Polio involvement and its relation to ability in terms of independence and perceived difficulty in activities in daily living (ADL) were studied in outpatients (median age 57 years) with poliomyelitis sequelae ($n = 133$). The use and need of assistive devices and housing conditions were recorded. The subjects had a high degree of independence in personal ADL, whereas more than 50% were dependent on cleaning, shopping and transportation. A considerable number of subjects independent in ADL reported difficulties in daily activities. The majority of interventions in the form of housing adaptation and assistive devices were provided for persons severely weakened by polio. Ratings of perceived difficulty indicated need of interventions to prevent overload and increased dependence in ADL. However, about half of the recommended mobility assistive devices were rejected. The results indicate that polio subjects try to maintain their independence despite perceived difficulties and may be reluctant to use assistive devices.

Keywords: activities of daily living, assistive devices, occupational therapy, postpolio syndrome, rehabilitation. J Rehab Med 2001; 33: 4–11

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INTRODUCTION

Over the last 15–20 years, studies of the late effects of poliomyelitis have been reported, demonstrating a complexity of new health problems 30–40 years after the acute phase. The main symptoms are muscle weakness, muscle and joint pain, fatigue and cold sensitivity (1–5). New or increased muscle weakness is the cardinal symptom and diagnostic criterion for postpolio syndrome (PPS) according to Gawne & Halstead (4). The percentage of persons with a history of poliomyelitis and experiencing new symptoms is not precisely known, but 50–85% are recurring figures (2, 4, 6–8) even though lower ones have also been reported (9).

The new symptoms affect the ability to perform daily activities and may lead to distress and disability (1, 4, 10, 11). The main impact of disability for most people with late effects of polio is in mobility-related activities (5, 7, 12, 13). To our knowledge, there is little information, however, on the relation between disability and polio involvement and the influence of environmental factors. Better knowledge of these matters would probably contribute to better intervention measures in these patients.

According to the International Classification of impairments, disabilities and handicaps (ICIDH), disability reflects performance and activity and represents disturbances at the level of the person (14). Disability is also considered the gap between personal capability and environmental demands (15). The importance of the environment was emphasized by Fougeyrollas (16), who claims that there is an interactive process between personal factors (intrinsic) and environmental factors (external), determining the situational result of the performance (16). Assistive devices and physical environmental barriers or modifications are examples of external factors that influence activities of daily living (ADL) in a positive or negative direction. When measuring abilities in ADL, it has to be made clear whether intrinsic capability (without equipment assistance) or actual capability (with such assistance) (15) is being assessed.

In Sweden, the healthcare system is responsible for providing assistive devices to prevent disability. In most cases, the devices are provided free of charge. Other ways to facilitate daily activities are to improve accessibility and housing conditions. There is a special allowance for housing adaptation to meet individual basic needs (17).

The aim of this study was to investigate polio involvement and its relation to ability in ADL in outpatients with poliomyelitis sequelae. In particular, three issues were related to the involvement of polio: (1) ability and perceived difficulty in daily life activities; (2) use and need of assistive devices; and (3) housing conditions.

METHODS

Participants

One-hundred and thirty-three consecutive patients (83 women, 50 men), admitted during the period September 1994 to June 1996 with poliomyelitis sequelae, were included in this study. They were referred or self-referred to the special polio unit at the Department of Rehabilitation Medicine, Sahlgrenska University Hospital, Göteborg. The mean age of the group was 56.6 years (SD 14.5; Md 57; and range 15–84). At the time of the study, 14 to 82 years (M 48; SD 12.9; Md 47 years) had elapsed since the onset of poliomyelitis. Of the total group, 101 (76%) subjects were born in Sweden, 32 (24%) elsewhere. The latter, multi-ethnic group was younger (mean 40 years, range 15–74) than the Swedish-born group (mean 61.8 years, range 39–84). Twenty-one nationalities were represented in the multi-ethnic group; at most
three subjects from the same country. The demographic characteristics of the subjects are given in Table I. The study was approved by the Ethics Committee of the Faculty of Medicine, Göteborg University, Sweden.

**Procedures**

As part of the admission procedure a questionnaire was mailed to the patients before the first outpatient appointment at the polio unit. It contained questions about patient demographics, age of polio onset, body part(s) affected, other diseases, new or increased health problems and mobility assistive devices. The questionnaire was completed during the first visit to the physician. An occupational therapist (A-LT-J) interviewed the subjects in the clinic using a semi-structured questionnaire on ADL, use of assistive devices, social conditions and housing conditions. A physiotherapist tested physical performance.

**Assessments**

The National Rehabilitation Hospital (NRH) post-polio limb classification (4) was used to describe the type and degree of polio involvement in each of the limbs and the trunk. Class 1 = no clinical polio, Class II = subclinical polio, Class III = clinically stable polio (no new or increased muscle weakness), Class IV = clinically unstable polio (increased muscle weakness), and Class V = severely atrophic polio. The classification was made by the attending physician according to a combination of patient history, physical examination and an electromyogram (EMG) in at least three to five relevant muscle groups.

The post-polio limb classification provided an opportunity to divide the subjects into subgroups for the purpose of studying the relation between polio involvement and ability in daily activities. The subjects were grouped according to the number of affected body parts and degree of polio involvement in the most afflicted part of the body (Table II): subjects with both legs and one or both arms afflicted (Group 1), subjects with both legs afflicted (Group 2), subjects with one leg and one or both arms afflicted (Group 3), participants with one leg afflicted (Group 4) and subjects with one or both arms afflicted (Group 5). In some data analyses, the first four groups were combined: Groups 1 + 2 and Groups 3 + 4.

Walking speed was chosen as a measure of physical performance capacity. Spontaneously chosen and maximum walking speed were measured for 30 m indoors. The test started with the spontaneously chosen speed. The subjects used their ordinary walking devices. The values were compared with those from an urban population sample (18), who served as controls.

The Staircase of ADL (19) was used in an interview to identify ability and disability in daily life activities. The ADL Staircase is a further development of Katz’s ADL index (20). It comprises five personal daily life activities (P-ADL) (feeding, transfer, toileting, dressing and bathing) and four instrumental daily life activities (I-ADL) (cooking, transportation, shopping and cleaning). Actual capability was measured, since participants used their ordinary assistive devices. In the ADL Staircase, disability is defined as dependence on assistance from another person.

The ADL measurements were extended with the subjects’ own rating of their perceived difficulty for each item from the ADL Staircase on a four-level ordinal scale: none (1), little (2), great (3) and impossible (4). If a respondent did not have the opportunity or preferred not to carry out an activity there was also a fifth response: do not do it for reasons other than health. In one analysis the four-level scale was dichotomized, with the intention to separate those who had no difficulties (level 1) from those who had difficulties (levels 2–4).

In connection with the semi-structured interview about daily activities, the patients were asked in detail about their use of assistive devices, their housing conditions and what, if any, housing adaptation had been carried out. Subjects were also asked about barriers in their physical environment. After that, they were asked if they thought they needed another place to live because of their disabilities and physical barriers. Four alternative answers were given: yes; no; don’t know; yes, but wait and see. Another question about their need for housing adaptation had the same alternatives.

Use of assistive devices was documented and further need of assistive devices was identified and discussed with the patient. After discussion in the polio team, devices were recommended to the patient, and if accepted they were prescribed. Prescriptions of devices during a period from the first visit to 6–18 months after the first visit were documented.

**Statistical methods**

Standard methods were used for calculating mean, median, standard deviations, percentiles, range and 95% confidence intervals. Significance was tested using the Mann-Whitney U-test with correction for ties for independent groups (21), statistic $w^2$, and Fisher’s exact test for small groups. Multiple significance testing was adjusted using the Bonferroni–Holm method (22).

**RESULTS**

Polio classification according to Gawne & Halstead (4) showed
no clinical polio of the trunk in 57% of the subjects and severe atrophic polio in trunk muscles in 4% (Table III). The upper extremities were less affected than the lower. There was a higher percentage of upper extremity involvement in class I and a higher percentage of lower extremity involvement in classes IV and V. The majority (88%) had severe weakness and/or unstable polio in some limb (Table II). Muscle weakness was asymmetric. Both upper and lower extremities were affected in 51 subjects (38%), only the lower extremities in 75 subjects (57%), and only the arms in 7 persons (5%).

The most common symptoms reported by the patients were new or increased weakness in previously affected muscles (86%), fatigue (81%), muscle pain on exertion (78%) and joint pain on exertion (69%) (Table IV). Only two persons in this clinical group reported no new or increased symptoms. More subjects belonging to class IV than to class V in the NRH polio classification reported muscle pain on exertion \( (p < 0.004) \) and joint pain \( (p < 0.05) \). No significant differences were found either between men and women or between groups based on the number of years since the onset of poliomyelitis.

The average spontaneous walking speed was 0.94 m/s (SD 0.28) in the women and 0.99 m/s (SD 0.28) in the men. The maximum walking speed was 1.14 m/s (SD 0.44) in the women and 1.19 m/s (SD 0.46) in the men. Walking speed was significantly lower \( (p < 0.001) \) in the polio subjects than in the controls (18). The difference between maximum and spontaneously chosen walking speed was significantly less \( (p < 0.001) \) in persons with polio than in the controls in different age groups (Fig. 1). Both the maximum and spontaneously chosen walking speeds in subjects in Groups 1 \( + 2 \) were significantly \((p < 0.05)\) lower than persons in Groups 3 + 4 (for definition, see Methods).

The vast majority (95%) were classified as independent regarding P-ADL (Fig. 2), whereas dependence was common in I-ADL, especially in transportation (69%), shopping (53%) and cleaning (58%). Significantly \((p < 0.05)\) more persons in Groups 1 + 2 were dependent on transportation (81%) and shopping (61%) compared with 57% and 43%, respectively, in Groups 3 + 4. Two persons (29%) in Group 5 were dependent on transportation. Subjects dependent on transportation, shopping and cleaning had a significantly lower walking speed

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### Table III. The National Rehabilitation Hospital (NRH) post-polio limb classification of 133 subjects

<table>
<thead>
<tr>
<th>NRH class</th>
<th>Upper extremity</th>
<th>Lower extremity</th>
<th>Trunk</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>158 (59)</td>
<td>48 (18)</td>
<td>76 (57)</td>
</tr>
<tr>
<td>II</td>
<td>24 (9)</td>
<td>18 (7)</td>
<td>13 (10)</td>
</tr>
<tr>
<td>III</td>
<td>32 (12)</td>
<td>41 (15)</td>
<td>20 (15)</td>
</tr>
<tr>
<td>IV</td>
<td>43 (16)</td>
<td>106 (40)</td>
<td>19 (14)</td>
</tr>
<tr>
<td>V</td>
<td>9 (4)</td>
<td>53 (20)</td>
<td>5 (4)</td>
</tr>
</tbody>
</table>

Extremity: \( n = 266 \); Trunk: \( n = 133 \).

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### Table IV. Perception of new or increased health problems related to polio

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>General fatigue</td>
<td>105</td>
<td>81</td>
</tr>
<tr>
<td>New or increased weakness in previously affected muscles</td>
<td>113</td>
<td>86</td>
</tr>
<tr>
<td>New weakness in previously “not affected muscles”</td>
<td>59</td>
<td>47</td>
</tr>
<tr>
<td>Muscle pain, rest</td>
<td>69</td>
<td>53</td>
</tr>
<tr>
<td>Muscle pain, exertion</td>
<td>103</td>
<td>78</td>
</tr>
<tr>
<td>Joint pain, rest</td>
<td>56</td>
<td>44</td>
</tr>
<tr>
<td>Joint pain, exertion</td>
<td>89</td>
<td>69</td>
</tr>
<tr>
<td>Back pain</td>
<td>87</td>
<td>66</td>
</tr>
<tr>
<td>Breathing difficulties, rest</td>
<td>18</td>
<td>14</td>
</tr>
<tr>
<td>Breathing difficulties, exertion</td>
<td>37</td>
<td>29</td>
</tr>
<tr>
<td>Cold intolerance</td>
<td>79</td>
<td>59</td>
</tr>
</tbody>
</table>

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Fig. 1. Mean values and 95% confidence intervals for difference between maximal and self-chosen walking speed in 107 polio subjects (\(\Box\)). Walking speed could not be measured for the six subjects who used wheelchairs and another eight subjects who had severely reduced ability in walking. Data were missing for a further twelve subjects. Control group (\(\A\)) from an urban population sample (18).
subjects in Groups 1 + 2 rated greater difficulty in more activities than subjects in Groups 3 + 4 and Group 5. Significant differences, corrected due to mass significance, were only found for public transportation, toileting and transfer. For public transportation, the median was impossible for subjects in Groups 1 + 2, great in Groups 3 + 4 and no difficulty in Group 5. The ratings in Groups 3 + 4 and Group 5 varied from no difficulty to impossible.

For toileting, the median for all three groups was no difficulty. The significant difference was between Groups 1 + 2 and Groups 3 + 4, and the ratings varied between no and little. For transfer, the significant difference was between Groups 1 + 2 and Group 5. No significant differences in perceived difficulty were found between the multi-ethnic and Swedish-born group.

Dependence in ADL meant that 93 subjects (70%) needed some help from other people. For most subjects (37%), this help was given by family members and other close relatives. A further 10% of the subjects were dependent on their family members but stated that their dependence was within the scope of distribution of tasks in the family, since they did other tasks instead. Private help and the home-help service were used by 12% and 11%, respectively.

Fig. 5 shows that the use and need of orthoses and assistive devices for mobility were extensive in Groups 1 + 2 and Groups 3 + 4. Orthopaedic footwear or shoe modification was the most common measure used by more than a third of the subjects. A further need of such devices and braces was identified and accepted by the subjects, and the devices were prescribed. Corsets were used by 12 subjects (9%) and 2 subjects had a respirator at night. Wheelchairs were significantly ($p < 0.001$) more used by individuals with both legs afflicted. Further need of canes, crutches, wheelchairs and work-chairs was identified, and 46% of the suggested devices were accepted and prescribed. Sixty-two persons (47%) always walked without assistive devices (orthoses not included), while 47 (35%) used canes,
crutches or walkers. After the subjects had met the polio team these numbers decreased to 43% and 28%, respectively, as people were prescribed to reduce exertion by using canes, crutches and/or wheelchairs (manual and/or electric or motorized scooter), especially for long distances. Thus, the number of persons who combined their walking (with or without walking devices) with using wheelchairs increased after intervention from 14% to 25%. A further 8% were recommended to use that combination but preferred to wait. Six persons (4%) had always used a wheelchair, but two with manual wheelchairs were prescribed electric wheelchairs.

Housing adaptation was mainly granted to subjects with widespread polio involvement. Twenty-nine subjects (36%) in Groups 1 + 2 had obtained housing adaptation compared with only four subjects (8%) in Groups 3 + 4 and one subject (14%) in group 5. All those who had obtained housing adaptation belonged to Class IV or V of the post-polio limb classification. No significant differences were found between housing adaptation to persons born in Sweden and that for persons in the multiethnic group. The most frequent type of housing adaptation was in the hygiene room, where the bath tub had been removed and replaced with a shower. Other common types were removing thresholds, putting up handrails and ramps. Thirty-seven subjects (28%) reported such barriers in the physical environment due to their disability that they needed another place to live: 26 persons (35%) in Groups 1 + 2, 10 persons (20%) in Groups 3 + 4 and 1 in group 5. In spite of the barriers, the majority (73%) of these subjects answered “yes, but wait and see”. The most frequent obstacles in the environment reported by 32 subjects (29% in Groups 1 + 2 and 18% in Groups 3 + 4) were staircases. Other difficulties were reaching shelves placed either too high or too low, especially in the kitchen, opening heavy, front doors and holding them open, and insufficient space for turning and storing wheelchairs.

Subjects in Groups 1 + 2 had received significantly ($p < 0.01$) more assistive devices than persons in Groups 3 + 4 and 5 (Table V). Further need of assistive devices and/or housing adaptation, which demanded investigation in the subjects’ homes, was found in 45 (34%) of the subjects, but 12 persons (9%) preferred to wait and see. No significant differences between groups were found. Since housing adaptation and assistive devices for hygiene were frequent measures, a comparison was made of the ratings of difficulties in bathing and toileting by subjects with and without such measures. Fifty-

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Fig. 4. Distribution of perceived difficulty in nine daily activities for subjects with different numbers of body parts affected by polio. Median values, 10th, 25th, 75th and 90th percentiles and significant differences between the groups are given. After correction according to Bonferroni–Holm method $^* p < 0.05; ** p < 0.01$.

Fig. 5. Percentage of subjects in Groups 1 + 2 (n = 75) and Groups 3 + 4 (n = 51), respectively with orthoses and assistive devices for mobility. Recommended devices refer to those subjects who were recommended but did not accept the assistive devices. $*** p < 0.001$ denotes a difference between groups.
two persons independent in bathing and 33 independent in toileting had obtained assistive devices and/or housing adaptations for these activities. Despite this equipment, these subjects rated significantly more difficulty in bathing ($p < 0.01$) and toileting ($p < 0.01$) than persons without such equipment.

**DISCUSSION**

In this consecutive clinical group of people with poliomyelitis sequelae, more than 98% experienced some new health problems, and 86% had new or increased muscle weakness and fulfilled the criteria of PPS. This prevalence is higher than might be expected in population-based studies (6, 8, 23), since people with actual problems are prone to contact the healthcare system. This limits the possibility of comparing the prevalence of symptoms in different patient materials. In a recent report (23) from The Netherlands, the prevalence of new or increased muscle weakness was 58% in a sample of survivors of the 1956 polio outbreak. As the appearance of new symptoms increases with the time since onset of polio (4, 9), the prevalence may be higher in the whole polio population in the Western countries. The multi-ethnic group was heterogeneous and further analysis was beyond the scope of this study.

The results of this investigation confirmed previous findings (5, 12, 24), since they showed that persons with poliomyelitis sequelae have a high degree of independence in P-ADL. More than 50% were found to be dependent in the most mobility-related I-ADL activities: cleaning, shopping and transportation. Both spontaneous and maximum walking speeds were reliable predictors of dependence in cleaning, shopping and transportation, which was in agreement with findings in a population of elderly people (25). One main finding in the present study was that ratings of perceived difficulty in daily activities gave a more complete picture of the situation, since a considerable number (12–49%) of the subjects who were independent in P-ADL reported difficulties in various activities. Corresponding figures in I-ADL among independent subjects were even higher (41–71%) and perception of difficulties occurred in all the groups irrespective of distribution of polio involvement. Ratings of perceived difficulty in daily activities indicated need of intervention to prevent overload and increased dependence in ADL. According to Jette (26), rating of difficulties in doing various activities is the primary assessment of disability, whereas dependence is an effect of disability. The perception of difficulty is a personal experience influenced by each person’s frame of reference. Aspects such as muscle weakness, muscle and joint pain, local and general fatigue might play a role for perceived difficulties. Findings in other studies (27, 28) show that persons with polio who have had their disabilities since childhood were used to “struggling and straining” in daily life. They had never been able to compare, and they had difficulty in perceiving what was normal and abnormal. They were unaccustomed or reluctant to acknowledge difficulties. Ratings of difficulties from a sample with polio might therefore be relatively low.

More subjects with unstable polio (class IV) reported of pain than did those with severe atrophic muscles (class V). This may indicate overload in daily activities and is in accordance with the findings of Willén & Grimby (29), namely that the pain experience was not related to the degree of muscle weakness but to the level of physical activity. The risk of overuse may be worse during a process of decreasing physical capability, since people continue to fulfill goals and role expectations. They need time both to recognize changes in their own capability and to modify their lifestyle and activities (28).

The distribution of polio involvement may indicate that, from a clinical point of view, polio mostly affects the lower
extremities. However, it is important to note that one-third of the subjects were affected in both the upper and lower extremities. This makes compensation with mobility assistive devices—canes, crutches and manual wheelchairs—more difficult due to the risk of overload of weak muscles in arms and shoulders. The number of affected trunk muscles might have been higher, but an EMG, which is required to discriminate between no clinical polio (class I) and subclinical polio (class II), is outside the clinical feasibility to record in most trunk muscles, so evidence is lacking. Persons with only upper extremities affected were few. However, the importance of evaluation of their abilities and problems in clinical practice must be stressed, since they reported difficulties in several activities and had few assistive devices to compensate for their muscle weakness.

The majority of measures—housing adaptation and prescriptions for assistive devices—were provided for persons severely weakened by polio. No difference was found between the Swedish-born and the multi-ethnic groups. This may be seen as an outcome component in quality assurance and some evidence of the quality in clinical practice.

Lower extremity orthoses—shoe modifications and braces—to support weakened muscles and joints were common. After intervention, almost half of the subjects with involvement of the lower extremities used some kind of shoe modification, and more than a third some kind of leg brace. Canes, crutches and wheelchairs were used to a greater extent in persons with both legs affected. Subjects with signs of overload were recommended to reduce exertion by using wheelchairs, especially for long distances. About half of the recommended mobility assistive devices were not prescribed, since subjects rejected them or preferred to wait (Fig. 5). This reluctance to compensate with assistive devices is probably not due to economic factors, since assistive devices are provided free of charge in Sweden, but might be seen in the context of the subject’s earlier life experiences (27, 28, 30). The majority of persons with polio have succeeded in minimizing the appearance of disability, maximizing independence and have learned to walk after discarding nearly all of their original assistive devices (27, 30). New recommendations such as conserving energy and using assistive devices imply accepting a changed lifestyle (4, 27). The process of accepting assistive devices could therefore be long, since subjects needed time to modify conceptions.

Findings in this study indicate that subjects try to maintain their independence in daily activities despite difficulties. This interpretation is supported by results from qualitative studies (28, 31) which report that stretching the limits of physical capability by trying to do or persist in doing activities was a common strategy in each person’s lifestyle. Behind people’s aspirations to remain independent were, besides being autonomous, a desire for freedom, integrity and concern for family members who mostly offered the help. Another reason was that dependence in daily activities might influence the balance in the relationship with close relatives. Performance in daily activities was also connected with experiences of creativity and pleasure, which were additional reasons for helping oneself. Hence, supporting people to maintain independence seems to be an essential task in rehabilitation, but it must be well-balanced and combined with different strategies to reduce overload in daily activities.

One important strategy is to consider environmental demands, because these may be amenable to change (32). However, lack of general accessibility in buildings (33) might require extensive conversion. About one-fourth of the subjects lived in dwellings with staircases that now caused them difficulties, since their impairment had increased. Doing the shopping, for example, was influenced, since mobility and carrying groceries home were included in shopping and were made worse by the stairs. However, few of the subjects were willing to move, which demonstrates the importance of general accessibility in dwellings so that people are able to remain in their homes.

There may be several reasons for the findings that subjects who report use of assistive devices and housing adaptations for hygiene rated the activities as more difficult than persons without this equipment. One explanation could be that most assistive measures were provided for persons with severe polio. Another that the need for devices to compensate for the impairment had changed with time. Since subjects reported that they used their assistive devices in ADL, it seems likely that they were effective. However, activities in everyday life are very complex. Thus, it is likely that only some part of the activity was facilitated while other parts remained difficult. Intervention studies are therefore required to evaluate the effects of assistive technology devices and environmental adaptation on both perceived difficulty and dependence and to identify activities not affected by interventions.

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