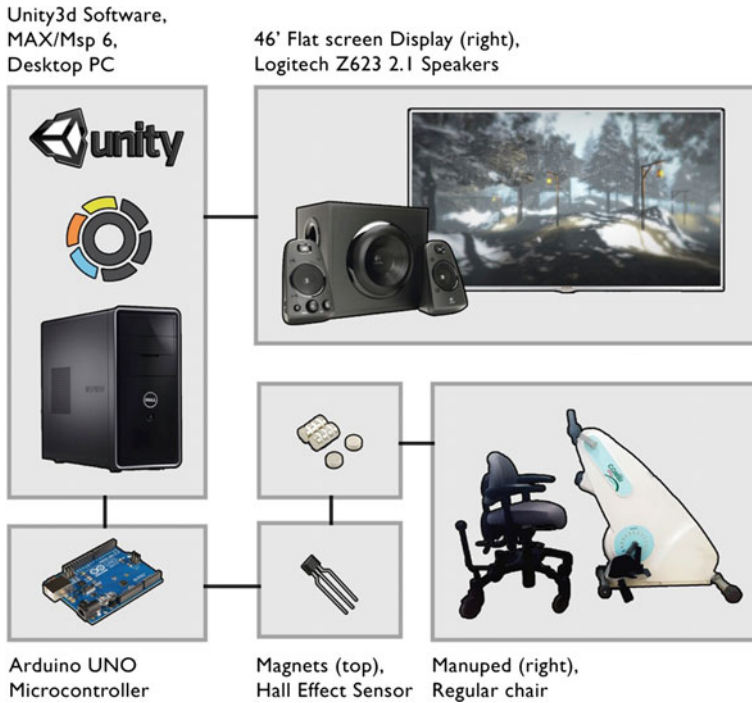


Fig. 12.2 The augmentation system

headphones provided the VE soundscape, but as headphones were generally found to be intrusive, the later study used a Logitech Z623 Black 2.1 stereo speaker set.

The dynamic, moving visuals (examples from the first study VE in Fig. 12.3) provided a welcome change of “scenery” from the original static view of the wall. Residents did in fact connect the manuped pedal actions with the forward movement through the VE, and the introduction of a (virtual) landscape to explore were very positively received by most subjects. They accepted the experience of traveling inside the (VE) landscape, and many expressed something close to a thrill, concerning being able to experience the natural beauty of the landscape.

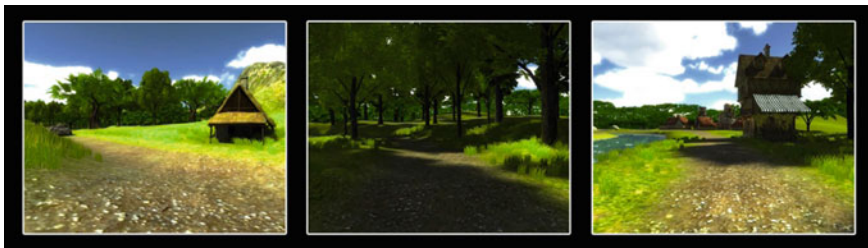


Fig. 12.3 The virtual environment used in the pilot study



Fig. 12.4 The four virtual environments used in the longitudinal study (with Danish titles)

The feedback of the system was perceived to place the (short term) purpose to the exercise actions, and one subject even mentioned that she now felt the ability to move herself forward outside the nursing home, which was a feeling she had not experienced for a long time (due to her weight issues in a wheelchair). In this sense, the pilot gave a real sensation of the exercise being transformed into something that could qualify as an enjoyable experience, which in turn placed it much closer to being classified as a leisure activity. However, the earliness of the implementation, as well as the fact that this experience was a first test, did not elude some of the subjects, who expressed the need for a higher diversity in VE content and more VEs to choose from, if the augmentation was to retain leverage over longer periods of time [8].

For the next study [9], a larger collection of (four) more content- and size-wise complex VEs was designed and implemented, using a design framework developed for the exact purpose [16] (as can be seen in Fig. 12.4). The purpose was to test the concept over a longer period of time and to evaluate the residents' intrinsic motivation to exercise, comparing the experience of the conventional manual exercise with the augmented one. During the development of the new implementation, over the course of approximately a year, the nursing home residents were only subject to the conventional manual exercise. Prior to installing the new system, a select group of subjects were responded to a set of questions relating to their positive, negative experiences with the exercise, their suggestions to improvements, and their level and orientation of intrinsic motivation (as defined by Ryan and Deci [17] in relation to Self-Determination Theory) in relation to the manual exercise.

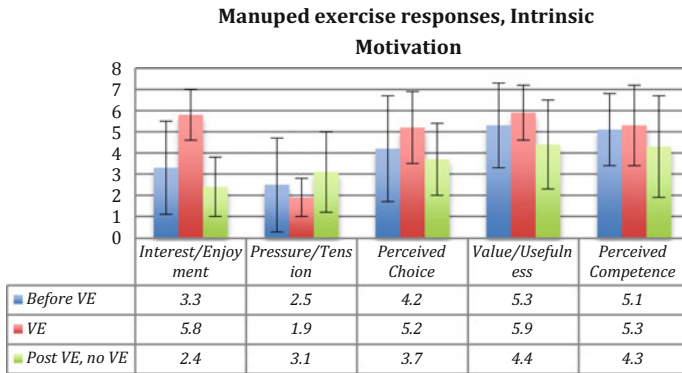


Fig. 12.5 The levels and factors of intrinsic motivation from the longitudinal study [9]

The level was measured on a 7 point scale, whereas the orientation was measured based on items relating to different factors of intrinsic motivation, taken from the Self-Determination Theory related Intrinsic Motivation Inventory¹ (IMI). The orientations (factors) chosen for the study were Interest/Enjoyment, Pressure/Tension, Perceived Choice, Value/Usefulness, and Perceived Competence [9]. Subsequently, the new augmentation was installed and ran at the nursing home for more than four months, after which the residents were asked to respond to the same questionnaire, only this time concerning their experience with the augmented exercise experience. In addition, they were also asked to respond accordingly to how they would feel about going back to exercising without the augmentation [9]. Results concerning the IMI orientations were very interesting, and can be seen in Fig. 12.5. Subjects responded as expected before the augmentation had been introduced (“Before VE”), if not slightly more positive than expected. As previously stated, it was the impression that they did not want to seem ungrateful, and that they were generally trying to be content with the opportunities they were offered. Results concerning the augmentation (“VE”) were consistently more positive towards the augmentation, and most said it had become an integrate part of their reason to want to exercise on the manuped. And results from residents concerning returning to the conventional exercise (“Post VE, no VE”) showed a clear negative curve, compared to both the augmentation and especially the original responses to the conventional manuped exercise. Four of the five motivation orientations had similar patterns between the three “conditions”, with a not too high increase from the conventional towards the augmented exercise, and then a larger decrease in motivation in relation to returning to the conventional exercise. One motivation orientation, Interest/Enjoyment followed the same trend, but stood out by having much larger jumps between values.

¹<http://www.selfdeterminationtheory.org/intrinsic-motivation-inventory/>.

The subject responses to the positive, negative and possible improvement aspects of conventional manuped exercise, all suggested that which was previously explained in this chapter; a useful activity for the functionality of the body but boring and repetitive. The augmented was praised highly in these categories, and the thought of returning to the conventional exercise form was poorly received. Meanwhile, by far the most clearly significant difference between “conditions” in Fig. 12.2 is that of Interest/Enjoyment, whereas the remaining orientations are much more similar. What the original publication suggested as the reason, was how many aspects of the other orientations were already quite ok for the conventional exercise form [18]. The results suggested improvement by the augmentation over the conventional form, but none even remotely close to the difference of Interest/Enjoyment. Combined with the user responses on positive/negative/improvements, which very clearly suggested the augmentation experience to be a substantially superior exercise experience, it looks logical to suggest that the leisure and entertainment aspect of the activity itself has proven to be a strong factor in improving the desirability of such type activity for nursing home residents. From that perspective, the inclusion of the augmentation, as a transport to another place, as well as being an entertaining layer on top of a meaningful exercise, could be argued to make a lot of sense.

Both studies showed also suggested how content variety, details and consistency was important for the users experience of riding through the VE, as well as liveliness inside the VE (animals, water, wind, etc.) [8, 9]. These aspects to the experience give believability to the experience, and add to the sensation of a recreational ride through nature, as also highlighted more in a paper by Bruun-Pedersen, Serafin and Kofoed, discussing various key considerations to design challenges when creating custom VEs for this purpose [18].

12.5 Research Challenges: Nursing Home Residents

Essential to the research just described was a constructive collaboration relationship with the nursing home residents. It demanded to meet them in their environment, during their everyday life routines at the physical therapy, and even required disturbing their privacy, unannounced, on occasion in their private homes.

Nursing home residents have unique characteristics as a user group, and it is necessary to consider those contextual properties in the planning and execution of studies. Many of these characteristics were not considered when beginning the project. Neither was the importance and necessary degree of empathetic understanding of the individuality and context of the residents, all of which were gradually discovered to be cardinal parts of conducting the research with residents.

12.5.1 Planning of the Study

On the practical level, it became necessary to recognize the daily rhythm, capabilities, and limitations of the residents as subjects. In this sense, planning is extremely important, but so is a high level of flexibility. Sudden changes cannot be expected from residents, but at the same time it is not possible for a researcher to rely upon agreements or schedules brought upheld by residents. This is not due to conscious neglect, but most often to the constant risk of illness, otherwise immediate loss of strength to participate or simply dementia. In this perspective, studying nursing home residents requires patience and studies require a lot more time than what would seem rational on paper.

Numerous unforeseen occurrences can happen from one day to the next. In the first study, 15 residents signed up, 10 participated, and the study took twice the time to perform the single trial in the pilot VE than expected. In the 4-month study, 17 agreed to participate and 8 completed the study (new subjects were added to the pool along the study, however), due illness, dementia, amputations, death, or hospitalization. It has also occurred a few times that a subject suddenly declined participation with no explicit explanation or reason, but overall, this type of situation has been rare. Over the course of a longitudinal study, a pre-defined group of subjects is therefore bound to change, sometimes dramatically, and it is a part of this type of research to follow its course.

12.5.2 Keeping the Residents Reminded

Especially when performing longitudinal studies, it can be very challenging to keep a position in the minds of residents unless the routine is soundly established in their schedule and mind. As many suffer from dementia and have poor recollection of people or faces, a resident would forget the face of the researcher, or the purpose of an arrangement made prior, on multiple occasions during the studies. Being part of their everyday life routines to the extent of being considered a part of the everyday actions is very constructive for many aspects of this type of research. It relates to residents being confident that social interactions will be pleasant and respectful has shown noticeable differences in the type of working relationship possible within the user group.

Another crucial way to keep focus is through a clear and constructive relationship to personnel. For longitudinal studies, it simply heightens the probability for support of the agreements made with residents for various study procedures, as well as performing practical tasks such as noting measures, etc., under circumstances where the research team not present at the nursing home. Perhaps even more importantly, the all-important relationship between researcher and residents (which will be addressed later) goes partly through the personnel as well.

Personnel essentially work as a gateway to be accepted by the residents, both directly and indirectly. The direct part is to introduce the affiliation of the researcher and the nursing home towards the residents. Personnel often have the trust of the residents, who will accept foreign people if they are clearly trusted and introduced by the personnel. Indirectly, the residents also observe many things, for instance the relationship between the personnel and the research team. Residents have described using this as part of the ‘measuring stick’, to evaluate whether a researcher was initially someone they want to interact with.

12.5.3 Establishing and Maintaining a Routine

Nursing homes like Akaciegården are much about rhythm and habit. Every day has a standard operation schedule (morning/evening assistance for individual residents, meals, etc.), and every week has a repeating activity schedule for specific weekdays, such as bingo, singing class, physical therapy, rhythmic gymnastics, the in-house hairdresser, a beautician, etc. Nursing home living thereby follows a recognizable pattern, which residents should be able to comfortably learn and rely upon. In addition, singleton events such as concerts, movie viewings, or various celebratory/traditional events occur on a regular basis throughout the year. Such general format for week schedules is necessary, as residents with decreased memory/cognitive capabilities are challenged even when navigating such recurring schedule. In addition, singleton events are not in small quantity per year. And while residents enjoy them, some need personnel to help keeping track of the activities interesting to them.

When performing especially longitudinal studies with residents, it is crucial that resident participation is structured, so that it becomes part of the fixed weekly rhythm. Otherwise, there is a high risk that they will forget or not enable themselves to go, because they might need help to get to the physical therapy and either won't ask (out of politeness) or simply cannot get help from the resources of personnel at a given time. A routine needs to be established around the group of residents who have agreed to participate as subjects. It thus becomes necessary to involve all personnel affiliated with each individual resident participating, and make detailed arrangements and agreements concerning each individual resident's study procedure activities. Residents regularly need personnel to remind them of their daily activities, and the study procedure needs to become part of this routine.

It even became necessary to schedule when individual subjects would be able to access the manuped, simply because of an overweight of subjects initially (and randomly) wanted to use the single available manuped device at the same time each session. To ensure the procedure to run smoothly, access to the manuped for residents was then scheduled into specific time slots, so certain divisions of residents had access to the manuped, at least on certain days, at least in certain time frames. Of course, none were unwelcome at any time during physical therapy



Fig. 12.6 A3 poster placed at all common areas to help residents remember their engagement

hours, but typically residents would follow a routine given to them, and not deviate too much.

Setting up such type of longitudinal study at nursing homes involves a surprising amount of people, besides the administration for permission and the physical therapy team working at the clinic. The nursing home facilities used in the studies are split into 8 separate departments. The group of residents used for the studies were spread on 6 of these departments. Each department has individual teams of personnel, and each team has changing shifts, substitutes and volunteers, whom all need to be informed to ensure that the routine is running every week. Each department needs to know which of their residents need to go and when, and make sure to fit this into their schedule concerning preparing and aiding the resident with clothing, baths, etc. outside the research schedule.

Besides having personnel assisting residents to uphold the scheduled research activities, residents' general connection to their participation agreement seemed to benefit as well from exposure to various types of paper media. A3 posters with images of the recreational VEs and a member of the research team with the physical therapists (as seen in Fig. 12.6) were placed in all central traffic areas inside the nursing home, serving as a constantly occurring reminder for subjects on their daily tours round the building.

In the monthly (in-house) nursing home newspaper, a page was dedicated to the purpose of the project, using short text and large pictures (see Fig. 12.7). This was confirmed by many residents to add to their awareness of the exercise initiative.

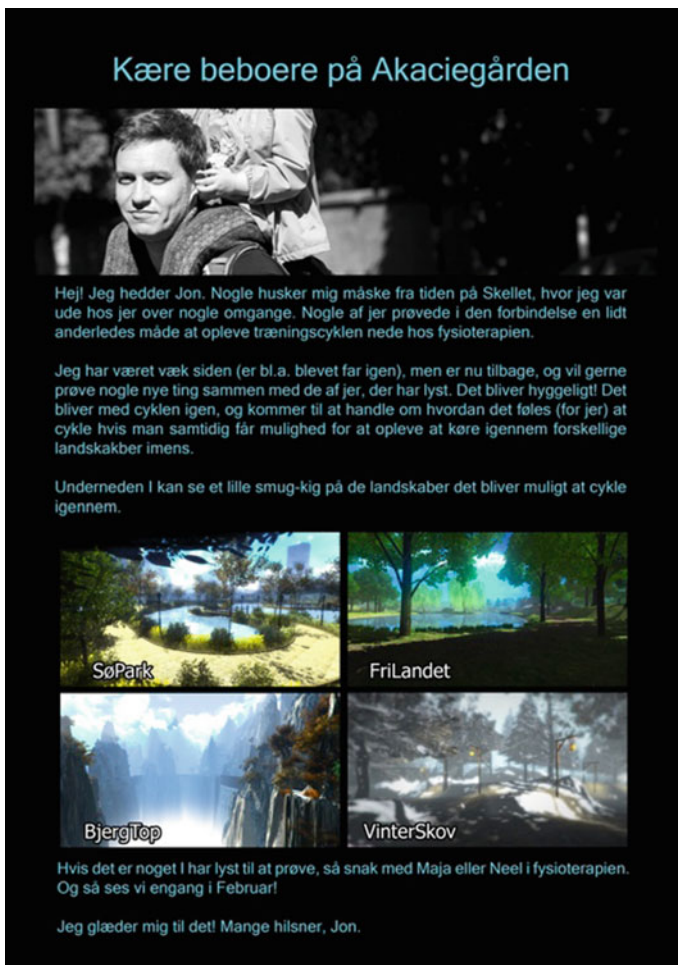


Fig. 12.7 A3 page from the in-house news paper

In conjunction, it was important for the research team to be present and visible at the nursing home as much as possible, despite not always having an active role in the data gathering.

12.5.4 A Trusting Relationship

No matter the methodology, studies that require inter-personal interaction of any kind with nursing home residents will include a variable degree of qualitative aspects. Whereas this inter-personal interaction might not be directly linked from

the empirical aspects of the research, it is very difficult to separate the person and the subject participation, when working with residents.

According to Truglio-Gallagher et al. [19], a personal relationship between researcher and subject is fundamental for qualitative inquiry with older adults, and most advantageously obtained through the establishment of trusting relationship between older adults and researcher. As qualitative approaches such as questioning, conversation or interviews invites for replies to inquiry, the quality of subjects' responses, meaning the quality of insight into the older adults' experience, obviously depends solely on the willingness of respondents to converse and share their experiences [19]. But whether or not the method is in fact qualitative, a trusting relationship and faith in the researcher is vital for the sheer possibility of retrieving information, as showed from the previous example, where the collection of quantitative data had to be conducted through a (for residents) demanding, pseudo-qualitative interview approach. Their hardship and effort in completing the cumbersome quantitative responses, clearly supports the notion from Truglio-Gallagher et al., on how trust and faith between the parties are essential for any meaningful communication, partnership and quality of data with older individuals [19].

12.5.5 Personal Boundaries

During the described studies, the trusting relationship to residents sometimes meant the difference between subject participation or not. Residents with whom it was not possible to build a personal connection or a type of social comfort, were difficult to recruit as subjects, and if recruited, showed low engagement into the routines. They also displayed very limited willingness to share their experiences when asked. Residents with whom it was possible to build a personal connection, showed the opposite traits.

According to Haal et al., trust can generally be regarded as the "the optimistic acceptance of a vulnerable situation in which the trustor believes the trustee will care for the trustor's interests" [20]. For older adults such as nursing home residents, vulnerability is a central phenomenon due to their gradually increasing physical and mental limitations, and thereby overall frailty [21], and a relationship depends on the inherent knowledge that they will not be harmed, by the impression of the good intention of the other person [19], and researchers must place careful attention to how they are to 'connect' to residents [22]. Connecting is not trivial, as individual residents have a varying degree of curiosity or acceptance to new elements in their everyday routine, which ranges from very open minded, to very cautious and alienated. Being mindful of the personal boundaries of a resident can prevent unfortunate situations, where a personal space or boundary is overstepped. It much depends on the personal situation of the individual resident (private life, illness, death of a friend, etc.), but to a degree, which was not initially considered sufficiently during the studies.

Moreno-John et al [23] point out in their literature review on trust relating to older adult participation in clinical research; how many groups of older adults have a general mistrust to the healthcare system as well as researchers, in addition to some older adults showing reluctance to sign consent forms [19]. The research team representatives was not initially aware, and thus did not consider this in one situation, where a female resident was asked to fill out a letter of consent. A signature would simply allow us the usage of video footage of her verbal and behavioral responses, exclusively for transcription purposes. When presented with the document for signature, she looked at the researcher with fear, took distance and expressed that she would not sign or further participate—and that she would now like to be left alone. After the situation had played out, staff gave background into how this particular resident had just placed a series of signatures for power of attorney, for her family home to be sold and most of her belongings to be taken to storage, only a few days before. This had left her very sensitive to formal documents, and people who wanted to intrude her personal life with demands and restrictions of freedom over her property. In reference to the above quote from Hall et al [20], is clear that this particular situation had no optimistic acceptance with the so-called trustor of the interests of the trustee, leaving the resident feeling exclusively vulnerable. The example illustrated the importance in creating a comfortable and trustful social space between researcher and residents, before initiating active processes or making direct requests. Introducing the written consent too early in the process resulted in mistrust and a loss of a subject for further studies. It will never be known whether the just described situation could have been avoided, but the experience served as an onwards reminder to remember, to patiently develop a personal connection to residents before proceeding to personal requests or commitments.

12.5.6 Establishing a Connection

Trojan and Yonge recommend investigators to think carefully about how to connect to potential participants [22], and in the case of the nursing home, establishing a personal relationship was eventually found not to be very complicated, but require time and personal investment.

In the beginning, it was found to be very difficult to approach residents and make simple, meaningful conversation. In hindsight, this was primarily due to generation-cultural differences (such as choice of language and terminology, as well as conversation topics and rhythm). Becoming accepted to a degree where individual residents would open up to a researcher, took very different amounts of time of obtain. Depending on the individual, this could literally take between minutes and months. And due to certain “less accessible” residents being obvious choices as subjects, some of the long periods spent to create a personal connection were deemed necessary.

Gilson points out how inter-personal trust evolves over time [24]. A substantial amount of effort to be present and visible at the nursing home was therefore placed into activities such as participating at the physical therapy center, in planned social events, visiting residents at their private apartments for a casual chat, or bringing family (kids) to the nursing home, in the attempt to become familiar face. The many hours spent allowed a lot of social interaction and personal connection. There is no doubt that ever since, making conversation, asking for participation, or conducting studies felt natural, and became significantly easier in relation to acquiring subjects, requesting their time, making appointments and retrieving information.

Spending time at the physical therapy was necessary and insightful in many ways for the purposes of understanding the rhythms, capabilities and limitations of the residents in an exercise-oriented context. However, for building personal and trustful relationships, the most constructive place to do so was at residents' private apartments, clearly being the location inside the nursing home, where most residents tend to feel relaxed and comfortable. In addition, apartments had a useful application when performing the first couple of visits, as some residents would not contribute much in the beginning of sessions, not yet knowing the researcher or procedure well. Most private apartments had many objects of meaning to the resident, such as images of grandchildren, or other possessions of personal significance. If the initiating conversation (for instance before the start of an interview or questionnaire) did not fuel itself naturally, such objects were extremely well suited conversation starters/topics, sometimes resulting in long conversations. In these cases, such topics gave residents a sensation of good intentions and focused, personally directed interest elicited by the researcher. The result was most often a strong foundation for further conversation, and leeway into research related topics. This conversation environment was presumably reminiscent to what Truglio et al. calls the "cornerstone in all qualitative studies" [19], being the point where trust is completely established and present, for proper dialogue to take place. With most residents, this was typically marked by a certain "critical" point, from which they will start talking and telling stories almost endlessly. Not only (and sometimes almost not at all) in relation to responses on asked topics or items, but past life stories, thoughts, inquiries to the researcher, etc. It would not be uncommon in this situation, to almost have to struggle for speaking time for the researcher.

In short, some residents have a barrier that needs to be 'broken down' gradually, respectfully and patiently by personal engagement from the researcher, into whatever captures their interest of conversation. After a certain time spent together, it has been the experience that most residents happily accept the relation, and thereby have become ready to partake in most interactions or challenges later proposed by from the researcher. To the experience of this author, the personal relation is *the* central aspect to achieving leeway for the research collaboration.

To fully appreciate the rationale behind this, it is important to remember the context of the nursing home, in terms of why the impression of an honest, personal engagement and interest with the residents has value to them. The nursing home, for all its merits, can be an extremely lonely place for many residents. While a certain group of the residents have (the luxury of) actively visiting family and friends,

many do not. Friendships do establish themselves between residents, but are subject to a combination of high risk of illness, high level of cognitively limited residents, and the frequent exchange in residents at the nursing home. When approached, many cognitively capable residents really like a meaningful dialogue whenever they can get one; meaningful in this context is (as described above) personally directed, attentive, interested and respectful. In the context of their everyday life, it is the impression that this is one of the things to which many residents do not have access to the degree they used to have. And for the cognitively well functioning residents, the experiences from conversations leaves this seeming like a substantial loss of everyday value and meaning.

Once personal relations are properly established, there are very few things this user group will not do for e.g. a research group. The experience has been that if personally engaged residents are in any way capable of helping the researcher towards his or her goal, making the effort to form relations a desirable investment to the resident. The positivity of this engagement is elaborated by Truglio-Gallagher et al., in how participation in research endeavors is able to provide some older adults a personal learning exercise, as well as a sense of importance from the personal role they play, providing a service and contribution which benefits others [19]. This has been recognizable throughout the project, by a sense of personal pride with certain resident individuals, from their contributions to the studies. A typical scenario would be a resident greeting the researcher, eagerly describing how many times or how long (etc.) the individual resident had been exercising with the augmentation since last time the researcher and resident had last seen each other. Or how the resident could actually feel a physical improvement since beginning the exercise routine anew, from following the established participation schedule.

12.5.7 The Difficult Conversations

There are some aspects to the interaction with residents that a researcher (in the role suggested in this chapter) has to be aware of and prepared to handle. For many reasons, the context of the nursing home also somewhat signifies conclusion for many. It is the last place they will most probably live, if not for a hospital in the very end. It is a place they *have* to live, because they or their relatives have shown incapable of properly maintaining an independent lifestyle. And for many, it is a place they live because they have outlived their contemporaries, amongst those partners or even children.

The nursing home lifestyle serves as constant a reminder of this, not only due to the change in environment from their life as it previously was, but due to the nursing home environment. The sheer amount of people partly or completely sharing this lifestyle is substantial, and could possibly serve as an overwhelming reminder of a specific individual's situation. As such, many residents find themselves looking backwards more than forwards. At this advanced age, the

combination of social isolation and loneliness, as well as comprised functional ability, leave many residents very vulnerable at times [19].

In the process achieving or maintaining a personal relationship through conversation, some residents pose the unique challenge of intense conversation topics concerning loss, death, and loneliness. Insights provided by senior nursing home personnel, such conversations are very important to the residents. Thus it is necessary for anyone who has ambitions to be a meaningful person for a resident, to fully submerge and engage into these conversations. Its importance was further highlighted by the notion that such conversations are not possible that often for the residents, as many social and health (Sосу) assistant personnel deviate from these topics when confronted. Despite most likely wanting to help residents, many Sосу assistants are simply not personally equipped to handle such comprehensive conversation topics.

Engaging in such conversations in the role of a researcher can make a real difference, for the purposes of establishing or maintaining personal relations. They *will* arise with most residents, and it is important to make the choice early on, to not refrain from the subject matter when it arises.

12.5.8 Advancing with VE Technology

One of the challenges with initial studies was for residents to participate with unknown and exotic technology, being unsure of whether they would have the necessary skills or perform as expected. Explaining the setup and making agreements with a majority of the residents was therefore not trivial.

When initiating the studies, many residents needed much time to get familiar with the technology and VEs. Similar to establishing personal relations with patience, introducing technological advancements would need to happen slowly. This was the reason the studies presented in this paper were performed using an LED TV, instead of using a Head Mounted Display (HMD). The HMD would almost certainly provide a more immersive and convincing experience of being inside the VE. But it was feared that pushing technology too fast would overload residents' upper threshold for novel technology experiences per time.

Over the course of the 4-month study, many residents developed a relationship to their favorite VEs, as well as a good relationship to the VE augmentation system. Increasingly positive attitudes towards the augmentation were seen from from residents. In periods where it has been shortly unavailable, residents have asked if they could get it running again soon. This has aspired confidence in relation to commencing with HMD studies, now that residents are experienced with the VEs, and comfortable with the LED TV based exercise augmentation.

12.5.9 *Gathering Data*

The items from the Intrinsic Motivation Inventory (see Footnote 1) (IMI) were in one of the studies used to measure the level and orientation of the motivation effect of the VE augmentation of the manuped exercise. However, using quantitative measures with nursing home residents was found to be a substantial challenge, and will not be replicate in future studies, if avoidable. First and foremost, written generally conflicted with often occurring instances of compromised vision for many residents, where small letters would be practically invisible, not to mention that some residents was actually lacking the ability to hold and place a pen to set their cross. What showed to be a central challenge however, was how most residents were conflicted by the arbitrary nature of placing their rating.

In the IMI questionnaire, items are statements to which subjects need to state their level of agreement to, corresponding to a 7-point Likert scale, (1 corresponds to “not true at all”, 4 is “somewhat true” and 7 corresponds to “very true”). While this method could seem straightforward to most, many nursing home residents, with the variance of cognitive limitations between them, seemed to severely limit their ability to fully comprehend this, perhaps slightly abstract concept. Only very few residents were able to fill out the form by themselves. Almost all residents required assistance from the present researcher, who was forced to adapt and read the items aloud, and subsequently try to conceptualize and step-wise isolate a correct answer. An example would be, having to read an item aloud and asking, “*would you say that you agree or disagree?*” Depending on the answer, the procedure would lead to a follow-up question such as “*so would you say that you completely agree, or only somewhat agree?*” A last follow-up question would be “*so, would you say that you lean towards better or worse than (answer)?*” In practice, the 17 IMI items would most often transform from a written form into a structured interview guide for the researcher, conducted through verbal conversation. In this adapted form, the response sessions were highly uncomfortable for both researcher and resident, due to how a verbal depiction of something quantitative is a challenging exercise. Based on this experience, the advice concerning this user group and data gathering would be to keep to purely qualitative methods, at least in anything related to user responses. In addition, qualitative measures, which encompass any sort of interview, speak to the residents’ desire to partake in conversations and have another moment to share their life story to someone who genuinely wants to listen.

12.6 **Conclusions**

This chapter has looked into various conditions relating to the lives of nursing home residents, predominantly through the search for an explanation for why many residents lack the desire to perform regular exercise, despite the obvious benefits. It has described the circumstances for the choice to either exercise or not, and

presented one suggestion to a solution, in the form of the VE augmented manuped exercise. The new manuped form sought to satisfy a need for short-term entertainment, to complement the long-term benefits of the exercise. It also provided an immediate feedback to the exercise actions, which gave a different sense of purpose to the exertion of the exercise, among other things. Besides that, the chapter suggests that the augmented manuped experience offered something not found in other regular nursing home activity offerings, which was the ability to travel to another place, and see and experience recreational landscape environments otherwise impossible for the residents to experience. The second part of the chapter looked into more circumstances and characteristics of the nursing home environment, seen from a researcher's perspective, in term of some concrete challenges and experience-based suggestions to constructive approaches to constructively improve the chances of success, when performing research with nursing home residents. There are many obstacles, but also many constructive solutions, which should be able to ease the working conditions of the researcher, as well as making the collaboration a better experience for the nursing home resident.

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