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J Aging Health 2009; 21; 1133
DOI: 10.1177/0898264309348197

The online version of this article can be found at: http://jah.sagepub.com/cgi/content/abstract/21/8/1133
Perceived Autonomy and Activity Choices Among Physically Disabled Older People in Nursing Home Settings: A Randomized Trial

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Abstract

Objectives: To evaluate the effect of individually tailored programs on perceived autonomy in institutionalized physically disabled older people and to describe participants’ activity wishes and content of the programs.

Method: This blinded randomized trial with follow-up included a total of nine nursing homes and 50 nursing home residents who were randomized into either a control group or an intervention group. Perceived autonomy was measured at baseline (T1), after 12 weeks (T2) of intervention and after 24 weeks (T3). Wishes for daily activities was identified at T1. Weekly reports of individual programs were drawn up.

Results: Both groups perceived autonomy as average at baseline and increased their mean score at T2 to high

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or close to high. At T3, both groups scored average but exceeded the level of T1. Activity wishes and the content of the programs indicate incoherence. **Discussion:** Although the correspondence between the individual wishes for activities and the concrete content of the programs was not obvious, results indicate potential for enabling the perception of autonomy among physically disabled older nursing home residents. The clinical consequences may suggest a focus on existing traditions, methods, and tools in the nursing home practice.

**Keywords**

disabled older people, nursing home, perceived autonomy, activity wishes, randomized trial

Development of care services for the frail and elderly people is of prime concern across Europe due to the demographic trends that show an increasing elderly population (World Health Organization, 1999). According to the Danish Technology Council (2002), it is likely that the elderly population will be polarized into two groups, one group of healthy and one group of frail elderly. The latter will live their lives with chronic diseases for more years than former generations. A proportion of this group of disabled elderly is obliged to leave their home and move into a nursing home because of either extensive physical or mental decline (Avlund, 2004; Danish Technology Council, 2002). This study concentrates solely on the group characterized as physically frail and thus seeks to contribute to increase the number of studies of physically disabled older people in nursing homes. Until now there are a limited number of studies in this area, which hinders the establishment of present and future care initiatives being based on evidence for best practice (Forster et al., 2003).

**Danish Nursing Homes and the Residents—A General Description**

Between 2004 and 2006, the proportion of older Danes living in nursing home settings has increased by 20% to approximately 48,000 and this number is expected to increase. The proportion of the total population of people aged 65 and above is 15% and of those 9% are living in a nursing home. It is expected that in 2035, 25% of the total population will be 65 years and above (Ældre Sagen, 2007, Statistics of Denmark, 2009).
Studies describing Danish nursing homes and their residents are scarce. A study by Beck et al. conducted in 2004 in 11 nursing homes among 441 residents described that 50% of residents were 85 years and above, 50% had been staying in the nursing home for less than 2 years and 20% were men. In addition, more that 50% of residents were suffering from reduced cognitive function, between 30% and 50% were totally dependent on assistance in different areas of personal activities of daily living (P-ADL), and more than 50% were medicated with analgesics on a daily basis (Beck, Damkjær, Kohly, & Schroll, 2008).

A recent Danish study by Kofod (2008) has elucidated that nursing home residents lack feelings of spark of life and that they perceive their body as a prison. One of the main problems in Danish elderly care provided in nursing home settings is the gap between the political intentions regarding the importance of offering the residents stimulation such as physical training and activities and the actual practice. Even though nursing home residents are much frailer when they move into the nursing home now than 15 years ago, it is still only one out of seven who are offered physical training (Kofod, 2008). Kofod stressed that staff were very skilled in providing care but had too little understanding of the importance of conserving and/or improving residents’ physically functioning (Kofod, 2008).

The majority of all Danish nursing homes fulfill the requirements of the law of Housing for the Elderly regarding accessibility and individual flats for residents (Danish Ministry of Social Welfare, 2002; Statistics of Denmark, 2009). The staff is comprised of nurses, auxiliary nurses, cleaning staff, and volunteers. Occupational therapists and physiotherapists are usually present on a daily basis.

Everyday life in Danish nursing homes is characterized by schedules for activities such as morning procedures, meals, physical training, social and creative activities, and bedtimes. Nursing homes are required by the Ministry of Social Welfare, and encouraged by organizations for the elderly (e.g., Age Concern), to be transparent regarding their quality standards, procedures, and moral values by listing these on their individual Web sites. These lists always include terms related to the preservation of residents’ autonomy.

**Implications of Moving Into A Nursing Home**

When older people are exposed to changes, such as moving into a nursing home, their physical and psychological deficits (Draper, 1996; Johannesen, 2004), feelings of being a burden, feelings of loss of control, and helplessness increase (Johannesen, Petersen, & Avlund, 2004; Kane, 1995; Rowels,
Furthermore, opportunities to make choices and decisions in daily life decrease and therefore residents’ ability for decision making decreases as well (Reinardy, 1999; Scott, Välimäki, Leni-Kilpi, Dassen, 2003; Svidén, Wikström, Hjortensjö-Norberg, 2002). It has been elucidated that decision making regarding P-ADL activities in relation to when, how, and so on, are of special importance for the majority of older people irrespective of level of assistance from staff in performing the activities (Duncan-Myers & Huebner, 2000). Not being asked about which activities one finds meaningful to engage in often means that one gives up these activities and this situation has been found to threaten personal identity and indicate near-future physical decline (Kane et al., 1997).

Moreover, Legarth found significant correlation between having the opportunity to engage in meaningful activities and experiencing satisfaction in life (Legarth, 2005). Therefore, it is stated as an important task for staff to support and empower residents in making choices regarding engagement and reengagement in valued activities (Shawler, Rowels, & High, 2001). Several studies have shown that a sense of being in control over one’s own activities exerts a positive influence on older adults’ well-being (Johnson, Stone Altmaier, & Berdahl, 1998) also when they are dependent on assistance in ADL (Draper, 1996; Johannesen, 2004; Kane et al., 1997). Furthermore, physical alertness and the participation in daily activities are increased (Draper, 1996; Kane et al., 1997; Reinardy, 1999) and this increased use of individual skills and resources strengthens the experience of self-efficacy (Jackson, 1996; Johnson et al., 1998). These positive outcomes increase the possibility of an even more positive result because self-rated well-being and physical resources are found to be positively influenced by, for example, experience of self-efficacy (e.g., Bean, Kiely, Leveille, & Morris, 2002; Przybylski et al., 1996; Ruuskanen & Parkatti, 1994). The actual speed of physical decline, perceptions of self-rated well-being, and personal identity are influenced by whether or not older people are encouraged through support to preserve both their mental and physical resources (Antonovsky, 2000; Baum, Jarjoura, Faur, & Rutchi, 2003; Beauchamp & Childress, 2001; Ripstein, 1999; Ryff, 1989; Spear & Kulbok, 2004).

**Autonomy and Dependence Among Residents in Nursing Homes**

Although the meaning of the concept of autonomy varies depending on context and setting, similarities across disciplines and ages were found in a
concept analysis by Spear et al. (2004). It was elucidated that autonomy is influenced by culture, religion, and by the individual’s predominant natural desire for independence and control. Spear et al. also stated that the concept of independence has been found to be the concept closest to autonomy (Spear et al., 2004). In 1995, Collopy discussed the dilemmas between dependency and the bioethical definition of autonomy as independence. He underlined that there is a need for rethinking and that dependency and autonomy must be seen as intertwined facets of one’s life and state of being in the nursing home setting (Collopy, 1995).

Research has shown that it is possible to experience autonomy whilst being dependent on assistance and that older people’s perception of independence changes during the process of functional decline (Agich, 1993; Davies, Laker, & Ellis, 1997; Haak, 2006). A recent meta-synthesis by Andresen et al. on physically frail and cognitively intact older people in nursing homes showed that they were able to express themselves clearly about the importance of making choices and exerting control in daily life. Choices related to the daily routines regarding when, how, and with whom to perform them and choices related to activities concordant with their intrinsic interests and values were of special importance (Andresen, Hoff, & Puggaard, 2009). In a study by Molony, it was elucidated that “at-homeness” among older people living in long-term care facilities was an experience rather than the location of home and that this experience involved feelings of control and choice (Molony, 2007).

So far, only a few studies have concentrated on measuring and enhancing autonomy through interventions and no clear tendencies in the results have been demonstrated. One of these studies was conducted by Langer and Rodin in 1976 and measured the effect of encouraging older people in a nursing home to make more choices and decisions for themselves. Results showed that it was indeed possible to encourage older people to make more choices and decisions and the intervention group showed greater mental alertness, increased active participation, and involvement (Langer & Rodin, 1976). However, results from a study conducted in 2000 demonstrated that a program designed to enhance psychological autonomy had no effect. The participants in the intervention group reported less well-being and autonomy than those in the control group (Desrosiers, Gosselin, Leclerc, Gaulin, & Trottier, 2000).

There are, however, no studies focusing on the possibility of exerting positive influence on perceived autonomy among physically disabled older people in nursing home settings through individualized interventions based on residents’ own wishes for activities in daily life. The present study was designed to assess the short-term (0-12 weeks) and long-term (0-24 weeks)
effects of individually tailored programs focusing on enhancing perceived autonomy.

**Method**

**Study Design**

This study was conducted as a blinded randomized trial with follow-up and it is the Danish contribution to a cross-sectional Nordic multicenter study (Frändin et al., 2008). In the Danish part of the study a measure of perceived autonomy was added which is the focus of this specific article, which assessed the status of perceived autonomy and the effect of individually tailored programs on perceived autonomy among physically disabled older people in nursing home settings. The individual programs were based on the participants’ individual wishes regarding the specific daily activities they wished to improve, to conserve and/or to revive.

**Intervention**

The intervention group participated in a 12-week program, whereas the control group received their usual care and treatment (Figure 1). For ethical reasons, the control group was offered an individual program after follow-up at 24 weeks.

The interventions took place in the local settings involving their usual nursing home staff which is comprised of nurses, under-nurses, physiotherapists and occupational therapists and thereby different professionals with different theoretical and practical backgrounds.

It was encouraged by the researcher that those who were usually responsible for organizing either physical training, social or creative activities also planned and carried out the individual programs utilizing their standard methods and equipment.

An interview inspired by The Canadian Occupational Performance Measure (COPM; Law et al., 1998) was conducted by blinded testers at baseline to reveal the individual wishes. These results were handed over to the staff and thereby served as an important tool for staff in planning the programs. Staffs were informed about the importance of organizing the content of the programs in accordance with the participants’ individual wishes.

Weekly written reports on each individual program regarding duration, frequency and concrete activities were conducted by staff.
Randomization and Blinding

Participants were divided by lot into either a control or an intervention group. The randomization was stratified according to sex. Participants’ identity and group allocation were only identifiable for the researcher. The staff who was responsible for planning and conducting the interventions was informed about group allocation by the researcher after Time 1 (T1). Blinded research assistants performed the testing.

Recruitment, Inclusion, and Exclusion Criteria of Participants

Participants were either recruited directly at the information meetings or at a visit to their individual flat conducted by a well-known staff member. At each nursing home, the staff was responsible for informing participants face-to-face and for collecting the signed informed consent. Participants were informed about the consequences of randomization to either an intervention or a control group.

Inclusion criteria:\ Aged 65 years or older, both men and women with a variety of diseases leading to physical frailty ensuring an unselected case-mix, dependence on daily assistance in minimum of one P-ADL activity, able to understand verbal instructions, willing to participate, expected to live in the nursing home during the intervention period.

Exclusion criteria: Terminal stages of disease, mini-mental state examination (MMSE) score below 16 (Folstein, Folstein, & McHugh, 1975).
Description of Dropouts and Cohort

A total of 55 older people were initially included of whom 50 participated. Five participants dropped out in the initial phase: 3 from the control group and 2 from the intervention group. Typical reasons for dropout at this stage were either aggravation of disease ($n=3$) or death ($n=2$). There were no significant differences between dropouts and participants regarding baseline characteristics and mean score of perceived autonomy.

Figure 2 presents an overview and reasons for dropouts among participants during the study. All nine nursing homes completed their participation.

**Figure 2. CONSORT flow chart of the study**
Recruitment, Inclusion and Exclusion Criteria for Nursing Homes

Some 220 nursing homes situated over a large geographical area in Denmark were identified through the Internet of which 105 met the criteria for inclusion and received an invitation letter.

Inclusion criteria: Nursing homes from rural areas, large cities, and the capital of Denmark, built or renovated to comply with Danish law (Danish Ministry of Social Welfare, 2002), with residents meeting the inclusion criteria.

Exclusion criteria: Nursing homes solely for specific groups of clients not matching the inclusion and exclusion criteria for participants such as special homes for people with dementia, and homes for younger adults with physical and mental handicaps.

The 105 nursing homes were contacted during a one and a half-year period from February 2005 to June 2006. A total of 20 nursing homes responded with an initial positive interest and out of these 9 continued to be interested in participating and were included in the study (Figure 2). The included nursing homes represent both small and larger nursing homes and are geographically situated in both the countryside, in cities, and in the capital of Denmark.

Residents, relatives, and staff from the nine nursing homes attended information meetings held by the first author. Information about participation, duration of the study, and clarification of staff’s assignments were presented at the meetings. If necessary the meetings were repeated to ensure that the staff working during day-time and night-time was equally informed.

Each of the nine nursing homes formed their own setting with a control and an intervention group.

Perceived Autonomy

Perceived autonomy was measured at Time 1 (T1), Time 2 (T2) and Time 3 (T3) by using The Autonomy Subdimension in The Measure of Actualization of Potential (MAP) test (Leclerc, Lefrancois, Dubé, Hébert, & Gaulin, 2001). In general the MAP test measures how older people perceive their possibilities for self-determination in daily life and it has been used in the Quebec Longitudinal Study on Aging (Leclerc et al., 2001) to examine the predictors and consequences of continuities and changes in the quality of life of the elderly population. The test consists of two dimensions; reference to self and openness to experience and five subdimensions; autonomy, adaptation, openness
to self, openness to others, and openness to life. The autonomy subdimension refers to the “reference to self” dimension (Leclerc et al., 2001).

Validity and reliability were tested and found high according to the Quebec Longitudinal Study on Aging (Leclerc, Lefrancois, Dubé, Hébert, & Gaulin, 1999; Lefrancois, Leclerc, Dubé, Hébert, & Gaulin, 1997; Lefrancois, Leclerc, Dubé, Hébert, & Gaulin, 1998). In agreement with the Canadian authors, The Autonomy Subdimension was approved for use in Denmark after an internal validation performed by the first author in 2005 under statistical supervision. Six items are scored on a 5-point Likert-type scale. The mean of all 6 scores forms the result and is categorized as either low (<3.15), average (>3.15-<4.00), or high (>4.00) degree of autonomy. The three categories and the cut scores were identified through three validation studies (Lefrancois et al., 1997). The test is performed as a paper and pencil test, and tester and participant sit at the same side of the table. Each item forms a sentence that is read out aloud and slowly either by the participant or by the tester. After the scoring, the sentence is read out aloud again to validate the wording. An example of a test item concerns how often one insists on making own decisions. Participants add either very rarely, rarely, sometimes, often, or very often to complete the sentence.

Sample size

Sample size estimations were based on the calculations performed in relation to the Nordic cross-sectional multicenter study (Frändin et al., 2008).

Missing data

If participants scored in less than four of the six items, data were excluded (Leclerc et al., 2001). On this basis, data from 3 participants were excluded at baseline, 2 from the control and 1 from the intervention group. At T2 and T3, data from 1 participant were missing in each group.

Analyses

Statistical Analyses

The changes from 0-12 weeks and 0-24 weeks within the 2 groups were assessed separately using paired t test and Wilcoxon matched paired test. Furthermore, bar charts were made for delta values for the changes during 0-12 weeks and 12-24 weeks.
The analyses were performed according to the intention-to-treat principle and carried out using a regression model incorporating difference in changes (delta values), and controlling for baseline values.

Participants in this study represent a population who might be in a deficit of stimulation due to physical frailty and institutionalization. Changes in the intervention groups were expected and due to the Hawthorne effect minor changes were expected in the control groups as well.

Statistical significance level was set at $p < .05$.

The statistics were performed in cooperation with the Research Unit for Statistics, Faculty of Health Sciences at The University of Southern Denmark.

The statistical analytical program SPSS version 15.0 and 16.0 was used for registration, analysis, and presentation of data.

**Thematic Analyses**

Baseline data regarding the most important activities for participants and data regarding the content of the individually tailored 12-week programs were analyzed using a qualitative approach. Thereby data from the COPM interviews and data from staff’s weekly reports served as raw data to build the analysis on. Each of the two areas, important activities and the programs, were analyzed separately using a content analysis in a four-step procedure inspired by Berg (1997). The four steps are (a) obtaining an overall view of the texts, (b) headings and categories were identified and an open coding applied, (c) second coding and condensing of the material, and (d) confirmation of categorization with a peer.

The process was performed in Danish and translated into English after the fourth step.

**Ethical Approval**

The study was approved by the Regional Scientific Ethics Committee in Denmark No. 2004-1-52 and the Danish Data Protection Agency.

**Results**

In the analysis, control groups and intervention groups of each of the nine nursing homes were coupled and thereby treated as 1 control group and 1 intervention group.

Regression analysis of participants’ perception of autonomy in relation to sex and age did not show any statistical significance. Even though data were normally distributed and showed correlation with the Quebec Longitudinal
Study on Aging, a Wilcoxon-matched paired test was performed and this analysis supported the results of the paired $t$ test. Baseline characteristics of participants divided by group allocation are presented in Table 1.

In addition to the data presented in Table 1, many of the participants were exposed to more than two diseases. The most frequent diseases were arthritis (13 from the intervention group and 9 from the control group), symptoms related to hemiplegic limbs (6 from the intervention group and 5 from the control group), cardiovascular problems, and chronic obstructive pulmonary disease (COPD; 8 from the intervention group and 9 from the control group).

Participants’ records showed that they all had one or more types of medicine prescribed and that there was a clear tendency in what was the most frequently prescribed medicine. Analgesics (16 from the intervention group and 13 from the control group) and antidepressants (9 in the intervention group and 16 in the control group) were the most common medicine among participants.

Seven participants in the intervention group and 5 in the control group were completely wheelchair-bound. The rest were walking either with a cane/stick or a rollator.

**Perceived Autonomy**

Although participants’ perception of autonomy revealed very small changes over time, results showed an increase in both groups and significant changes between baseline and 12 weeks in the control group.

### Table 1. Baseline Characteristics of Participants

<table>
<thead>
<tr>
<th>Intervention group</th>
<th>Control group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women $n = 19$</td>
<td>Women $n = 16$</td>
</tr>
<tr>
<td>Men $n = 9$</td>
<td>Men $n = 6$</td>
</tr>
<tr>
<td>Overall $n = 28$</td>
<td>Overall $n = 22$</td>
</tr>
<tr>
<td>Age/yr</td>
<td>Age/yr</td>
</tr>
<tr>
<td>Mean 84.4</td>
<td>Mean 83.5</td>
</tr>
<tr>
<td>Minimum 65</td>
<td>Minimum 66</td>
</tr>
<tr>
<td>Maximum 97</td>
<td>Maximum 96</td>
</tr>
<tr>
<td>Length of stay in the nursing home/months</td>
<td>Length of stay in the nursing home/months</td>
</tr>
<tr>
<td>Mean 32</td>
<td>Mean 28</td>
</tr>
<tr>
<td>Minimum 12</td>
<td>Minimum 7</td>
</tr>
<tr>
<td>Maximum 96</td>
<td>Maximum 72</td>
</tr>
</tbody>
</table>
Table 2 shows the main results and the number of participants in the 2 groups who completed their scores at the different stages of the study. In Figure 3, short-term and long-term comparisons between groups are illustrated and a significant change compared with baseline is demonstrated. Both the intervention and the control group perceived autonomy as average at baseline (mean in both groups is 3.53). After 12 weeks both groups had increased their mean score. The intervention group reached 3.89 (+0.36) and the control group scored 4.03 (+0.50) and thus exceeded the level of 4.00 indicating a high perception of autonomy.

At 24 weeks, both groups presented a higher level compared to baseline despite a decrease of their mean score. The control group decreased their mean score from 4.03 to 3.94 (–0.09), whereas the intervention group decreased from 3.89 to 3.71 (–0.18).

The minimum score in the intervention group increased throughout the process from 2.50 to 2.75 at T3, whereas the minimum score in the control group decreased from 2.80 to 2.00 from T1 to T2 and at T3 it increased again to 3.00.

Maximum score in both groups increased from T1 to T2. In the intervention group there was an increase from 4.70 to 5.00, and in the control group maximum score increased from 4.50 to 5.00. The maximum score from T2 was kept at 5.00 in both groups at T3.
Both the paired t test and the Wilcoxon test showed significant differences in perceived autonomy at T2 in the control group. Beyond this there was no significance in short or long-term effects.

**Activity Wishes**

Based on the thematic analysis, three categories of most important activities emerged; *P-ADL, mobility, and social/creative/mental activities*. The category of P-ADL activities includes activities such as dressing, bathing, and eating. As an example, a participant expressed that he would like to be able to shave and wash himself using both hands. For another participant, it was of special importance to conserve her abilities to put on her long stockings in the morning. Mobility activities are related to the transportation of oneself either as an activity in itself or as an activity leading to another activity. Mobility activities imply moving oneself from one place to another inside one’s own flat, inside the nursing home, and/or outside in the local community. One participant expressed that she wanted to be able to walk to the nursing home café with her rollator.

*Figure 3. Short-term and long-term comparisons between groups*  
* = significant change within group compared with baseline
Social/creative/mental activities include a number of activities that do not necessarily require the same amount of physical functioning as the activities in the two other categories although we are aware that a certain amount of physical strength will always be needed. The category of social/creative/mental activities includes visiting fellow residents, spending time with fellow residents in the nursing home by participation in group activities (cooking, playing cards, listening to music etc.), entertaining family and friends, doing needlework, painting pictures, conserving mental resources by reading books, writing letters, doing crosswords, and watching the news.

In Table 3 the five most important activities are presented as prioritized by the participants. Three categories; P-ADL, mobility, and social/creative/mental activities emerged from the thematic analysis. Some participants were unable to define important activities and therefore data are missing in both the intervention group (6) and the control group (4). The tendencies show that both groups have the highest “total” score in the category of social, creative, and mental activities.

In the intervention group, the first priority was P-ADL activities, whereas the control group expressed that their first priority was on activities related to mobility. In the control group the second priority was social, creative, and mental activities and in the intervention group the second priority was equally distributed between mobility activities and social, creative, and mental activities. The biggest difference between the groups was that the intervention group had more wishes for P-ADL activities in total (21) than for mobility activities.
activities (16), whereas the control group had more wishes for mobility activities (15) than for P-ADL activities (8).

Content of Intervention Programs

The analysis of the content of the individual programs shows that half of the participants in the intervention group participated in individual and pure physical training sessions up to five times a week. The physical training sessions include elements such as muscle strength, balance, and range of motion.

The typical content of a program is a weekly combination of physical activities (three to five times per week) and social activities (up to two times per week). One third placed their first priority on social, creative, and mental activities and the programs reflect that approximately one quarter of the participants are joining some kind of social activity. The social activities typically include cooking or baking in the cafe with a group of fellow residents. A number of participants had clear wishes for creative and mental activities, but less than 1/8 of the programs reflect this. Even though more than one half of the participants in the intervention group placed their first priority on P-ADL, the programs reflect that less than 1/8 participate in activities directly related to P-ADL.

Discussion

The individually tailored programs did not lead to significant differences in perceived autonomy in the intervention group compared to the control group who received the usual care and treatment. Both groups increased their mean total-score from T1 to T2, which resulted in a shift from average perception of autonomy to either high or very close to high. Both groups increased their scores in all six items between T1 and T2. Between T2 and T3 the control group almost kept the same level in all scores, whereas the intervention group decreased their scores in five of the six items. For instance, the item “Criticism—very rarely, rarely, sometimes, often, very often—prevents me from doing what I feel like doing” had the highest increase in the intervention group between T1 and T2 but decreased the most between T2 and T3.

In both groups the score in the item “I am a person who values myself—very little, a little, somewhat, very much, enormously” increased between T2 and T3.
In general, there seemed to be long-term changes in both groups because they still exceeded baseline scores after 24 weeks.

**Design and Method**

The design of the present study excludes a number of potential biases because nursing homes and intervention and control groups appeared well matched. If the study had been conducted, for example, as an observation study, later adjustments for differences would have been necessary. Nevertheless, potential reasons for the lack of significance may be linked to different biases in the study design.

The power calculations were performed in relation to the Nordic cross-sectional multicenter study and due to this fact the number of participants may have been too small. We are aware that power calculations specifically for the part regarding perceived autonomy might have indicated a need for a larger sample.

Small sample sizes are often a challenge in studies representing this area because recruitment and adherence are influenced by participants’ frailty. This fact could have been taken into account by a higher intake of participants, but in the present study it was also a challenge to include nursing homes and therefore all interested nursing homes matching the criteria ended up participating (Ferrucci, Guralnik, & Studenski, 2004).

Nevertheless, small sample sizes should not prevent researchers from conducting studies among this group or there may be a risk that the old and physically frail will remain a less prioritized field of research. A more qualitative approach is a possible design for a study that does not require a large sample. This could lead to a more in-depth understanding of participants’ perceptions of autonomy.

It may have biased the results that each of the nine nursing homes formed its own setting with an intervention group and a control group. Even though thorough information was given at each setting about the role of staff during the 24 weeks, it might have been a challenge for staff to distinguish participants from each other in terms of intervention.

Because the study was conducted in original settings, we were aware of a variety of conditions, such as staff members coming from different educational backgrounds, acting as a possible influence on their level of skills in complying with participants’ activity wishes.

It was not part of the design to manage and check on the planning and conducting of the individually tailored programs. Instead it was important that staff, once they were provided with the individual wishes for activities,
used their local resources, methods, and equipment as tools to comply with participants’ wishes. A follow-up on the initial information meetings during the 24 weeks of the study might, however, have provided staff with more guidance and awareness of the activity wishes and also minimized the risk that the controls received any intervention other than their usual care and treatment. In total, it might have caused a less effective intervention period and thereby a possible answer to why the changes in perceived autonomy did not show significance.

Another explanation of the outcome of the interventions could be overstimulation of participants during the interventions. We did not make observations during the intervention period and we had no previous information of participants’ daily life before they entered the study. Therefore it is possible that the 12 weeks of individually tailored programs might have been a more stimulating period than usual and for some participants this might have caused experiences of overstimulation and thereby affected their scores in a more negative way.

The relatively high scores and the significant result of perceived autonomy at T2 in the control group might be explained by the Hawthorne effect from the attention during the three test-rounds (T1, T2, & T3). Furthermore, the attitude of engagement and interest among staff toward participating in this study and positive expectations might also be an explanation because participants, once they recognized they were in the control group, could look forward to an individual program after the 24 weeks.

An alternative to the present study design might be a design based on randomization on a nursing home level rather than randomization on an individual basis. Cluster randomization is considered a reliable method when effect of a certain intervention is to be measured in a large number of small areas (Altmann, 1999). Randomization on a nursing home level might have prevented the pitfalls regarding the possible effect on the control groups.

Results

It has been demonstrated that perceiving oneself as autonomous has direct influence on both mental well-being and physical alertness (e.g., Johnson et al., 1998; Kane et al., 1997; Reinardy, 1999). Results of this study indicate that even a “small” amount of intervention—not even particularly individualized—and expectations of an individualized program can make a positive short-term and long-term difference in physically disabled older people’s perceptions of autonomy. The present study included participants ranging from 65 years to 97 years of age, but adjustment for age through a regression analysis showed no relation between perceived autonomy and age—nor with
autonomy and sex. This is not in line with the results from Walker’s study, which found a difference between how young-old and very-old noninstitutionalized people defined and perceived autonomy (Walker, 2005). For the young-old, physical health and capacity played an important role in perceiving autonomy, whereas the very-old associated perceptions of autonomy with feelings of control and having freedom of choice (Walker, 2005). This might indicate that age-related distinctions can be diluted by institutionalization and that institutionalization in itself has an impact on the perception of autonomy. This is important knowledge and indicates that there is a great potential for development of practice in nursing homes and for creating a more stimulating environment for residents, which supports and empowers them to express themselves about choices in daily life.

During recent years a number of initiatives have been taken regarding nursing home residents’ rights. Nevertheless none of these initiatives involve the focus of individual rights for making choices and decisions in daily life activities. The Danish Ministry of Social Welfare has laid down guidelines for nursing home residents’ rights with regard to informed consent in matters of their personal health and for decision making in these areas (Danish Ministry of Social Welfare, 2004). Unexpected inspections supervised by the official doctor is another initiative that is stated by law and carried out once a year in all nursing homes to ensure that rules and standards regarding medication and residents’ rights are kept and that residents are satisfied with daily life in the nursing home. During these inspections, a random group of residents are interviewed about their satisfaction with the nursing home (e.g., meals, activity, offers, etc.) and the individual nursing homes’ values and standards are discussed with its staff and residents (Danish Ministry of Social Welfare, 2007). The conclusions of the inspections are official and therefore nursing homes are obliged to present them on their Web sites.

The standards and values written on the nursing homes’ individual Web sites usually reflect awareness of the importance of preserving residents’ autonomy. Still, results from the present study and the recent study by Kofod (2008) indicate that it might be difficult for staff to exercise their intentions.

Knowledge related to activity wishes defined by disabled and old people in nursing homes and staff’s translation of those into individualized programs has not been investigated before. This study revealed rather clear tendencies, as activities related to P-ADL were either a first or a second priority, which is in line with existing research in this area (Blair, 1999; Borell, Lilja, & Sadlo, 2001). Nevertheless, the weekly reports on the
individually tailored programs did not reflect a focus on P-ADL activities. One reason for this might be that staff were aware of the fact that P-ADL implies some level of physical functioning and therefore physical training was suggested to participants (e.g., Desrosiers et al., 2000; Ruuskanen & Parkatti, 1994; Rydwik, Frändin, Akner, 2004). Another obvious tendency in participants’ activity wishes was the high score in both groups on social, creative, and mental activities, which is in line with existing research (Legarth, 2005). The programs did not, however, reflect the extent of these wishes even though all the nursing homes had suitable and accessible physical environments with, for example, cafes, common areas with kitchen facilities, facilities for creative activities, and gardens.

The participation in an interview at baseline about preferences regarding activities might in itself have had a positive impact on the individual perceptions of autonomy and thereby blurred possible differences between groups. In a study by Lantz, Buchalter, and McBee (1997), it was elucidated that a group education program for nursing home residents, which included interviews about decision making and preferences, had a positive effect not only on their abilities for decision making but also on their perceived autonomy (Lantz et al., 1997).

**Perspectives**

It has not previously been investigated how the disabled and old residents in nursing homes perceive autonomy and which activities they prioritize to participate in. There are no studies focusing on the effect of an individualized intervention program on the perception of autonomy. And finally, it has not been investigated what kind of individualized intervention staff in nursing homes choose to offer if they have to plan the intervention on the basis of residents’ specific wishes.

Results indicate that physically disabled older people in nursing homes can improve their potential for perceiving themselves as autonomous through participation in interventions aiming at fulfilling individual wishes for activities. Despite the fact that the content of the intervention programs was not predominantly corresponding with the individual wishes for activities, an increase in perceived autonomy from average perception to close to high perception of autonomy was seen in the intervention group as well as in the control group. Although the changes in general appeared to be small, the clinical relevance might be of importance. Most of the residents were able to express clear wishes for activities and it seems that this attention to their wishes in itself might have had a positive influence on perceived autonomy in both groups. This indicates that the residents’ perspectives of autonomy
should be addressed when organizing and reorganizing the procedures and routines of daily life in nursing homes.

We suggest that this new knowledge is taken into consideration by offering staff additional training in communication with residents about their perceptions of autonomy, including their activity wishes, and in planning interventions for the residents on this basis.

If evidence for best practice in this field continues to be lacking, the well-being of the future disabled and old in nursing homes is at stake. Results from this study might guide future research and assist response to both present and future challenges in relation to health promotion initiatives for the institutionalized disabled and old people.

Further studies, based on both qualitative and quantitative measurements, in the group of disabled old people are needed.

**Authors’ Note**

The authors thank Jacob v. B. Hjelmborg, PhD, for statistical assistance and guidance. The present study forms part of a comprehensive study, “A Nordic multi-centre study on physical and daily activities for residents in nursing home settings”. It was initiated by Kerstin Frändin, senior lecturer at Karolinska Institutet, Lena Borell, professor at Karolinska Institutet, Stockholm, and Karin Hellström, senior lecturer at Uppsala University, Sweden and performed in cooperation with Astrid Bergland, professor at Oslo University College, Jorunn Helbostad, senior lecturer at Norwegian University of Science and Technology, Randi Granbo, senior lecturer at Sør-Trøndelag University College in Trondheim, Norway, and Helena Grönstedt, doctoral student at Karolinska Institutet, Sweden.

**Declaration of Conflicting Interests**

The authors declared that they had no conflicts of interests with respect to their authorship or the publication of this article.

**Funding**

The authors declared that they received the following financial support for their research and/or authorship of this article: Grants from VELUX-FONDENE, Denmark; University of Southern Denmark; University College Sealand, Denmark; and Research Foundation of the Association of Occupational Therapists in Denmark.

**Notes**

1. Difficulty or dependency in carrying out activities essential to independent living, including essential roles, tasks needed for self-care and living independently in a home, and desired activities important to one’s quality of life (Fried, Ferucci, Darer, Williamson, & Anderson, 2004).
2. The primary and personal Activities of Daily Living such as eating, drinking, and bathing (Hulter-Åsberg, 1990).

3. Inclusion and exclusion criteria were based on the Nordic cross-sectional multi-center study (Frändin et al., 2008).

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