# The Late Effects of Polio:

## A Descriptive Survey of the Post Polio Syndrome in British Columbia

Prepared by

Castle House Medical Research Group

for the

Post Polio Awareness and Support
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# 1. INTRODUCTION

The problems being encountered by survivors of Polio have been described in the literature, much of which is included in an excellent recent review and bibliography (Teichroew, 1988). As the literature dealing with the more practical aspects of occurrence and diagnosis of post-polio syndrome (PPS) is very meager, two useful articles not included in this review are mentioned in this report. Aimed at Physicians and written by Physicians who are themselves PPS sufferers, they provide a readable discussion of the epidemiology and diagnosis of PPS.

The June 15, 1988, issue of **Patient Care** carried an article entitled *Postpolio syndrome: How you can help* (M.K. Eulberg et al.). The senior author of this informative paper is an MD who is both a Polio survivor, and a sufferer of the late effects of the disease. Dr. Eulberg discusses problems of diagnosis and treatment of PPS in a practical manner and provides some useful guidelines and suggestions for lifestyle changes. Her comments, concerning the difficulties experienced by PPS patients in having their problems recognized by the medical profession, illustrate the reason why the present survey was conducted:

> *"During this time, I became very interested in late effects of Polio, such as I was experiencing, but found it very difficult to find physicians who knew anything about Polio. It occurred to me that if I, a physician myself, was encountering so much difficulty, other Polio survivors were facing a serious challenge in finding a physician to treat their symptoms."*

This survey is intended to help survivors of Polio face this challenge.

**Postgraduate Medicine** carried an interesting article called *Post-polio syndrome: The battle with an old foe resumes* (Holman, June 1986). Dr. Holman, also a victim of the late effects of Polio, focuses on epidemiological and clinical aspects of PPS. Given the large numbers known to have been affected during the major Polio epidemics, her point that the "disease (polio) progresses to CNS involvement and paralysis in only 5% of persons infected (with the Polio virus)" (p. 44), begs the question of how many more might have been affected with sub-clinical forms of the disease. If these are at risk for PPS, then the epidemiology of the late effects of Polio, already complicated by serious over- and under-reporting of paralytic Polio itself may never be clearly understood. Dr. Holman refers to surveys which have been

> *"conducted to determine the number of post-polio patients experiencing late effects. Depending on the criteria used, 20% to 80% of post-polio patients have late symptoms." (p. 46)*

The acknowledged unavailability of accurate denominator data concerning Polio itself, constitutes a serious barrier to a full epidemiological investigation of its late effects, i.e. the occurrence of PPS. We do not have accurate records of a) the number of persons who contracted paralytic Poliomyelitis, b) the number of persons whose systems were compromised by sub-acute (perhaps sub-clinical) infections with the Polio virus, or c) the mortality rate among those who survived the initial acute phase of the disease. Consequently, the denominator required to construct the incidence of the late effects of Polio cannot be established with any certainty. However, the possible **range** of incidence figures is, at least in rough terms, less elusive. Given the above estimates, the incidence range could extend from 20% to 80% of the number of persons who survived Polio infections (both paralytic and non-paralytic). Somewhere between these two large numbers lies the 'true' incidence of PPS. Regardless of criteria used to define PPS, it would appear that a significant health problem exists among those who have already beaten Polio in one form and who are now faced with "Polio's backlash".

The survey reported herewith is an attempt to shed more light on the nature and extent of the problem as it exists in Western Canada, and primarily in British Columbia.

## 2. PURPOSE OF THE SURVEY

The survey was undertaken to determine the number of polio survivors (self-reported) in B.C. and Alberta who are or have been experiencing symptoms which may be due to their earlier acute polio episode. The object was to ascertain the nature, severity, and impact of the reported problems, in the expectation that any insight gained into the extent of PPS in B.C. will contribute to the establishment of a better diagnostic climate for patients, and ultimately to the development of effective therapeutic, rehabilitative, and palliative programs.

# 3. SURVEY METHOD

## 3.1 Study population

The population surveyed consisted of a self-selected group of people who were afflicted with polio in the past **and** who are currently experiencing various degrees of a complex syndrome consisting of muscle and joint pain, weakness, fatigue, depression, etc., which appear to be related to their having had polio in the past[1]. Participants were reached through the Post Polio Awareness and Support Society (PPASS) of British Columbia.

## 3.2 Survey instrument

A mail questionnaire approach was selected with which to conduct the survey. A self-completion questionnaire was developed, piloted, and distributed to all individuals identified by PPASS as having had polio and now experiencing new or worsening symptoms.

## 3.3 Mailing and follow-up

Announcement of the impending survey was made in the PPASS Newsletter early in 1988, well in advance of the mailings. Questionnaires were mailed or handed to 1,250 individuals identified to the research team by PPASS staff. Questionnaires were accepted until November 30, 1988, at which time work on the data base was begun.

## 3.4 Completion rate

The survey completion rate is as follows:

| | |
|---|---|
| Questionnaires distributed | 1,250 |
| Questionnaires returned (undeliverable) | 42 |
| Questionnaires returned (patient deceased) | 2 |
| Questionnaires returned ("never had polio") | 3 |
| Questionnaires completed | 629 |

Survey completion rate: 629 / 1203 = 50.3%

A self-selected sample of 50% of the target group is too small to be adequately representative. This is however not a problem, as it is as not at all clear what population, in an epidemiological sense, the total group of 1250 potential participants represents.

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[1] The circumspect nature of certain statements should be interpreted as neutral objectivity, not skepticism.

# 4. FINDINGS

## 4.1 Demographics

### 4.1.1 Age and sex

Twice as many females as males responded to the survey. This is consistent with the 2:1 sex ratio of the Society's membership. Male and female respondents did not differ in age. The age distribution of respondents is as follows:

Table 1. Mean and range of age by sex.

| | | Age | | |
|---|---|---|---|---|
| Sex | (N) | Mean | 1 s.d. | Range |
| Males | (206) | 54.2 | 12.1 | 26-79 |
| Females | (423) | 55.3 | 11.7 | 30-82 |
| Total | (629) | 55.0 | 11.9 | 26-82 |

### 4.1.2 Country of birth

No sex differences were found in terms of country of birth. By far the largest group are those born in Canada.

Table 2. Place of birth by sex.

| | Males | | Females | |
|---|---|---|---|---|
| Place of birth | N | % | N | % |
| Canada | 179 | (87) | 347 | (82) |
| United States | 6 | (3) | 25 | (6) |
| Europe | 16 | (8) | 45 | (11) |
| Other | 5 | (2) | 6 | (1) |
| Total | 206 | (100) | 423 | (100) |

## 4.2 History of Polio

### 4.2.1 Year diagnosed

It should be noted that the higher incidence of paralytic polio reported in males (e.g. Teichroew, p. 7ff) is not reflected in the sex ratio of respondents, i.e. that of the PPASS membership. The reasons for this are not clear, other than to speculate that fewer men are actually afflicted with the late effects of polio. Differential mortality in male and female polio survivors may also play a role. The present study did not address this question.

The overall incidence (or diagnosis) pattern is otherwise consistent with known polio morbidity rates (Teichroew, p. 8). With the small number surveyed, there is little to be gained by trying to discern a precise pattern as to the year of diagnosis. The only clear grouping is in the 5-year period 1950-55, a period during which the major polio epidemic occurred. That the largest group of respondents should have been diagnosed in those years was to be expected. In terms of the onset of their acute disease episode, therefore, these findings support the contention that the group we are dealing with are polio survivors.

Table 3. Year of diagnosis by sex.

| | Males | | Females | |
|---|---|---|---|---|
| Year | N | (%) | N | (%) |
| 1905-09 | 0 | (0.0) | 1 | (0.0) |
| 1910-14 | 1 | (0.5) | 5 | (1.2) |
| 1915-19 | 1 | (0.5) | 6 | (1.4) |
| 1920-24 | 5 | (2.5) | 16 | (3.8) |
| 1925-29 | 12 | (6.0) | 25 | (5.9) |
| 1930-34 | 11 | (5.5) | 10 | (2.4) |
| 1935-39 | 7 | (3.5) | 29 | (6.9) |
| 1940-44 | 10 | (5.0) | 31 | (7.4) |
| 1945-49 | 24 | (12.1) | 65 | (15.5) |
| 1950-54 | 95 | (47.7) | 179 | (42.6) |
| 1955-59 | 23 | (11.6) | 37 | (8.8) |
| 1960-64 | 10 | (5.0) | 16 | (3.8) |
| 1905-64 | 199 | (100.0) | 420 | (100.0) |

### 4.2.2 Age at diagnosis

The age at which respondents were diagnosed as having polio is the same for both males and females (Table 4).

Table 4. Mean and range of age at diagnosis, by sex.

| Sex | (N) | Age<br>Mean | <br>1 s.d. | <br>Range |
|---|---|---|---|---|
| Males | (206) | 14.2 | 11.5 | 0-46 |
| Females | (423) | 13.8 | 10.8 | 0-43 |
| Total | (629) | 13.9 | 11.0 | 0-46 |

### 4.2.3 Country/continent of diagnosis and hospitalization

These variables (Tables 5 and 6) demonstrate that the bulk of those claiming to suffer from PPS in B.C. were diagnosed and hospitalized in Canada.

Table 5. Place of diagnosis, by sex.

| Place of diagnosis | Males<br>N | <br>% | Females<br>N | <br>% |
|---|---|---|---|---|
| Canada | 183 | (90) | 363 | (86) |
| United States | 4 | (2) | 19 | (5) |
| Europe | 12 | (6) | 33 | (8) |
| Other | 5 | (2) | 6 | (1) |
| Total | 204[2] | (100)[3] | 421[2] | (100) |

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[2] Discrepancies relative to total number of respondents are due to some cases having missing values (questions not answered).

[3] Percentages do not add up to 100 due to rounding error.

Of the 206 male and 423 female respondents, 167 and 328 respectively were hospitalized due to the initial acute episode of polio.

Table 6. Place where hospitalized, by sex.

| Hospitalized | Males N | Males % | Females N | Females % |
|---|---|---|---|---|
| Canada | 152 | (92) | 274 | (84) |
| United States | 5 | (3) | 17 | (5) |
| Europe | 7 | (4) | 29 | (9) |
| Other | 2 | (1) | 6 | (2) |
| Total | 166 | (100) | 326 | (100) |

### 4.2.4 Paralysis

#### *4.2.4.1 Frequency of paralysis*

In order to ascertain the nature and degree of the effect of the acute episode of polio, respondents were asked whether or not they had experienced any temporary or permanent paralysis. The high proportions of males and females reporting some extent of paralysis support the assumption of polio (Table 7).

Table 7. Occurrence of paralysis, by sex.

| Paralysis | Males N | Males % | Females N | Females % |
|---|---|---|---|---|
| No | 4 | (2) | 11 | (3) |
| Yes | 186 | (90) | 364 | (86) |
| Not known | 16 | (8) | 48 | (11) |
| Total | 206 | (100) | 423 | (100) |

### *4.2.4.2 Patterns of paralysis*

The nature of paralysis was ascertained by asking respondents to indicate the areas affected. A detailed listing was provided, which allowed for the specification of: feet, lower legs, upper legs, hands, lower arms, upper arms, abdomen, chest, diaphragm, stomach, back, neck, throat, and face. These categories were subsequently collapsed into five (5) areas of the body (Table 8) which were labeled: Legs (including feet), Arms (including hands), Trunk (abdomen, chest, diaphragm, stomach), Spine (back, neck, head areas).

Altogether there were 14 and 15 different patterns of paralysis in males and females respectively, ranging from '0000' (no paralysis in any system) to '1111' (paralysis in all 4 systems). All combinations of reported paralysis were tabulated by frequency of occurrence (Table 8).

The top seven (7) patterns are the same for both males and females and they account for the same proportion of cases, 87% and 89%, respectively.

Table 8. Patterns of paralysis, by sex.

| Pattern of Paralysis | Area affected* | | | | | |
|---|---|---|---|---|---|---|
| | L | A | T | S | N | % |
| * Key: Legs, Arms, Trunk, Spine | | | | | | |
| Males | | | | | | |
| All systems | 1 | 1 | 1 | 1 | 49 | 26.3 |
| Legs only | 1 | 0 | 0 | 0 | 39 | 21.0 |
| Legs & arms | 1 | 1 | 0 | 0 | 24 | 12.9 |
| All x arms | 1 | 0 | 1 | 1 | 15 | 8.1 |
| Legs & trunk | 1 | 0 | 1 | 0 | 14 | 7.5 |
| Legs & spine | 1 | 0 | 0 | 1 | 11 | 5.9 |
| All x trunk | 1 | 1 | 0 | 1 | 9 | 4.8 |
| Females | | | | | | |
| All systems | 1 | 1 | 1 | 1 | 100 | 27.5 |
| Legs only | 1 | 0 | 0 | 0 | 79 | 21.7 |
| Legs & spine | 1 | 0 | 0 | 1 | 40 | 11.0 |
| All x arms | 1 | 0 | 1 | 1 | 35 | 9.6 |
| All x trunk | 1 | 1 | 0 | 1 | 34 | 9.3 |
| Legs & arms | 1 | 1 | 0 | 0 | 27 | 7.4 |
| Legs & trunk | 1 | 0 | 1 | 0 | 10 | 2.7 |

The same ranking of the top two patterns, 'all systems' and 'legs only', suggests that we are dealing with a clinically distinct population, and therefore perhaps with a distinct clinical condition. It is proposed that the symmetrical frequencies shown, by males and females, in the patterns of paralysis as well as other variables, are evidence that the late effects of polio represent a more-or-less uniform condition and should be taken more seriously than has been the case.

### 4.2.5 Respiratory problems

With regard to respiratory problems, the experience reported by respondents is again remarkably similar for both males and females. Table 9 shows that 56 (27%) male and 101 (24%) female respondents reported having had respiratory problems at the time of the initial polio episode. Of these, varying fractions reported having received the interventions listed.

Table 9. Respiratory problems with initial polio episode, by sex.

| Respiratory problems and interventions | Survey respondents | | | |
|---|---|---|---|---|
| | Males | | Females | |
| | Yes | (%) | Yes | (%) |
| <u>(All respondents)</u> | (N = 206) | | (N = 423) | |
| Any problems | 56 | (27.2) | 101 | (23.9) |
| <u>(Group w. problems)</u> | (N = 56) | | (N = 101) | |
| Tracheotomy | 9 | (16.1) | 22 | (21.8) |
| Rocking bed | 10 | (17.9) | 6 | (5.9) |
| Iron lung | 24 | (42.9) | 44 | (43.6) |
| Chest respirator | 14 | (25.0) | 21 | (20.8) |

### 4.2.6 Mobility aids, bracing, surgery, etc.

#### *4.2.6.1 Mobility aids*

Table 10. Use of mobility aids, past and present, by sex.

| | Males (N = 206) | | Females (N = 423) | |
|---|---|---|---|---|
| Mobility aids | Ever (%) | Now (%) | Ever (%) | Now (%) |
| Wheelchair | 86 | 38 | 185 | 79 |
| | (42) | (18) | (44) | (19) |
| Crutches | 89 | 22 | 153 | 28 |
| | (43) | (11) | (36) | (7) |
| Cane(s) | 76 | 33 | 124 | 66 |
| | (37) | (16) | (29) | (16) |
| Other aids | 69 | 28 | 142 | 45 |
| | (34) | (14) | (34) | (11) |
| Any current aids? | | 98 | | 191 |
| | | (48) | | (45) |

#### *4.2.6.2 Bracing*

Table 11 demonstrates the overall similarity of male and female respondents in terms of their use of braces and other supports to improve their level of functioning.

Table 11. The use of bracing, etc. and its perceived usefulness, following the initial polio episode, by sex.

| | Males (N = 206) | | Females (N = 423) | |
|---|---|---|---|---|
| Bracing, etc. | Yes | (%) | Yes | (%) |
| Any bracing | 128 | (62) | 255 | (60) |
| Splints | 20 | (10) | 50 | (12) |
| Braces | 100 | (49) | 188 | (44) |
| Corsets | 37 | (18) | 98 | (23) |
| Other bracing | 18 | (9) | 30 | (7) |

### *4.2.6.3 Surgery*

About 30% of males and 40% of females received some form of surgery to relieve symptoms of polio (Table 12).

Table 12. Surgery related to polio, by sex.

| Surgery | Males (N = 206) Yes | Males (N = 206) (%) | Females (N = 423) Yes | Females (N = 423) (%) |
|---|---|---|---|---|
| Any surgery | 60 | (29) | 177 | (42) |
| Muscle transplants (MT) | 10 | (5) | 18 | (4) |
| Bony fusions (BF) | 6 | (3) | 41 | (10) |
| Other (O) | 18 | (9) | 45 | (11) |
| MT and BF | 9 | (4) | 18 | (4) |
| MT and O | 2 | (1) | 11 | (3) |
| BF and O | 8 | (4) | 30 | (7) |
| MT, BF and O | 7 | (3) | 14 | (3) |

Within these slightly different rates the pattern of interventions is largely similar with regard to sex. Small numbers obviate any conclusion that bony fusions are really three times as common among females as males.

The preceding three tables (Tables 10, 11, 12) describe the use of mobility aids, bracing and surgery to alleviate the problems caused by polio. Without knowledge of the comparable rates in polio survivors **not** afflicted with PPS, it is impossible to say whether or not PPS is in any way related to, or predicted by, the use of these aids and surgical interventions. Again, the similarity between males and females supports the view that the respondents derive from one clinical population, namely, a particular group of polio survivors. It is hoped that future work will shed light on those factors which predispose towards becoming affected by the late effects of the earlier polio episode.

### 4.3 Symptom-free periods

An attempt was made to determine whether or not, and for how long, the new symptoms of PPS were being experienced following a period during which the polio survivors being studied felt themselves to have been relatively free of polio symptoms. Responses to the question as to whether a symptom-free period lasting for one year or longer had been experienced are shown in Table 13.

Table 13. Symptom-free period > 1 year, by sex.

| Symptom-free period | Males N | Males (%) | Females N | Females (%) |
|---|---|---|---|---|
| Yes | 88 | (43) | 197 | (47) |
| No | 105 | (51) | 187 | (44) |

## 4.4 Late effects of Polio

### 4.4.1 Diagnosis of PPS

**Subjective**. Diagnosis was ascertained by asking if respondents were "ever told by a doctor that (they) may be suffering from the late effects of polio". Of the male respondents, 55 (26.7%) said yes, as did 153 (36.2%) of the female respondents. In the absence of other diagnostic data (and EMGs were not done frequently enough to be useful), this item is used to indicate at least that a Physician had been aware of the possibility that his/her patient may be afflicted with PPS. The responses to this question will be used to investigate which other factors tend to correlate with reported PPS sensitivity on the part of Physicians.

**Objective**. EMGs were reported by 56 (27.2%0 male and 94 (22.2%) female respondents. The proportion of those for whom EMG findings supported a diagnosis of PPS was found to be nearly identical in both males and females, 32.1% and 33%, respectively.

### 4.4.2 New symptom pattern

### *4.4.2.1 Start of new or worse symptoms*

A worsening of symptoms was reported by 148 (72%) males and 343 (81%) females.

### *4.4.2.2 Nature of new or worse symptoms*

Six (6) factors were investigated with regard to the nature of new polio-related symptoms: Joint pain, muscle pain, muscle weakness, fatigue, respiratory symptoms, and anxiety/depression. For each category it was asked whether the symptoms were periodic or continuous.

To facilitate analysis, the two pain variables were combined and symptom responses were dichotomized.

The combination of **all** three classical features of PPS (pain, weakness, and fatigue) was by the far the most common symptom pattern, with 119 (57.8%) male and 276 (65.2%) female respondents reporting new or increased symptoms in all three areas. Altogether 395 (62.8%) of respondents reported the classical symptom pattern.

A substantial fraction of these participants, also indicated increased anxiety and/or depression. Among male and female respondents with the classical PPS symptoms, the frequency of anxiety and/or depression was the same, 65%. Of those respondents who reported classical symptoms **and** who had received medical confirmation or suggestion of PPS, a slightly higher number indicated increased psychological symptoms. The increases, 61% and 70% in males and in females respectively, are again not very dissimilar. This finding is discussed briefly later in the report.

Respondents who reported increases in any two of the three classical symptoms accounted for 76.2% of males and 83% of females. This proportion goes up sharply in those who have been given a possible diagnosis of PPS: 95.8% (52/55) of males and 91.5% (140/153) of females.

### *4.4.2.3 Side/location of new or worse symptoms*

There is considerable disagreement about using the location of the symptoms (i.e. same location/side as earlier polio or other location/side) as a criterion for diagnosis of PPS. Some have taken the position, without compelling evidence for its validity, that PPS is ruled out if new symptoms are at sites other than the sites affected by the original polio episode. Although these findings do not solve the dispute, they do indicate that same side/location of symptoms is common among those who claim to be suffering from the late effects of polio.

Again, it is striking that males and females show identical frequencies of 'same location' of symptoms, 164 males (71.4%) and 303 (71.6 %) females, respectively. This tends to confirm that PPASS members comprise a uniform clinical population, with a single source of disease, namely the late effects of polio.

### *4.4.2.4 Diurnal factors related to new or worse symptoms*

Respondents were asked "when during the day (they) experience symptoms". Results are shown in Table 14.

Table 14. Time of day and activity level correlated with symptoms, by sex.

| Time of day or activity level | Males (206) N | % | Females (423) N | % |
|---|---|---|---|---|
| Symptoms occur: | | | | |
| Any time, no apparent reason | 82 | (40) | 222 | (53) |
| After light activity | 62 | (30) | 140 | (33) |
| After strenuous activity | 85 | (41) | 205 | (49) |
| More in the morning | 35 | (17) | 84 | (20) |
| More in the evening | 89 | (43) | 191 | (45) |
| Continuously | 57 | (28) | 132 | (31) |

Little can be said about the above information other than that it is clearly meaningful data, to judge by the degree of agreement between male and female respondents. These findings will be further analyzed at a later date in an attempt to determine whether or not they are related to the nature and severity of symptoms.

### *4.4.2.5 Treatment*

Current treatments for PPS symptoms were reported by only 71 (34.5%) male and 186 (44.0%) female respondents. These varied widely and neither the kind nor the reported effect of such treatment were further investigated.

### *4.4.2.6 Impact of symptoms on daily activities*

An effort was made to ascertain the occurrence of symptoms sufficiently severe to make it difficult to carry out daily activities. Such disabling symptoms were reported by a large proportion of respondents: 134 (65.0%) males and 279 (66.0%) females.

### *4.4.2.7 Activity level during active period of life*

The similarity between male and female respondents reaches an extraordinary level in this variable. Table 15 shows these remarkable findings.

Table 15. Activity level during most active time of life, by sex.

| Activity level | Males (206) | | Females (423) | |
|---|---|---|---|---|
| | N | % | N | % |
| Continuously high | 75 | (36.4) | 154 | (36.4) |
| Periodically high | 70 | (34.0) | 145 | (34.3) |
| Marginal | 45 | (21.8) | 89 | (21.0) |
| Very low | 10 | (4.9) | 23 | (5.5) |
| Missing data | 6 | (2.9) | 12 | (2.8) |

## 4.5 Patients' perception of medical response to PPS

### 4.5.1 Physician awareness of PPS

Males and female respondents were agreed on the fraction of physicians felt to be unaware of PPS. Ninety-nine males (48.1%) and 229 females (54.1%) reported that the physicians they consulted were unaware of PPS.

### 4.5.2 Open-ended comments

Given an opportunity for open-ended comment, respondents reported serious difficulties in getting physicians to recognize problems as being related to polio. A lengthy selection of comments is reproduced here to illustrate respondents' perceptions of how the medical profession sees their complaints. While this report makes no claim about the truth or validity of these comments, they are accepted as reflecting legitimate perceptions concerning the way PPS is being handled by some members of the medical profession.

### 4.5.2.1 Doctor diagnosed depression

- "Given antidepressants though not depressed."

- "Doctors thought I was depressed. Tried 5 specialists."

- "I was given antidepressants - wasn't depressed."

- "Doctors thought suffering from depression."

- "Doctor thought I was depressed or bored."

- "Doctor suggested I see a psychiatrist."

### 4.5.2.2 Doctors ignorant about PPS

- "I can't find anyone in _______ who knows anything about PPS."

- "Doctors in _________ unaware of problem, painkillers and muscle relaxants standard medication."

- "GP knew nothing or very little."

- "Doctors were unaware of PPS, one wanted to sell me a high priced corset of his own design."

- "Young Doctor knows nothing about polio."

- "Doctor doesn't understand the problem."

- "I knew more about it than he did."

- "Doctor unaware of PPS, doesn't believe me re joint and muscle pain."

- "Doctor knows very little about PPS."

- "Doctors not aware of PPS problems."

- "GP knows nothing of PPS - thought neurological colleagues would laugh at him if consulted."

- "Doctor doesn't know too much about PPS."

- "Doctor poorly informed."

- "Doctors didn't know what to do about it."

- "Doctor has very little knowledge of PPS."

- "I find current Doctors know very little about PPS."

- "Family Doctor not convinced about diminishing strength, others do not know about PPS."

- "Doctors don't seem to know anything about polio."

- "Doctor not aware of PPS."

- "Doctors in the area generally unaware, my own Doctor is only casually interested."

- "Doctor admitted he had never dealt with polio as it is an illness of the past."

- "Doctor admits to having little knowledge of PPS."

- "Orthopedic surgeon won't admit the problem, knew little about it, doesn't seem interested."

- "Doctor has heard of, but knows nothing about, PPS."

### 4.5.2.3 Doctors ignore patient-supplied literature

- "I showed a list of information books to my Doctor, he said he was too busy to send for them."

- "Doctor showed little interest in PPS literature."

- "Doctor did not take time to read what I collected on polio."

- "Doctor said neurology was too difficult so would not read articles I gave him."

### 4.5.2.4 Doctor said it's "all in my mind"

- "I was made to feel its all in my mind."

- "Doctor made me feel it was all in my head."

- "Doctor did not accept that PPS may be responsible, treated for many other things including hypochondriac."

- "Doctors sure it was all in my mind."

- "Doctor brushed it aside, said it was a figment of my imagination."

- "My Doctor sent for tests, he thought I was a hypochondriac."

- "Doctor shrug shoulders, no comment, make me feel like a hypochondriac."

### 4.5.2.5 Strange ideas re polio

- "Doctor says I had polio too long ago to make a difference now."

- "Doctor and neurologist say there are 'no side effects from polio - period'."

- "Neurologist says PPS completely unfounded with no evidence supporting its existence."

- "Since I had polio so long ago (Doctors) don't feel they can do anything."

- "Doctor said "you've been over that (polio) quite a few years"."

- "I was by told by Doctor that there is no permanent damage from polio once you recover."

### 4.5.2.6 Doctors ambivalent, show disbelief in PPS

- "Doctor's opinion was that my symptoms were unrelated to the past polio."

- "Doctor would not acknowledge that PPS may be involved."

- "Doctors did not believe symptoms related to polio."

- "Doctors never believed my symptoms were related to polio."

- "Doctor would not acknowledge that PPS may be involved."
- "Doctor does not believe PPS symptoms related to polio."
- "Did not consider polio relevant to complaints."
- "Doctor did not pay any attention."
- "Most Doctors ignore comments and treat their specialities."
- "One specialist ... denied any possibility of connection."
- "I couldn't get any Doctors to listen."
- "Doctor disbelieved, one laughed, don't believe in PPS."
- "Doctors do not think it is related."
- "Doctor failed to believe problems related to PPS."
- "Doctor does not admit to the syndrome."
- "Doctors have found no correlation with polio or give it any credence."
- "Doctors feel it is unrelated."
- "Doctor does not believe PPS exists."
- "Symptoms played down and ignored, Doctors too busy."
- "Doctor will not comment on possible link of PPS with polio."
- "Doctors uncomfortable discussing problem."
- "Doctors stress difficulty in proving relationship between polio and PPS symptoms."
- "PPS not a real issue."
- "Doctor said symptoms not polio related."
- "Doctor says nothing can be done."
- "Doctor did not relate symptoms to PPS."

- "Doctor would not admit to PPS symptoms."

- "Family Doctor not concerned about polio re symptoms."

- "Doctors unaware of new medical practises, prescribe pain killers."

- "Doctor non-committal, not convinced of possibility."

- "Most Doctors impossible to talk to, too busy due to overbooking."

- "Doctor suggested that I discuss my problems with a physiotherapist, had little interest."

- "Doctor did not relate symptoms to PPS."

- "Doctor would not take time to listen."

- "Doctor could find no medical reason for problems."

- "Doctor would not discuss PPS."

### 4.5.2.7 Doctors claim PPS related to aging

- "Doctors belittle symptoms such as emotional weakness and physical debility as being due to age."

- "Doctor indicated symptoms were normal aging process."

- "Doctors felt symptoms due to age."

- "Doctor kept telling me I was getting old."

- "Doctor said problems due to age."

- "Doctors in area supremely unaware of polio and PPS, regard it as aging problems."

### 4.5.2.8 Doctors' diagnoses and prognoses off the mark

- "Doctor thought I had stress related situation."

- "Doctor diagnosed lack of exercise."

- "Doctor said there was no hope of treatment, said I will end up in wheelchair."

- "Symptoms first diagnosed as minor stroke then Doctor said PPS."

- "Young Doctor thinks problems due to being overweight."

- "Doctor thought everything that was wrong was due to being in wheelchair."

### 4.5.2.9 Doctors deny patients' symptoms

- "Doctor has complete disdain and disbelief, said 'nothing wrong with your muscles'."

- "Bone specialist says nothing wrong with me."

- "Doctor seemed to think it was all imagined on my part, that there was no such complaint, prescribed painkillers."

### 4.5.2.10 Doctors aware but not helpful

- "Doctor aware of PPS but not of any treatment that may help."

- "Doctors agree on PPS but don't know what to do."

### 4.5.2.11 Doctor indifferent to polio background

- "I get the impression that Doctors do not believe I ever had polio."

- "One Doctor said 'so you had polio, so what'; another didn't believe it was relevant."

- "Doctor did not want me to lay medical problems on polio."

- "My Doctor listens but he thinks I'm over-reacting; a physiotherapist tells me that they no longer teach about polio in medical training."

- "Doctor said 'you can't blame everything on polio', and prescribed painkillers."

### 4.5.2.12 More interesting reactions

- "Doctor very sympathetic - said 'that's life'."
- "Doctor accused patient of seeing too many Doctors."
- "Disbelief in patient being more informed than Doctor, unwilling to refer to specialist."
- "Doctors openly sneered, said I was trying to gain attention."
- "Doctor indicated he thought PPS was a farce."
- "Doctor said he only heard of PPS 3 years ago - how could I have it."

## 5. DISCUSSION

**Analysis**. While the nature of the survey data precludes complex statistical analyses, the possibility is being investigated of applying nonparametric techniques to some of the factors described. The results of this work will be reported to the PPASS Board of Directors as soon as it has been completed. Publication of findings in the medical literature will follow.

**Diagnosis of PPS**. Much of the problem with PPS concerns an apparent inability on the part of the medical profession to diagnose accurately and treat effectively the late effects of polio. Largely responsible for this are a lack of awareness as to the magnitude of the problem plus a dearth of research results indicating what to do with such patients. As the results of surveys such as this one become more widely publicized, the profile of PPS on the medical horizon will become more pronounced and the requisite research will be stepped up. Patients should then experience a more receptive and helpful response when reporting the symptoms described above.

**Classical symptoms.** Some evidence was found that **continuous** (as opposed to periodic) symptoms are consistently correlated with a diagnosis of PPS in **all** classical symptoms (pain, weakness, and fatigue) and for both sexes. Anxiety and depression showed a similar increasing pattern but in the 'periodic' category, as there were relatively few complaints of continuous psychological impairment. These analyses are not completed and will be reported at a later date.

**Anxiety/depression.** Anxiety seems to be correlated in a minor way with Physicians having suggested or agreed with a diagnosis of PPS. Several things could be at work here: First, patients who were more initially more anxious may have put more pressure on their physicians, and this perhaps yielded a slight increase in the acceptance or suggestion by the physician to consider PPS as a possible factor. On the other hand, if it was the physician who first raised the specter of a return of polio-related symptoms it is possible that anxiety and depression might have been increased in the patient. Thirdly, and potentially of importance to PPS victims, the actual presence of such psychological factors may increase the manifestation of PPS in polio survivors. Because the sequence of events and other details are not available, no causative explanation or link can be proposed at this time; however, the phenomenon will be investigated in a future study.

**Activity levels.** Besides the (puzzling) identical frequencies of levels of activity reported by male and female respondents, the most significant information provided here is that sufferers of PPS appear to have been highly active at some stage of their lives. This could of course be a universal, and therefore unremarkable, phenomenon in that it might be expected that few individuals would be unable to identify a high activity period at some time in their lives.

## 6. CONCLUSIONS

The present descriptive survey did not have as its objective to come up with major conclusions regarding PPS. Rather, it was undertaken to describe the distribution of polio-related symptoms among a group of polio survivors, the members of the Post Polio Awareness and Support Society of British Columbia. The findings tend to support the contention that PPS is a single (if variable) clinical entity, the characteristics of which are uniform in their effect on male and female survivors of polio. This finding has important implications for the conduct of future research into the occurrence of PPS.

The findings of the survey as well as the available literature, lead one to conclude two things: PPS exists, and it is a larger health problem than currently acknowledged by the medical profession. The difficulty (due to both over- and under-reporting of the initial acute cases of the disease) of determining the actual incidence of Polio itself, plus the lack of medical agreement as to the very existence, let alone the cause, of the late sequelae, suggests that the true incidence of PPS will be very difficult if not impossible to establish. If nothing else, the disagreement among physicians as to the nature and size of the population at risk (of PPS) should make it clear that there is now a pressing need for more and better research efforts into both the epidemiology and treatment of this phenomenon. The strong positions being taken by some members of the medical profession against a liberal interpretation of PPS appear to be both premature and unjustified.

What is now needed is an open-minded pursuit of a better understanding of the nature and extent of the problem. Furthermore, the latter should, at least provisionally, be estimated simply on the basis of the numbers and characteristics of patients **who perceive themselves to be afflicted with PPS**. This will contribute more to the understanding of the syndrome and the establishment of a sound care plan for PPS sufferers, than will needless argument based on inadequate theory and non-existent data.

The resurgence of polio-like symptoms is obviously a major trauma for people who already spent much of their lives struggling to overcome the effects of a disabling disease. Much work now remains to be done to extend these preliminary efforts to a broadly-based research initiative to identify the nature, extent, diagnosis, and treatment of the late effects of polio. It is hoped that these findings will have a positive effect on the development of this research.

## 7. REFERENCES

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