#### Polioundersokelsen LFPS 1994

## The Norwegian Polio Study 1994

## A summary

## Aim of the study

The aim of Polioundersokelsen LFPS 1994 (The Norwegian Polio Study 1994) was to make a survey of the medical and social situation and of the needs of polio survivors, in particular as a basis for the planning of future public services, especially public health services. Besides, the results would also give general information about polio survivors to the Norwegian Health and Social Services, politicians and others interested in the material, among them especially polio survivors themselves.

### Material/method

A questionnaire was sent to a total of 2392 polio survivors, the names given by Landsforeningen for polioskadde (the Association for polio survivors). 1449 persons answered (61 %), 980 women (answering percentage 76) and 459 men (answering percentage 42). However, between 5.000-10,000 persons in Norway are estimated to be polio survivors.

The questionnaire consisted of 133 questions, with sub-questions, concerning medical problems and needs during the different phases of polio (the acute phase, the rehabilitation phase, the stable phase and eventually the late sequelae phase.) The questions also included social, physical and employment status, as well as the polio survivors' opinion of the services offered by the public health today, and wishes for the services in the future.

Statistical evaluations were made by the use of the statistical program SPSS.

### Results

Those participating in the survey were from all Norwegian counties, with a distribution similar to the distribution of the population in Norway.

### Age

66% were between 45 and 64 years of age, 9% were below 45 years, and 25% were above 64 years.

## The acute phase/the rehabilitation phase

Acute poliomyelitis afflicted 78% of today's survivors during the period from 1940 to 1954, while only 3% were struck after 1960. 82% were below the age of 18, and 63% below the age of 10 when they were struck. A few more women than men stated that they had polio before the age of 5, otherwise polio affected both genders equally.

The paresis in the acute phase were most frequent and most serious in the legs. A total of 73% had paresis in the legs versus 44% in the arms. The paresis were equally frequent in the left and right side of the body. In the acute phase 55% stated that they had paresis of the back-muscles, 47% of the abdominal muscles, and 22% of the respiratory muscles.

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In the acute phase a total of 71% were hospitalized, and 18% attended hospital for more than one year. 20% were hospitalized far away from their homes, and 47% stated that they rarely or never had visitors while attending hospital/institutions during the acute and rehabilitation phase. Some were sent abroad for treatment, in this survey totally 130 subjects (9%).

One or several operations were performed in 45% of the polio survivors. These were stated as successful in approx. 60% of the cases.

Physical exercise during the rehabilitation period took place more than three times weekly for approx. 1/3, two to three times weekly for another 1/3, and once or fewer times for the last 1/3.

## The stable phase

The majority achieved a considerable improvement of the paresis during the rehabilitation phase, and thereafter they experienced a long-lasting, stable phase. However, a majority of the polio survivors have experienced new health problems related to their polio, and the outbreak of these problems most frequently occurred 30-40 years after acute polio, independent of the age at their acute illness.

## Late sequalae

When specifying new health problems 85% stated that they had experienced increased weakness in muscles affected by polio, while 58% had experienced increased weakness in previous non-affected muscles. Other health problems related to polio were fatigue during exercise (80%), general fatigue (57%), joint pain (58%), muscular pain (53%), cold intolerance (62%), numbness (47%), sleep disturbances (48%), swelling of legs/feet (43%), dyspnoea during exercise/general dyspnoea (41%/16%) and concentration problems (39%).

#### Need of assistance

The participants in this survey indicated an increasing need of aids, but 80% were still independent of help from others during daily activities when the conditions were organized. 74% were still able to walk, with or without walking-aids, 70% could walk in stairs, but only 38% could "carry things" and only 46% could perform ordinary housework.

## **Employment**

Only 15% of the participants stated that they never had had paid employment, and 57% stated that they still were employed, fully or part-time. Several had changed from full to part time work, or had changed jobs because of their polio, but a total of 65% had been, or were still, working full time.

#### Health services

Only 17% of the participants stated that they were satisfied or very satisfied with the public health services for polio survivors, while 26% were dissatisfied. However, 67% were satisfied with the comprehensive examinations given at e.g. Sunnaas Hospital, Haukeland Hospital and at the Regional Hospital in Trondheim. Such examinations have so far been offered to approx. 30% of the participants of this study, but more than half of those remaining wanted a similar examination. The reason for this lack of medical service was lacking expertise in their home county, lack of guarantee for transferring into another county, or because the doctor did not want to apply for such an extensive examination. Thus there is a

large geographical difference in the medical services for polio survivors in Norway.

### Social services

The treatment at the social services offices were considered good or very good by 50% of the participants, while only8 % stated that they were treated badly. Our results also show that it might be useful to appeal cases refused by the social services office.

Approx. half of the participants had extra expenses because of their polio, which were not covered by the social security system, and it was discovered that several did not take advantage of their lawful rights to have these extra expenses covered, such as payment for physical therapy, orthopedic shoes, special reductions in their taxes, etc.

### Treatment

Of the different forms of treatment approx. 2/3 stated that they had beneficial effects of physical therapy, massage and treatment in hot water (extra warmed up swimming pool). A regular contact with a doctor/specialist and a physical therapist was wanted by a majority of the participants, including a comprehensive multidisciplinary examination and evaluation as mentioned above.

A most wanted treatment is therapy travel to a warmer climate (approx. 50%). Out of the 30 % who had already stayed in warmer climate on their own initiative, more that 90% stated a subjective improvement of their problems, and only 6% had a duration of this positive effect of less than five weeks after their return to home.

#### Conclusion

The results of this survey confirm the results of previous surveys from Norway, Denmark and USA, considering that most polio survivors experience new health problems and an increased need for aids and health services because of their polio.

Many of the polio survivors in Norway are dissatisfied with the present medical and health services, and there are large geographical differences in such services. However, most participants are satisfied with the type of multidisciplinary examinations/evaluations given at some few regional hospitals, but these services are so far only available to a maximum of 1/3 of those who need them. Such services must therefore be given priority in all health regions.

As the group of polio survivors will constitute a relatively large group in the society for many years to come, it must be an obvious demand that society gives satisfactory and equal health services to everybody in this group. This survey can hopefully be the basis for a positive construction of better services, involving to a significant degree the experiences from the polio survivors themselves.

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# PSYCHOLOGICAL ADAPTATION, DISTRESS AND COPING BEHAVIOUR

## AMONG POLIO SURVIVORS.

A follow-up study of 63 polio-survivors, 20 males and 43 females, aged 33 to 77 years (M= 55,2) were assessed with the following methods: Hospital Anxiety and Depression Scale (HAD), Sickness Impact Profile (SIP), Brief Type-A Questionnaire, COPE, Fatigue Severity Scale and heart rate reactivity. 23,8% of the patients showed elevated score on the anxiety scale (HAD-A > 8), 11% showed elevated score on the depression scale (HAD-D > 8). The patient group had increased score on the fatigue scale (M= 5,5) and on the Sleep/Rest SIP-subscale (M=23,7). With respect to coping styles we found that the post-polio patients have high score on problem-focused coping and low on avoidance coping. No significant sex differences were found. In contradiction to previous reported studies we did not find any indication of Type-A behaviour in our sample, supported by results showing no increased heart rate reactivity compared to an aged-matched control group. Our results are discussed in relation to the importance of timing in research in psychosocial adaption, noting that people tend to be more distressed closer to the onset of the stressor. Thus, the length time between the onset of new symptoms and psychometric and psychosocial testing may be a performance variable reflecting the process of adaptation.

