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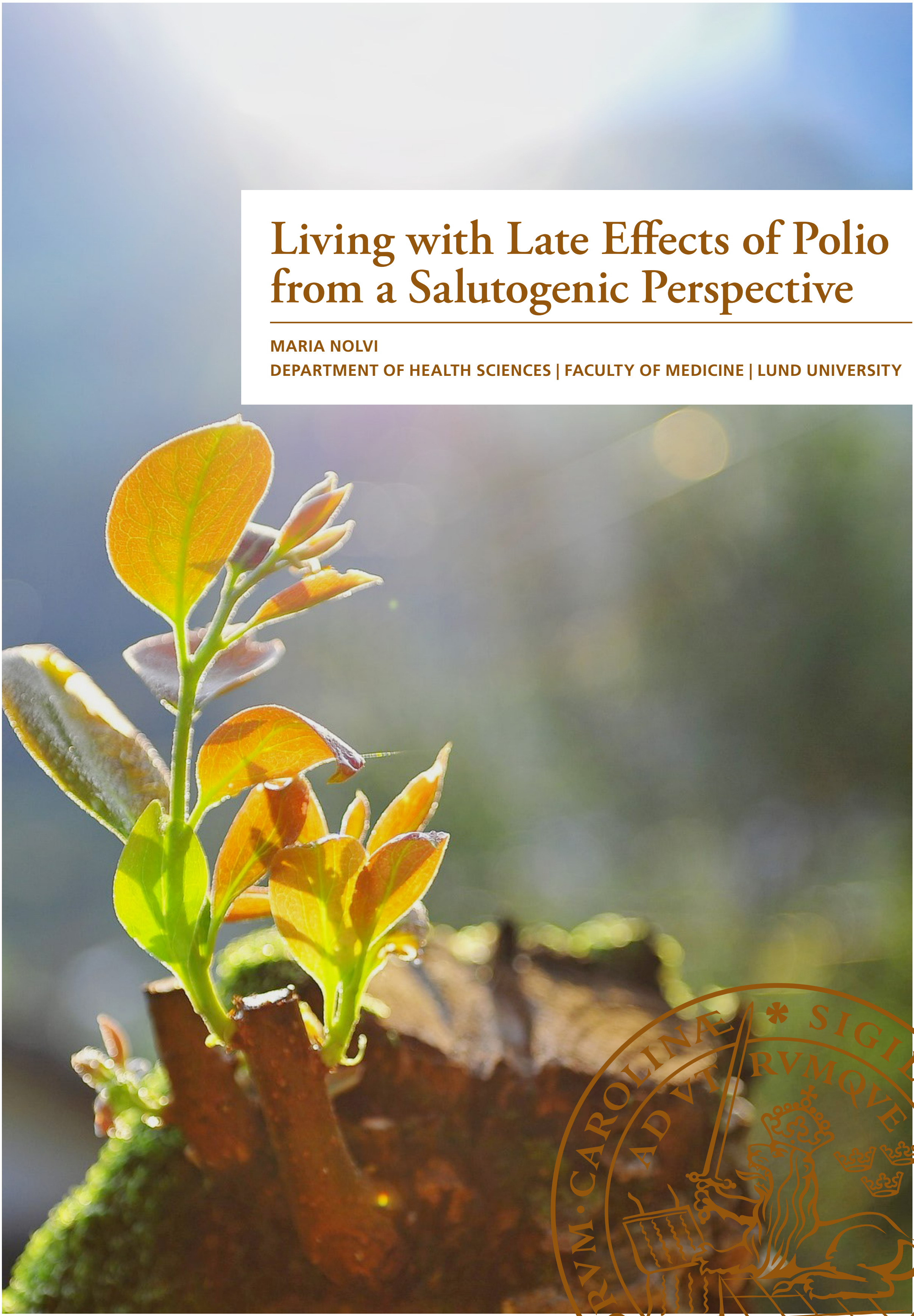

Living with Late Effects of Polio from a Salutogenic Perspective

MARIA NOLVI

DEPARTMENT OF HEALTH SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY

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Salutogenesis, meaning "origin of health", is important for the sense of living a good life among people with lifelong disabilities. Late Effects of Polio (LEoP) is a condition that leads to progressive, lifelong disability. This thesis provides a deeper and broader understanding of *Living with Late Effects of Polio from a Salutogenic Perspective*, and the gained knowledge can be used in rehabilitation interventions improving the life situation for people with LEoP.

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Living with Late Effects of Polio from a Salutogenic Perspective

Maria Nolvi

DOCTORAL DISSERTATION

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Docent Bengt Lindström
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Abstract

Salutogenesis, meaning “origin of health”, focuses on health-promoting factors instead of factors promoting illness and disease. Sense of Coherence (SOC), comprising comprehensibility, manageability and meaningfulness, is a way to conceptualize salutogenesis, and is important for the sense of living a good life among people with lifelong disabilities. Late Effects of Polio (LEoP) is a condition that leads to progressive, lifelong disability.

The overarching aim of this thesis was to provide a deeper and broader understanding of living with LEoP from a salutogenic perspective. The specific aims were to assess SOC in people with LEoP, to investigate SOC and associated factors and to gain an in-depth understanding of the meaning of SOC in people with LEoP.

Three quantitative studies with 93 people with LEoP investigated SOC and associated factors. Rating scales of SOC and associated factors were used, and the responses were analyzed with multiple regression. Face-to-face interviews were carried out with 14 people with LEoP in a qualitative study to gain an in-depth understanding of the meaning of SOC. The data were analyzed with a directed content analysis.

The results showed that people with LEoP generally have a strong SOC, but there are major variations with some people scoring very low on the SOC scale. Being married/cohabitating, having a higher level of education, having experienced more years prior to onset of LEoP, perceiving a mild or moderate disability, less bothered by impairments due to LEoP, better Perceptions of Self and a higher level of life satisfaction contributed to a higher SOC score, while less useful coping contributed to lower SOC scores. The qualitative study revealed two overarching themes: SOC among people with LEoP existed in a state of motion and in a state of being, visible in all three categories of SOC. The state of motion was a process aiming at attaining greater comprehensibility, manageability and meaningfulness, and the state of being was the comprehensibility, manageability and meaningfulness that the people currently experienced. The study also showed close interactions in the states of motion and being, as well as in comprehensibility, manageability, and meaningfulness.

In conclusion, people with LEoP generally have the ability to understand, handle and be motivated to deal with the stressors that arise from their disability. Being married/cohabitating and having a higher level of education was associated with a stronger SOC, as well as perceiving fewer symptoms of LEoP, better Perceptions of Self and higher life satisfaction. People with LEoP and lower SOC scores tend to cope in a less useful way. SOC exists in a state of motion and a state of being in people with LEoP. The states of motion and being, as well as comprehensibility, manageability and meaningfulness are closely intertwined. Together, the studies provided a deeper and broader understanding of living with LEoP from a salutogenic perspective, and the gained knowledge can be used in rehabilitation interventions improving the life situation for people with LEoP.

Key words Post poliomyelitis syndrome; Sense of Coherence; Adaptation, psychological; Rehabilitation

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MADE IN SWEDEN

For you who found strength,
meaning and a will to go on

Table of Contents

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List of papers

This thesis is based on the following papers:

I. Nolvi M, Brogårdh C, Jacobsson L, Lexell J. Sense of Coherence in persons with late effects of polio. NeuroRehabilitation. 42:103-111, 2018.

II. Nolvi M, Brogårdh C, Jacobsson L, Lexell J. Sense of Coherence and the association with sociodemographics and disability related factors in persons with late effects of polio. PM & R: the journal of injury, function and rehabilitation. 12:154-160, 2020.

III. Nolvi M, Brogårdh C, Jacobsson L, Lexell J. Sense of Coherence and coping behaviours in persons with late effects of polio. Annals of Physical and Rehabilitation Medicine. 65-3:101577, 2022.

IV. Nolvi, M, Forsberg, A, Brogårdh, C, Jacobsson, L, & Lexell, J. The Meaning of Sense of Coherence (SOC) in Persons with Late Effects of Polio - A Qualitative Study. International Journal of Environmental Research and Public Health. 19(10), 6314, 2022.

Abbreviations

GRR General Resistance Resource

ICD-10 International Classification of Diseases and related health problems, 10th edition

ICF International Classification of Functioning, Disability and Health

LEoP Late Effects of Polio

PPS Post-Polio Syndrome

RNL-I Reintegration to Normal Living Index

SD Standard Deviation

SIPP Self-reported Impairments in People with late effects of Polio scale

SOC Sense of Coherence

SOC-13 Sense of Coherence 13 item scale

SRR Specific Resistance Resource

SWLS Satisfaction With Life Scale

WHO World Health Organization

Definitions

Activity *"The execution of a task or action by an individual" (1)*
Activity limitations *"Difficulties an individual may have in executing activities"* (1)
Axonal sprouting The process where fine nerve processes - sprouts - grow out from intact axons to make contacts with muscle fibers that have lost their nerve contacts
Body functions The physiological functions of the body (such as hearing). Body functions also include psychological functions (1)
Body structures The anatomical parts of the body (such as ears) (1)
Coping *"constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person"* (2)
Disability An umbrella term for impairments, activity limitations and participation restrictions (1)
Environmental factors *"The physical, social and attitudinal environment in which people live and conduct their lives"* (1)
Functioning An umbrella term for body functions, activities and participation (1)
Health condition Disease, disorder, injury etc as classified in ICD-10 (1)
Impairment *"Problems in body function or structure such as a significant deviation or loss"* (1)
Life satisfaction *"A conscious cognitive judgment of one's life in which the criteria for judgment are up to the person"* (3)
Motor unit A motor neuron and the muscle fibers which it innervates
Paralytic polio Polio infection that has led to full or partial paralysis
Participation *"Involvement in a life situation"* (1)
Participation restrictions Problems a person might experience in participation (1)
Personal factors Attributes of a person that is not part of the health condition but influence functioning and disability (1)
Rehabilitation *"A set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment"* (1)
Salutogenesis Origin of health

Foreword

I visited the rehabilitation medicine department at Skåne University Hospital in Höör (Orupssjukhuset) in the first year of medical school. I met a person then who, despite severe disability, was very happy and content with his life. He had found strength, meaning and a will to go on. This fascinated me, and I came to wonder what he was doing to be able to have such life satisfaction. I asked myself *"How does he do it?"* and I was thinking that I could learn something from this person. I met with other people at the hospital the same day who were having rehabilitation, and they were very content with their rehabilitation experience. This made me interested in rehabilitation medicine as a speciality.

I remembered the first person I had met at the rehabilitation clinic when it was time to write my master thesis. I contacted Professor Jan Lexell who worked at the clinic, and we suggested a research question that seemed to investigate the thoughts this person had evoked in me. Jan suggested I should investigate *Sense of Coherence*, which was a topic that was entirely new to me at the time. Furthermore, the department had a large outpatient clinic at that period in time and had received well over 500 people with Late Effects of Polio. It was thus convenient to approach them and ask if they would be interested to take part in my master thesis work.

I had the opportunity to continue with the same research question in a PhD-project after completing my master thesis, and with Jan Lexell as my main supervisor. I also had the opportunity to start my residency at the rehabilitation medicine department, and during my time there I met several people with Late Effects of Polio. I noticed that many of them managed very well, they were positive and willing to make adjustments.

My thesis is the gained knowledge when trying to answer my naïve question *"How does he do it?"* I found an answer to some extent.

Background

There have always been times in the past when people have been frightened by pandemics. One such pandemic during 20th century was polio, a viral disease also known as “infantile paralysis”. The cause of it and how it was transmitted was not understood initially, and there was no cure or vaccine. Polio was one of the most frightening diseases during the first half of 20th century as mostly children were affected, and some died of the virus while others became permanently disabled.

The children who survived grew up and learned to live with their disability, and many of them led highly successful lives. They educated themselves, became parents, were employed and functioned very well in society. Many of them, however, experienced new symptoms, often in their 50-ies, a condition known as Late Effects of Polio (LEoP) or Postpolio syndrome (PPS). Acquiring LEoP entails a person suffering from a progressive disability that she/he once again has to adapt to. Many people with LEoP are satisfied with their lives despite having previously faced a serious threat to their health in their childhood, having a life with disability and subsequently a progressive disability. They have found strength, meaning and a will to go on. The fact that many of these people continue to live a good life despite their adversities is highly interesting for rehabilitation professionals. If we can understand which factors are important for the sense of living a good life, we can use that knowledge to support them during their rehabilitation.

One concept that is relevant is salutogenesis, literally meaning “origin of health”. Salutogenesis focuses on health promoting aspects, instead of focusing on the causes of disease. Those with LEoP who live a good life seem to understand the core of salutogenesis in their situation. It is the core of their salutogenesis that is the main subject in my thesis. I believe we can learn a great deal from these people, and that this knowledge can be transferred to people with similar life changing situations, and to all of us, since we all experience periods of adversities in our lives.

Polio

It is not known when the polio virus first appeared among humans, but it is likely that it has been present since ancient times. An Egyptian stele from the period 1403 to 1365 BC is shown in Picture 1, which features a priest with a withered leg, and the cane he uses as a mobility device. This is believed to be a depiction of a polio survivor, since a shorter, atrophic limb is a common feature after paralytic polio.

Picture 1. Ancient depiction of polio survivor. Ny Carlsberg Glyptotek Museum.

Patophysiology and clinical picture

The polio virus is an Enterovirus belonging to the picornaviridae family. There are three types of the polio virus: PV-1, PV-2 and PV-3 (4). Of these, PV-1 is the form that causes the largest number of cases of paralysis (5). PV-1 is the only one of these still circulating, since PV-2 and PV-3 have been declared eradicated in 2015 and 2019 respectively (4). The virus is spread through the faecal-oral route, i.e., faeces contamination of fingers, food and water (6). The virus is highly contagious, but most people (95%) are asymptomatic or only acquire mild symptoms, such as a common cold or influenza. In rare cases (less than 5%), the virus enters the nervous system, causing a meningoencephalitis and even more rarely damage to motor neurons resulting in paralysis (5). If the motor neurons to the breathing musculature are affected, the person gets difficulties or an inability to breathe. A device helping the person to breathe was developed by an engineer Drinker and a physician Shaw in 1928, two Americans who were active researchers at Harvard medical school. This device was commonly referred to as the "iron lung", which saved the lives of thousands of children (7). Picture 2 shows a ward in an epidemic polio hospital with rows of children in iron lungs and healthcare staff attending to them.

Picture 2. Children in iron lungs in the US in the 1950s. Photograph: Britannica Image Quest.

Most surviving people are able to gradually regain some function when the damaged motor neurons regenerate, and the surviving motor neurons take over the functions of motor neurons that were permanently damaged. This process is triggered by axonal sprouting from surviving motor neurons, generating enlarged motor units up to 7 times their original size (5). The paralysis from the polio virus is often asymmetrical, which could cause scoliosis or a slowing down of the growth of a limb when the child is developing.

Polio epidemics in Sweden

Polio infections are believed to have occurred at a low "steady-state" until the late 19th century, when polio epidemics began to affect the western world (8). Interestingly, other infectious diseases were decreasing due to higher living standards and better medical care during the same period. It is still not fully understood why polio cases increased at the same time. One theory is that the improved living standards that prevented the spread of other infectious diseases had the opposite effect regarding the polio virus. People lived close together before these improvements were made and "everyone" was infected at a very young age, while they still had some immunity from their mothers during pregnancy and breast-feeding, thus preventing them from becoming seriously ill when infected by the polio virus (8, 9). Moreover, the increased number of polio cases might reflect the rapid increase in population that occurred during this period (10).

The first known local polio epidemic in Sweden was described in 1881, when 18 children and adolescents were struck with paralysis in the area of Umeå. The first nationwide polio epidemic occurred in 1905, when more than 800 people were afflicted by paralytic polio. Nationwide polio epidemics were subsequently recurrent in Sweden during the first half of the 20th century, with the highest incidence of polio cases in the world (9). The last major polio epidemics were a few years after the end of the Second World War, more specifically 1949, 1950 and 1953, when more than 5000 people were afflicted by paralytic polio (11).

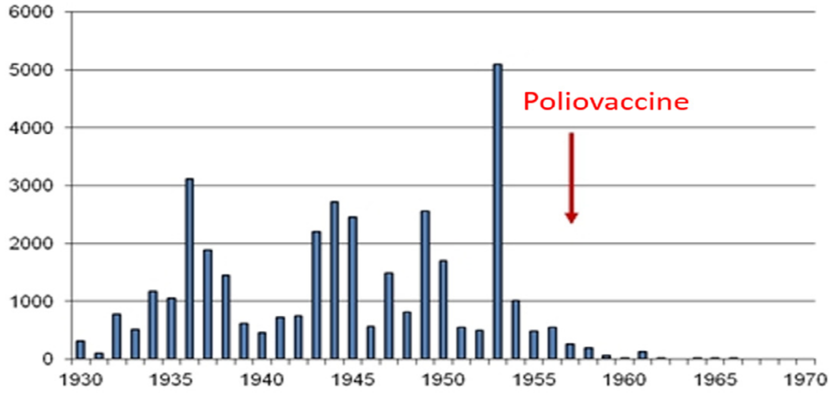


Figure 1. Polio cases in Sweden 1930-1970. Figure (modified) from www.folkhalsomyndigheten.se.

Most children and adolescents with paralytic polio were transferred to specialized epidemic disease hospitals, where they stayed until the fever had decreased and the paralysis had stabilized. Many people with permanent paralysis were transferred for aftercare in special disability institutions (when these institutions existed, they were called "Vanföreanstalter" in Swedish). The people received treatments, such as physiotherapy, bandages and hot baths in these institutions. Some surgical treatments were also performed, such as the lengthening of tendons for increased mobility (9).

The patient organisation for children with polio was founded in 1946 in order to support people with disabilities from polio, as a result of the epidemics after the end of the Second World War (12). The organisation still exists and has an important role in information and education about LEoP to all those who were affected during the 20th century and are living with the condition as well as those with LEoP who come from other parts of the world.

The period when the child was separated from their parents in hospitals or the special institutions could be very long, lasting for months and even years (13). Being on their own and dependent on the hospital staff could be a sad and frightening experience, forcing them to become obedient and "good" (14, 15). There could be a variety of remaining disabilities from the paralysis, such as a reduced limb length, misalignments of joints, scoliosis etc, which could lead to difficulties with activities such as running, playing and participating in school gymnastics. However, "normality" was expected in society and their childhood experiences had a major impact on their lives. They learned to struggle to overcome everyday difficulties when they grew up and made great efforts to function in society and not differ from others (13) (15). Survivors of paralytic polio have also been shown to be more likely to achieve a university degree compared to their non-paralytic counterparts (16).

One study (17) suggested that many polio survivors developed a "Type A-behaviour", meaning that they became hard-driving, competitive and self-denying in their efforts to reach "normality". This behaviour is typically learned through the active avoidance of punishment in people who chronically struggle to overcome difficulties (14). Polio survivors have more years of education and a higher proportion of employment and marriage compared to the general population (14). Many of them thus became even more successful than the average person in society in their efforts to reach "normality".

The vaccine

The National Foundation for Infantile Paralysis was founded in 1938 by President Franklin D. Roosevelt, who himself was a polio survivor, in order to combat polio. A campaign called "The march of dimes" was held every year which aimed at collecting 10 cents (a "dime") from every person (Picture 3). Both Sabin and Salk (see below), two polio virus researchers, received funding from the foundation for their vaccine development (18).

Picture 3. Flyer from The March of Dimes campaign. Uploaded from https://www.wnyc.org/series/march-of-dimes.

The first successful polio vaccine was developed in 1950 by Hilary Koprowski, a Polish virologist and immunologist based in the United States. The vaccine was an attenuated polio virus taken orally. This weakened living virus vaccine was later developed further by a colleague of Koprowski, the Polish-American physician Albert Sabin, and this oral vaccine was approved for administration in 1960 (19). The advantages with a living attenuated vaccine are that it is easily administered, inexpensive, and could provide immunity to more people than the person taking it, by it being transferred via the faecal-oral route, which is similar to how the wild polio virus spreads. The disadvantage with a living vaccine is that, in very rare cases (2-4 people in a million), the vaccine could generate paralysis, possibly due to immune deficiency in the affected people. Moreover, a circulating weakened polio virus can mutate and re-acquire neurovirulence, thus making the virus dangerous again and lead to paralytic polio (4).

The American physician Jonas Salk presented a vaccine based on inactivated polio virus in 1953, which was instead administered by injection (19). There was no risk that it would cause paralysis being as the vaccine did not contain any living virus (4). The director of the Poliomyelitis Vaccine Evaluation Center at the University of Michigan declared the Salk vaccine to be “safe, effective and potent” in 1955 (20). Mass vaccination subsequently started, which rapidly reduced the number of new polio cases (18).

A Swedish vaccine developed by Sven Gard, Gunnar Olin and Tore Wesslén was presented shortly after that of Salk. This was similarly based on inactivated polio virus that was administered by injection. This national vaccine came to dominate in Sweden, and mass vaccination started in 1957. This led to a substantial reduction in new polio cases and the last polio case was reported in Sweden in 1977 (9).

The oral vaccine is currently administered in countries that still have cases of wild polio, and countries considered to be “at risk” for wild polio strains. The reasons for using the oral vaccine are the advantages mentioned above; in particular, the simple administration, and the lack of the requirement for professional healthcare staff or sterile needles. The inactivated vaccine is given in countries where the polio virus has been eradicated, since cases of vaccine-derived polio are not seen as justifiable in places where polio has been eradicated (4).

Polio today

The World Health Organization (WHO) adopted a resolution to eradicate polio in 1988, The Global Polio Eradication Initiative. The eradication programme has been a great success, and the number of polio cases has been reduced by 99.9% since the campaign started. The reasons for the success are believed to be that the human being is the only reservoir, as the polio virus has never been found transmitting among animals. Moreover, infected people are only infectious for about 1-2 weeks.

Wild polio strains are only present in Afghanistan and Pakistan today. Several countries are still considered to be at risk, and vulnerable for wild polio strains. A total of 576 cases were reported world-wide in 2021; 4 of these were wild polio cases and 572 were vaccine-derived. The number of vaccine-derived polio cases are just a fraction of what the numbers of wild polio cases would have been, had the vaccinations not taken place (4).

Late Effects of Polio

The remaining disability after the acute polio infection has for a long time been believed to be stable. The first description of new muscular weakening and atrophy in polio survivors was made in 1875 by Fulgence Raymond and Jean-Martin Charcot (21), two French neurologists. However, this was not widely acknowledged in the medical society until the 1980's when the new symptoms became more systematically reviewed than had previously been performed (22).

The term Postpolio syndrome (PPS) was introduced in 1985 by the American physician and polio survivor Lauro Halstead (23). Late Effects of Polio (LEoP) is a broader term, also covering symptoms not required for PPS (24). All people with LEoP do thus not meet the criteria for PPS. However, the terms are often used synonymously, and in my thesis, I have used the words as synonyms, and the people participating in my studies all met the PPS criteria.

There are approximately 15-20 million polio survivors in the world (5). Up to 80% of these will develop LEoP, making it one of the most common neuromuscular conditions (25). There are no detailed data on the number of polio survivors in Sweden. The patient organisation and clinicians working in the field estimate that there are about 5000 people with LEoP living in Sweden. With the increase in immigration from, for example, the Middle East, Africa and Asia where polio still existed until a few decades ago, we can expect that there will be people with LEoP needing health care for many years to come.

Pathophysiology

The pathophysiology of LEoP is not completely understood. The enlarged motor units that develop during recovery from acute polio are believed to be unstable over time, with a progressive loss of the axonal sprouts, leading to decreased innervated musculature. Metabolic stress, combined with overuse and normal aging are thought to contribute to functional decline (5). Some studies propose that an inflammatory process might be present, since increased levels of cytokines have been observed in serum and cerebrospinal fluid in people with LEoP (26). However, a correlation to symptom severity has not been found (5), and intravenous treatment with immunoglobulins has not been proven beneficial regarding the LEoP associated muscle weakness (27).

Symptoms and diagnosis

Typical symptoms in people with LEoP are muscle weakness, fatigue, muscle or joint pain, muscular atrophy and cold intolerance (28). Less frequent symptoms, such as breathing difficulties, problems with swallowing, sleeping difficulties, memory problems, concentration difficulties and mood swings are also reported (29). The muscle weakness is due to the loss of motor neurons, and most commonly affect muscles that were already affected during the acute infection. However, muscles that were only mildly paralyzed during the polio infection could also be affected later in life (25).

The muscular weakening is a slow process (30), with an annual reduction in strength of about 2-4% (25). Muscle atrophy is due to the loss of motor neurons, and the subsequent loss of muscle mass. Two types of fatigue have been described: the inability to maintain muscle force (31) and also a more general exhaustion where overall energy is drained, referred to as mental fatigue (32). The inability to maintain muscle force is due to the muscle weakness. The mental exhaustion is more commonly described in people who had severe meningitis in the acute polio infection. This fatigue usually arises after too many activities during the day. Muscle and/or joint pain is a result of the muscle weakness, leading to incorrect posture and overload (25). One study suggests that the pain might be specific for LEoP and of multimodal origin (33). Cold intolerance is the feeling of coldness, and an inability to regulate temperature. This could be due to damage to the nerves or the thermo-regulating area in the brain, and reduced muscle mass (25).

There is no specific test that can confirm LEoP. It is a clinical diagnosis, which is often made by using the Halstead criteria (Table 1) (28). The criteria have been revised in 1991 and 2000, so that new muscle weakness is mandatory (34) and the symptoms must persist for at least a year (18).

Table 1. The Halstead criteria.
Prior history of polio
Full, or incomplete recovery after the acute phase of polio
A stable period of at least 15 years
At least two of typical symptoms (muscle weakness, fatigue, muscle or joint pain, muscular atrophy, decline of functional status, cold intolerance)
Other medical reasons must be excluded
New muscle weakness
Symptoms persisting for at least a year

An electromyography (EMG) is also typically performed when making the diagnosis. The EMG can confirm a prior history of poliomyelitis, showing abnormally enlarged, polyphasic motor unit action potentials and decreased recruitment of motor units during muscle contraction (35).

Consequences of LEoP

The new symptoms after onset of LEoP might cause new problems, such as difficulties walking, climbing stairs, carrying things, dressing oneself or driving. These difficulties might also affect the person's self-esteem, cause problems with participation in leisure activities and social activities and generate worries such as a fear of falling (36). A correct diagnosis is sometimes delayed since the symptoms are not exclusive for LEoP, thus leaving the person not knowing what is happening to them. Managing this new situation might be very challenging. The feeling of "being on a downward slope without control" has been described (37). Many people with LEoP thus need professional support to manage the consequences of their LEoP.

Management and interdisciplinary rehabilitation of LEoP

There is no curative treatment for LEoP. Group training, regular follow up of the people with LEoP, and patient education are emphasized as important for the management of LEoP (23). Support from many different professionals is needed, such as physiotherapists, occupational therapists, speech and language therapists, social workers, psychologists, physicians and nurses being as the symptoms and needs are complex and diverse.

The cornerstone in the management of people with LEoP is thus interdisciplinary rehabilitation from a team with expert knowledge of LEoP (25, 38). The rehabilitation process basically comprises four steps: assessment (description of the disability and the consequences), goal setting (short-term and long-term goals according to the person's wishes and realistic possibilities), interventions (actions to reach the goals, and who is taking responsibility for the specific intervention) and outcome measures (objective, such as ability to perform a physical task, or self-reported, such as perceived life satisfaction). The rehabilitation process should continue as long as the person is in need of interventions (25).

The person learns about his/her condition and how to be active at an appropriate level during the rehabilitation process. This is important, since physical recommendations could be very different to the ones they learned in their childhood (39). Energy conserving techniques could make a great improvement on fatigue. Other possible causes of fatigue should also be investigated and treated, such as depression and sleep disturbances. Muscle pain is usually due to overload. Lifestyle changes, e.g., to be active on an appropriate level, and sometimes using mobility aids, are necessary to prevent this. Joint pain is usually reduced by appropriate movement training, orthoses and mobility aids. The home environment should be assessed since more disability-friendly arrangements could be needed (25).

A holistic approach has been emphasized in order to cover all important aspects of the person's life (1). Such an approach is necessary, since physical, environmental and psychological aspects all impact the sense of living a good life. One way to cover all important aspects is to use the International Classification of Functioning, Disability and Health (ICF) model.

The ICF model

The ICF model was developed by WHO in order to provide a framework for health and disability. It is a biopsychosocial model that not only focuses on morbidity but includes functional aspects and health, and as such includes a person's entire life situation. The ICF model is based on three components: body functions and structures, activities and participation, and contextual factors (i.e., environmental and personal factors) (1). (Figure 2).

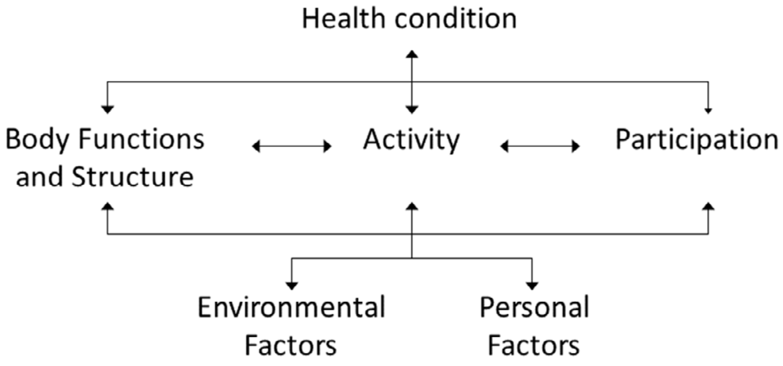


Figure 2. The ICF model

A framework for describing all aspects of a disability, and assisting in setting meaningful, realistic goals and selecting effective interventions is provided by incorporating ICF in the rehabilitation process and the rehabilitation plan (40).

Interdisciplinary rehabilitation focusing on the person's whole life situation has been described as "a positive turning point in life" in people with LEoP. By participating in the rehabilitation program people were writing and taking responsibility for their own rehabilitation plan, which forced them to reflect on their situation, their difficulties and what they wanted to achieve in their daily life. This, in turn, made them aware of which changes they had to make in order to accomplish these goals. They were able to accept their disability, establish new habits and describe having a different, but good life after a year, with support from the rehabilitation team (37).

Living a satisfactory life with LEoP

People with LEoP have described that the consequences following the polio infection, which they acquired in childhood, shaped their future lives (13, 15) They got used to struggling and overcoming difficulties and did their best to blend in society just like anyone else. Coping behaviours such as "never give up" have been adaptive to achieve this (14). They face a new situation when struck with LEoP, where the most adaptive coping behaviours, the right amount of physical activity and their life situation, are not the same as when they were children. It has been shown that many people with LEoP are generally satisfied with their lives in spite of all the challenges (41).

All aspects of the ICF model, i.e., body functions and structures, activities and participation, and environmental and personal factors, have an influence on the sense of living a good life. Personal factors have not been classified formally in the ICF model, and are not routinely taken into account in rehabilitation, but include gender, age, social background, coping behaviours, personal character and other factors that influence how the person experiences their health condition. One concept that is related to personal factors, and important for the sense of living a good life, is the concept of salutogenesis.

Salutogenesis

Salutogenesis, meaning "origin of health" focuses on health-promoting factors instead of factors promoting illness and disease. This approach is not new and some traces of salutogenesis can be found since the time of Aristotle (42). However, the term as such was developed by Aaron Antonovsky, who also found a way to conceptualize salutogenesis.

The salutogenic perspective – the history of Sense of Coherence

Aaron Antonovsky was an Israeli-American sociologist who lived and worked both in the United States and in Israel in the decades following the second world war (43). He came to encounter survivors from the Nazi concentration camps in his work, and he noticed and began to ponder about the fact that quite a few of the survivors were still in a good psychological health. He found it remarkable that this was possible after the horrors experienced in the concentration camps, and he asked the question “What was the miracle?” (44)

In an attempt to find an answer to his question, salutogenesis became Antonovsky’s main research topic for the remainder of his life, and his answer to the salutogenic question was gradually taking form. He had previously identified the importance of general resistance resources (GRRs) in his earlier work about stressors and social class (43). GRRs are resources that are available for a person to solve a problem at hand, by oneself, someone else or something else. Examples of GRRs are intelligence, social support, wealth and cultural stability. He theorized that all GRRs send positive signals to the person, such as “here is the right track; you can handle things; you are of worth” (45).

Antonovsky proposed in his work on the salutogenic model that repeated messages of that kind strengthened something in the person, a “factor X”, whereas such messages that are absent or confusing led to a weak factor X. Antonovsky believed initially that factor X was a cognitive element, however, he later realized that it also consisted of a behavioural and a motivational component (43).

Antonovskys wife Helen named factor X “Sense of Coherence”, and Antonovsky defined it later as:

> *“The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that: 1) the stimuli deriving from one’s internal and external environments in the course of living are structured, predictable, and explicable; 2) the resources are available to one to meet the demands posed by these stimuli; and 3) these demands are challenges, worthy of investment and engagement”* (44)

Antonovsky also identified specific resources, SRRs, which are resources that are helpful in specific situations of stress. An SRR can, for example, be a telephone lifeline for suicide prevention (46).

Sense of Coherence, from now on referred to as SOC, became Antonovsky’s answer to the salutogenic question. He continued working on his salutogenic model throughout his life, and he expressed a wish that other people should continue and add new knowledge to the concept. SOC became more commonly known through his book *Unraveling the mystery of health* from 1987. SOC has since then acquired a great deal of attention worldwide and has been an area of research in many different populations (43). Many studies have found that SOC is related to mental health, and positive aspects such as optimism and self-esteem. SOC is also correlated to perceived health, whereas the correlation to health in general shows varying results (47).

The three components of SOC

SOC consists of three components: one cognitive component (comprehensibility), one behavioural component (manageability) and one motivational component (meaningfulness). A description of the three components is presented in Table 2.

Table 2. The three components of SOC

Comprehensibility	The perception that you understand the environment and the daily events and demands. You understand the character of the stressor at hand.
Manageability	The confidence that you can handle problems arising in your life, by yourself or by the help of other people or resources.
Meaningfulness	The motivation, the perception that life is worth living and that challenges are worthy of investment.

According to Antonovsky, these three components are founded in childhood and adolescence. Comprehensibility is developed when a child experiences the environment as predictable and structured. The right proportion of challenges, according to your abilities, develop manageability. Neither overload nor underload is good for manageability. Meaningfulness is developed when the child experiences being a person of importance, a part that matters for the result. Repeated life experiences of consistency, load balance and participation in decision-making are thus deciding the strength of a person's SOC (44). A fourth important life experience was added by Shifra Sagy and Helen Antonovsky: emotional closeness; this also strengthens the component meaningfulness. Emotional closeness is the feeling of emotional bonds and belonging in the family; that you are important for the family members and that you have confidence in the knowledge that there is someone you could turn to with personal problems (48).

Rating SOC

Antonovsky developed a self-rating scale for assessing a persons' SOC, which was based on a series of interviews of people who had experienced a major trauma that they had managed remarkably well. Antonovsky asked them about their life stories and how they reflected on them. Common expressions were translated into the "orientation to life" scale. The original scale consisted of 29 items. He later developed a shorter, 13 item scale, where some of the items from the full scale were removed (44, 49).

The respondents consider different questions and statements concerning either comprehensibility, manageability or meaningfulness in the 13-item scale. Examples are: “Do you have the feeling that you are in an unfamiliar situation and don’t know what to do?” (comprehensibility), “Many people – even those with a strong character – sometimes feel like sad sacks (losers) in certain situations. How often have you felt this way in the past?” (manageability), “How often do you have the feeling that there’s little meaning in the things you do in your daily life?” (meaningfulness).

Responses to the 13 items are given on a 7-point Likert scale with statements at each end such as “very often” (1 point) or “never” (7 points). The total sum score for the SOC-13 is scale is 13-91 points. Even though each item of the scale concerns either comprehensibility, manageability or meaningfulness, the components are not to be assessed separately. The total sum score should be calculated instead, since Antonovsky claimed that the components are insolubly intertwined (44). A greater total sum score indicates a stronger SOC, but there are no cut off values indicating a strong or weak SOC, since the exact value where SOC loses the health protective effect is not known.

The SOC scale has been found valid and reliable, with Cronbach’s alpha values ranging from 0.70-0.92 for SOC-13 and 0.70-0.95 for SOC-29 (50). Factorial analyses also indicate that the scale is multidimensional, rather than unidimensional as proposed by Antonovsky (50, 51).

SOC in the general population and in people with disabilities

The mean SOC-13 score in a study of 2003 people, selected to be representative of the Swedish population, was 64 points for women and 65 points for men (52). Antonovsky meant that SOC is more or less stable after the age of 30. However, several studies suggest that SOC continues to develop and increase with age (52-54). Nilsson and co-workers found a mean SOC-13 score of 72 points in people aged 70-74 years in the general population. The participants’ ages are presented in the text below about SOC values in people with disabilities since age influences the SOC score.

Both higher and lower SOC-13 values compared to the general population have been reported in people with disabilities. People diagnosed with stroke and with a mean age of 68 years had a median SOC-13 sum score of 78 points (55). An even higher median SOC-13 value of 80 points was reported by Ekstam and co-workers in people with stroke and a median age of 73 years (56). Lower SOC-13 scores were found.in people with Parkinson’s disease. Gison and co-workers reported a mean SOC-13 score of 54 points (mean age 67 years) and Rosengren and co-workers found a mean SOC-13 score of 66 points (mean age 70 years) (57, 58). Values close to the general population were reported in people with traumatic brain injury (mean age 44 years); 63 points for those with a moderate-severe brain injury, and 66 points for those with a mild brain injury (59). A follow-up study of older people (median age 66 years at second assessment) with spinal cord injury showed that SOC increased from a median of 73 points to 77 points over 6 years (60).

No studies with an assessment of SOC in people with LEoP had been performed when I started my thesis work. Knowledge of an aspect important for the sense of living a good life was thus lacking, and there was a need for studies investigating this.

SOC and associated factors

Multiple factors have been found to be associated with SOC over time. The associations with demographics, disability related factors (self-perceived impairments, participation in life events, life satisfaction) and coping behaviours have been investigated in the studies in this thesis.

Some studies have found greater SOC scores for men than women (50, 52, 54), whereas other studies have found no difference (53, 61). Several studies have reported stronger SOC with increasing age (50, 52-54, 62). A study that reported an increased SOC over time in people with spinal cord injury found that a change from being single to having a partner significantly contributed to a positive change in the SOC score (60). Educational level shows various relationships to SOC. Some studies report a positive relationship (63-65). Other studies have reported no, or very small differences in SOC in people with different educational levels (52, 53) (66).

There was no significant relationship between SOC and impairments or medical characteristics in people with Parkinson's disease (67). SOC was associated with participation in life events in people with chronic illnesses (68). However, SOC did not significantly contribute to participation (69) in people with spinal cord injury. A strong SOC was associated with a higher life satisfaction in people with Parkinson's disease, traumatic brain injury and multiple trauma (58, 59, 70).

Studies of associations between SOC and coping behaviours show varying results. SOC has been positively associated with problem-focused coping behaviours in the general population (61), and SOC was positively associated with the emotion-focused coping behaviour acceptance in people with spinal cord injury (71). Another study of people with spinal cord injury found that both SOC and acceptance was significantly associated with less depressive symptoms (72).

There were, however, no studies that had examined SOC and associated factors in people with LEoP when I started work on this thesis. There was consequently no knowledge of this, and important information that could be used in the rehabilitation of this group of people was lacking.

The meaning of SOC

Antonovsky hoped for research that would better explicate the SOC components (73). However, studies investigating the in-depth meaning of comprehensibility, manageability and meaningfulness are difficult to find. A study investigating what it meant to live with muscular dystrophy from a salutogenic perspective found that it was important to be seen as an individual, to have informal social support and to have meaningful activities (74). To the best of my knowledge, other studies investigating the in-depth meaning of SOC (ie, the meaning of comprehensibility, manageability, and meaningfulness) in people with long-term conditions or disabilities are lacking. There is thus a need for studies exploring this concept from the perspective of the people with a lifelong disability.

Rationale

Countries all over the world have been greatly successful in combatting polio, but thousands of people in the world still live with LEoP. They have been struck by disability not once, but twice. The need to cope with the stressors of losing functions and adapting to their disability is an on-going process being as the condition is progressive. Some people with LEoP find the challenges related to their condition very demanding, whereas others are well adapted and very satisfied with their lives; they appear to have understood the core of salutogenesis in their situation. We need to understand what is important for living with LEoP from a salutogenic perspective to be able to support the people that find their situation demanding.

One way to understand life with LEoP from a salutogenic perspective is to assess and explore the concept of SOC. No studies had been performed about SOC among people in this population when I started working with my thesis, despite the large number of people living with LEoP. Consequently, an important piece of knowledge was missing for understanding the salutogenic perspective and how to live a good life despite LEoP.

Understanding the salutogenic perspective can help rehabilitation professionals in their clinical work. Personal factors are not routinely taken into account in rehabilitation but are important for the sense of living a good life. A greater understanding of the concept of SOC can be a step towards evidence-based rehabilitation interventions founded on the salutogenic perspective. This can enhance the possibility for people with LEoP to live a good life despite their disability.

Overall aim

The overarching aim of this thesis was to provide a deeper and broader understanding of living with LEoP from a salutogenic perspective.

Specific aims

The specific aims were:

- to assess SOC in people with LEoP, and to explore the association between SOC, demographics and variables related to their polio and LEoP;
- to explore the associations between SOC and disability-related factors (self-perceived impairments, participation in life events, life satisfaction) in people with LEoP;
- to assess coping behaviours and to explore the association between SOC and coping behaviours in people with LEoP;
- to explore the meaning of SOC in people with LEoP.

Overview of this thesis

My thesis comprises three quantitative studies (Studies I-III) and one qualitative study (Study IV). An overview of the four studies is presented in table 3.

Table 3. Overview of the four studies in this theses.

	SOC and associated factors			**The meaning of SOC**
	Study I	**Study II**	**Study III**	**Study IV**
Aims	To assess SOC in people with LEoP, and to explore the association between SOC, demographics and variables related to their polio and LEoP.	To assess the associations between SOC and disability related factors in people with LEoP.	To assess coping behaviours and to explore the association between SOC and coping behaviours in people with LEoP.	To explore the meaning of SOC.
Design	Quantitative Cross-sectional			Qualitative Deductive and inductive
Number of participants	93			14
Data collection	Postal survey			Semi-structured interviews
Outcome	SOC-13, questionnaire of demographics and self-rated disability	SOC-13 SIPP RNL-I SWLS	SOC-13 Brief Cope	Participants' experiences
Analyses	Bivariate analyses			Directed content analysis
	Hierarchical multiple regression		Linear regression	

SOC-13=13-item Sense of Coherence Scale; SIPP=Self-reported Impairments in People with Late Effects of Polio Scale; RNL-I=Reintegration to Normal Living Index; SWLS=Satisfaction With Life Scale; Brief Cope=Brief Cope scale.

Methods

The quantitative studies (Studies I-III) and the qualitative study (Study IV) were conducted to provide a deeper and broader understanding of living with LEoP from a salutogenic perspective. Participants, data collection and analyses will be presented under two themes of my thesis: i) SOC and associated factors (quantitative studies) and ii) the meaning of SOC (qualitative study). The questionnaire, rating-scales and the interview guide used in the studies are enclosed in the Appendix.

Participants

The participants for the studies of SOC and associated factors were chosen from people taking part in a previous study (36). The participants in The meaning of SOC were chosen from people taking part in the studies of SOC and associated factors. A flowchart of the recruiting process is presented in Figure 3, and a more thorough description of the recruiting process is provided below.

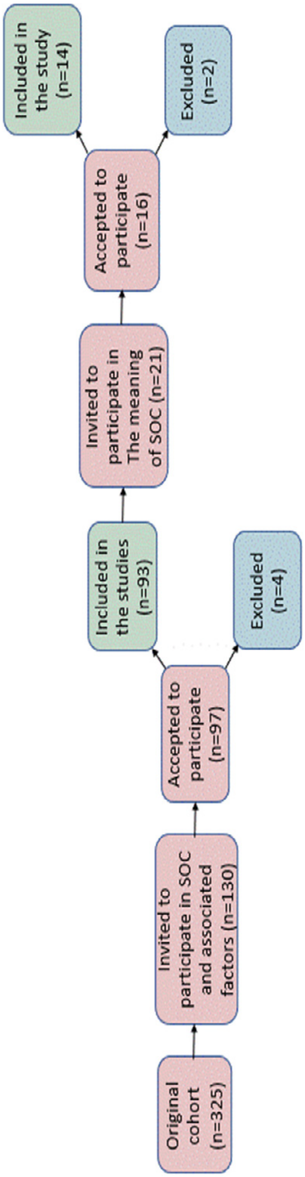


Figure 3. Flowchart of the recruiting process

SOC and associated factors (Studies I-III)

Participants were recruited from a clinical database of people with LEoP in the Department of Rehabilitation Medicine at Skåne University hospital, Lund, Sweden. They were randomly selected from a cohort of 325 people who had previously been part of a study of falls, fear of falling, self-reported impairments and walking limitations (36). All the participants had a confirmed history of acute poliomyelitis in their childhood or youth and were experiencing new symptoms after a period of stability of at least 15 years. In the verification process of prior polio, the participants had an electromyogram (EMG) conducted in all four limbs, and all had EMG findings indicative of prior polio in at least one limb.

All the participants lived in their own homes and were ambulatory and able to walk with or without mobility devices. No one was using a wheelchair as their main mode of transportation. Exclusion criteria were other major medical conditions (such as stroke or Parkinson's disease) that could influence their condition, and an inability to understand Swedish.

From the cohort, 130 people were invited to take part in the studies of SOC and associated factors. Ninety-seven (acceptance rate 75%) of these gave their written informed consent to participate. Four of them were excluded due to missing data on the Sense of Coherence 13 items scale (SOC-13). The final sample thus comprised 93 people. Data on the 93 participants are presented in Table 4.

Table 4. Characteristics of the 93 participants in the studies of SOC and associated factors.

Gender	
Men, n (%)	45 (48)
Women, n (%)	48 (52)
Age (years)	
Mean (Median, SD, range)	74 (75, 8, 41-91)
Marital status	
Single, n (%)	36 (39)
Married/cohabiting, n (%)	54 (58)
Level of education	
Primary school (≤9 years), n (%)	31 (33)
Secondary school (10-12 years), n (%)	31 (33)
Higher education (≥13 years), n (%)	29 (31)
Number of years before onset of late effects of polio	
Mean (Median, SD)	46 (45, 9)
Self-rated disability	
Mild, n (%)	18 (19)
Moderate, n (%)	54 (58)
Severe, n (%)	20 (22)

The meaning of SOC (Study IV)

Participants for the study of the meaning of SOC were recruited from the 93 people taking part in the studies of SOC and associated factors. We aimed to attain an equal gender distribution and an age-range that covers most people with LEoP in the western world. Moreover, we wanted to include participants who were both single and married/cohabitating and people of different educational background, in order to provide a rich source of experiences. Exclusion criteria were inability to take part in an interview and having a clinically verified depression. A total of 21 potential participants were invited to take part, 16 of these gave their written informed consent to participate. Two people were excluded; one due to a hearing loss and a clinical depression, and the other due to a very late response when interviews were already completed. The final sample thus comprised 14 people. Data on the 14 participants are presented in Table 5.

Table 5. Characteristics of the 14 participants in the study of the meaning of SOC.

Gender	
Men, n (%)	7 (50)
Women, n (%)	7 (50)
Age (years)	
Mean (Median, SD, range)	73 (74, 5, 65-84)
Marital status	
Single, n (%)	2 (14)
Married/cohabiting, n (%)	12 (86)
Level of education	
Primary school (≤9 years), n (%)	0 (0)
Secondary school (10-12 years), n (%)	8 (57)
Higher education (≥13 years), n (%)	6 (43)

Data collection

SOC and associated factors (Studies I-III)

Procedure

Each potential participant received an invitation letter with information about the studies of SOC and associated factors. A questionnaire concerning demographics (gender, age, marital status and educational level), a self-rating scale about disability level (mild, moderate or severe), the rating scales of associated factors and the informed consent form were included in the letter. The questionnaire, rating scales and informed consent form were returned within two months in a prepaid envelope.

Rating scales

The Swedish versions of rating scales measuring different aspects of the ICF were used to assess SOC and associated factors in people with LEoP. The rating scales are enclosed in Appendix. We used the following rating scales:

- Sense of Coherence scale (SOC-13)

The shorter 13-item form of the Sense of Coherence scale developed by Antonovsky was used (44). The total sum score ranges from 13 to 91 points, where higher values are in accordance with a stronger SOC. For a further description of the SOC-13 scale, see Rating SOC.

- Self-reported Impairments in People with Late Effects of Polio Scale (SIPP)

The SIPP scale was developed to describe self-rated impairments, as defined by the ICF, in people with LEoP. It is a 13-item scale, measuring the degree the participant has been bothered by various impairments the past 14 days, directly or indirectly related to their LEoP. Response options range from 1 (not at all) to 4 (extremely). The total sum score ranges from 13 to 52 points; higher sum scores means that the person is more bothered by their impairments. The SIPP scale has been Rasch analysed and is unidimensional (29). It has also been examined for test-retest reliability and has an intraclass correlation coefficient of 0.88 (75).

- Reintegration to Normal Living Index (RNL-I)

The RNL-I measures self-perceived activity limitations and participation restrictions after incapacitating illness or trauma (76). It has been found to adequately assess participation according to the ICF (77). The RNL-I consists of 11 items; the first eight assess Daily Functioning and the last three assess Perceptions of Self. Daily Functioning covers activities and participation in everyday life, while Perceptions of Self covers aspects such as comfort with self and personal relationships (76). The respondent considers statements like “I move around in my community as I feel necessary”. Answers are given on a 4-point Likert scale, where 1 point means “Does not describe my situation” and 4 points means “Fully describes my situation”. The total score is 8-32 points for Daily Functioning and 3-12 points for Perceptions of Self, and the sum score for the entire scale is 11 to 44 points; higher values mean better reintegration. The RNL-I is valid and reliable with a Cronbach’s α of 0.73-0.97 (78, 79).

- Satisfaction With Life Scale (SWLS)

The SWLS rates a person’s subjective perception of satisfaction with his or her life situation. The scale consists of 5 items covering aspects such as the perception of having an ideal life and having achieved goals. Responses are given on a 7-point Likert scale anchored to the statements “Strongly disagree” (1 point) to “Strongly agree” (7 points). The total sum score is 5 to 35 points, where higher scores mean greater life satisfaction. The SWLS has a Cronbach’s α value exceeding 0.80 (80).

- The Brief Cope scale

The Brief Cope scale consists of 28 statements where the respondent considers how he or she normally reacts in stressful situations. The scale covers 14 coping behaviours and each behaviour is represented by two items in the scale. Responses range from “Very seldom” (1 point) to “Very often” (4 points). The higher the score a person has on a coping behaviour, the more he or she is using that behaviour (81). The scale can also be divided into three broader coping categories: problem-focused coping, emotion-focused coping and less useful coping, where several coping behaviours belong to each category (82). The coping behaviours are often used separately to investigate associations with other variables being as the scale is multidimensional and there is no total sum score for the whole scale. The coping behaviours in the Brief Cope scale have acceptable Cronbach’s α levels of 0.50-0.90 (81).

The meaning of SOC (Study IV)

Procedure

All the potential participants were sent a letter with information about the study of the meaning of SOC and an informed consent form. The people who volunteered to participate returned their written informed consent in a prepaid envelope. The participants were then contacted by phone and a time and place for the interviews were decided. Eight interviews were performed face-to-face, and six interviews were performed digitally. The face-to-face interviews took place in the participants’ homes (n=7) or at the location of the research team (n=1). All the interviews were performed individually, except for one interview where the spouse was present but without interacting. I was convinced that the relevant results could be identified after the 14th interview, and that they seemed consistent. The data collection was thus terminated.

Interviews

Semi-structured interviews were used to collect data about the meaning of SOC. An interview guide was developed based on the categories of SOC, i.e., comprehensibility, manageability and meaningfulness. The interview guide is enclosed in Appendix. The interview guide comprised open-ended questions exploring the meaning of SOC for the interviewees, such as: “What gives you meaning in your everyday life?”. Follow-up questions were asked if needed, such as: “Could you give examples…”. The interviews lasted 10 to 56 minutes (average

31 minutes). The interviews were recorded and transcribed verbatim, and they were checked against the audio files to be sure of the accuracy of the transcripts.

Analyses

A quantitative approach was used for the studies of SOC and associated factors and a qualitative approach for the study of the meaning of SOC.

SOC and associated factors (Studies I-III)

Means, medians, standard deviations and minimum and maximum values were used for the descriptive statistics.

T-tests, Mann-Whitney U-tests and Chi square tests were performed to examine differences between people who chose to participate in the studies and those who declined (83).

The Spearman rank correlation coefficient (Spearman's rho) was used to assess bivariate relationships between SOC and the other variables, as well as between the variables used in the regression analyses.

Hierarchical and linear regression analyses were performed to explore how SOC was associated with the other factors, with SOC as the dependent variable. The regression analyses met the criterion of having at least 10 participants per variable. Moreover, no multicollinearity was found since none of the variables had a Variance Inflation Factor (VIF) above 2.0 or tolerance below 0.2, and the highest bivariate correlation was below 0.6 (84, 85). There were no residual outliers in the models except for one in the model with Emotion focused coping. This outlier, however, had very little influence on the model since the maximum Cooks distance was far below 1 (85).

All the analyses were performed using the IBM SPSS statistics version 22 (86). Significance levels below 0.05 were considered statistically significant.

The meaning of SOC (Study IV)

A directed content analysis was performed to explore the meaning of SOC (87). This analysis was chosen since we wanted to add further knowledge to an existing concept (SOC). The analysis was carried out in the following steps:

1. Obtaining a naïve understanding by reading all interviews.
2. Identifying text units involving comprehensibility, manageability and meaningfulness and copying these text units into an individual matrix sheet for each of the SOC categories.
3. Analysing and interpreting the text units and condensing the meaning units into codes.
4. Sorting the codes into subcategories, covering the meaning of comprehensibility, manageability and meaningfulness.
5. Identification of two over-arching themes.

The interpretation of the data in qualitative research can always be influenced by the interpreter's pre-understanding. All the authors had access to the full transcripts of the interviews, and all findings and interpretations were discussed by the authors during the process to achieve an objective interpretation as possible.

Ethical considerations and reflections

The declaration of Helsinki (88) is a development of the Nuremberg code. This was declared in 1947 after the Nuremberg trials, where doctors were held accountable for conducting unethical medical human experiments during the Second World War. The declaration of Helsinki was first declared in 1964, and has since then undergone several revisions. The latest version covers 37 paragraphs in order to protect people when participating in medical research. The fundamental principle is that “The health of my patient will be my first consideration”. This means, among other things, that the study must be approved by an ethical committee, that the person has interest in the research conducted, and that the person must give an informed consent to take part in the research. Research must also be conducted with precautions concerning the limitation of potential harm to the research person.

We followed the principles of the declaration of Helsinki in my thesis. All four studies were approved by the Regional Ethical Review Board in Lund, Sweden (Studies I-III: Dnr 2016/134) and the Swedish Ethical Review authority (Study IV: Dnr 2021-01217). The people involved were those who would benefit from research progress in the area, i.e., they have interest, themselves, that the research is conducted. All the participants gave their written informed consent to take part before they were included in the studies. Several precautions were also taken to limit any potential harm to the participants.

The participants’ involvement in the studies of SOC and associated factors consisted of completing and returning a questionnaire about demographics and several rating scales. We used the short forms of the rating scales in order for the participants to avoid experiencing the task as being too burdensome. The studies involved no other discomfort for the participants.

The study of the meaning of SOC was performed with semi-structured interviews. The participants chose a time and place for the interview, and they also had the possibility to meet digitally. The participants were allowed to finish what they were saying, before another question was asked, and they were also allowed to diverge from the subject without interruption. Speaking about their situation might evoke feelings of sadness or anger. One participant became very sad when talking about their childhood polio experience and was thus given time to talk about it as long as the person needed. Moreover, the interviews might evoke new thoughts or questions for the participants. Before leaving, they were encouraged to make contact if they had any questions or further thoughts that evolved after the interview. One participant took contact via email and was answered promptly. The two people who wanted to participate but were excluded were also paid attention to. One person was excluded due to a hearing loss and a clinical depression. I spoke to the person concerned by telephone and verified that the person had a clinical contact for the depression. One person was excluded due to a very late response when the interviews were already performed. The person was thanked for wanting to take part and was told that the interviews were already completed.

Being part of research can generate several positive aspects for the participants. It can give a positive feeling of helping with the research progress, and in the longer run improving clinical care. This can give a positive sense of being part of something that is beneficial for many people with LEoP. I believe that many people in my studies experienced these positive feelings. Some participants added messages where they thanked us for doing the studies when returning the questionnaire and rating scales. Moreover, it should be a positive feeling knowing that their condition is not “forgotten”. Several participants in the interviews expressed an opinion that many clinicians lack knowledge about LEoP and that more knowledge is needed, and satisfaction that research was being carried out.

My overall ethical summary of my project is that the people were not harmed, and that some of them experienced a positive feeling of helping in making progress in the research area of LEoP.

Results

SOC and associated factors (Studies I-III)

Descriptive findings

Of the 93 participants, 48 were women (52%). The mean age was 74 years (median 75, SD 8, range 41-91). A majority (54 people, 58%) were married or cohabitating. Their highest educational level was distributed equally between primary school (31 people, 33%), secondary school (31 people, 33%) and higher education (29 people, 31%).

Data on the descriptive findings of the rating scales are presented in Table 6. The mean SOC-13 score was 72 points (SD 14.5), median value was 76 points. The mean SIPP score was 28 points (SD 7.7). The mean RNL-I score was 25 points (SD 6.4) for the subscale Daily functioning and 10 points (SD 2.0) for the subscale Perceptions of Self. The mean SWLS score was 24 points (SD 6.9).

Table 6. Summary of the rating-scales. Higher scores indicate a stronger SOC (SOC-13), more bothered by symptoms of LEoP (SIPP), better reintegration (Daily functioning, Perceptions of Self) and higher life satisfaction (SWLS). Numbers in brackets represent number of complete questionnaires.

	Range	Mean	Median	SD	Min	Max
SOC-13 (93)	13-91	71.8	76	14.5	26	90
SIPP (87)	13-52	28.2	27	7.7	14	47
Daily functioning (90)	8-32	24.8	26	6.4	9	32
Perceptions of Self (93)	3-12	10.1	10	2.0	5	12
SWLS (92)	5-35	24.7	26	6.9	5	35

The most used coping behaviours were acceptance, active coping, planning and positive reframing, belonging to the broader categories of problem-focused coping and emotion-focused coping. The least used coping behaviours were substance use, behavioural disengagement, religion and denial, belonging to the broader categories of less useful coping and emotion-focused coping. Descriptive findings of the ratings on the subscales in the Brief Cope scale are presented in Table 7.

Table 7. Summary of the ratings on the Brief Cope scale. Higher scores indicate more usage of the coping behaviour.

	Range	Mean	SD	Median	Min	Max
Problem focused coping						
Active coping	2-8	5.8	1.6	6	2	8
Instrumental support	2-8	4.7	1.6	5	2	8
Planning	2-8	5.7	1.7	6	2	8
Emotion focused coping						
Acceptance	2-8	5.9	1.5	6	2	8
Religion	2-8	3.3	2.0	2	2	8
Humor	2-8	4.3	1.7	4	2	8
Emotional support	2-8	4.9	1.8	5	2	8
Positive reframing	2-8	5.4	1.4	6	2	8
Denial	2-8	3.4	1.5	3	2	8
Less useful coping						
Mental disengagement	2-8	3.9	1.4	4	2	7
Substance use	2-8	2.3	0.7	2	2	6
Venting of emotions	2-8	4.4	1.6	4	2	8
Self-blame	2-8	4.6	1.7	4	2	8
Behavioral disengagement	2-8	3.0	1.2	3	2	6

Associations

The results of the bivariate analyses are presented in Table 8. Higher SOC scores were significantly associated with being married/cohabitating (rho 0.26, $p<0.05$), having a higher education (rho 0.25, $p<0.05$) and more years before onset of LEoP (rho 0.32, $p<0.01$) in the bivariate analyses. There was no significant relationship between SOC and gender or age. Rating a more severe disability level (rho -0.34, $p<0.01$), as well as being more bothered by symptoms of LEoP (rho -0.54, $p<0.01$) was associated to lower SOC scores. Both sub-scales of the RNL-I were significantly and positively associated to SOC in bivariate analyses (Daily functioning; rho 0.43, $p<0.01$, Perceptions of Self; rho 0.64, $p<0.01$); better reintegration was associated with higher SOC scores. Life satisfaction, measured with the SWLS, was also associated with higher SOC-scores (rho 0.67, $p<0.01$).

Table 8. Bivariate associations analyzed with the Spearman rank correlation coefficient (Spearmans rho). Correlation is significant at the 0.05 level (*) and at the 0.01 level (**).

	Gender (female)	**Age**	**Marital status**	**Level of education**	**Years before onset of LEoP**	**Self-rated disability**	**SIPP**	**Daily functioning**	**Perceptions of Self**	**SWLS**
SOC-13	–0.05	0.15	0.26*	0.25*	0.32**	–0.34**	-0.54**	0.43**	0.64**	0.67**

The bivariate relations between SOC, coping categories (bold text) and coping-behaviours are presented in Table 9. SOC scores were significantly associated with the Less useful coping category (rho -0.59, p<0.001), and with the coping behaviours denial (rho -0.34, p<0.001), self-distraction (rho -0.38, p<0.001), self-blame (rho -0.46, p<0.001) and behavioural disengagement (rho -0.51, p<0.001). There was no significant positive association between SOC and any coping behaviour.

Table 9. Bivariate correlations analyzed with the Spearman rank correlation coefficient (Spearmans rho). Correlation is significant at the 0.001 level (***).

Problem focused coping	0.17
Active coping	0.11
Instrumental support	0.05
Planning	0.19
Emotion focused coping	-0.18
Acceptance	-0.05
Religion	-0.16
Humor	-0.11
Emotional support	0.08
Positive reframing	0.11
Denial	-0.34***
Less useful coping	-0.59***
Self-distraction	-0.38***
Substance use	-0.15
Venting	-0.17
Self-blame	-0.46***
Behavioral disengagement	-0.51***

The final models of the multivariate regression analyses showed that:

i) being married/cohabitating, having a higher education, having experienced more years before onset of LEoP and perceiving a mild or moderate disability contributed to higher SOC scores. The final model explained 37% (R2 adj 0.37, p < 0.001) of the variance in SOC.

ii) higher age, less bothered by impairments due to LEoP, better Perceptions of Self and higher life satisfaction contributed to higher SOC scores. The final model explained 60% (R2 adj = 0.60, P < 0.001) of the variance in SOC.

iii) less useful coping contributed to lower SOC scores. The model explained 34% (R2 adj 0.34, p<0.001) of the variance in SOC.

The results from the analyses are presented in Tables 10-12.

Table 10. Results of the hierarchical multiple regression analysis with SOC-13 as dependent varable. Standardised beta coefficients are presented.

	SOC-13			
Gender (female)	–0.12	–0.09	–0.04	–0.05
Age	0.17	0.27**	0.18	0.22
Being married/cohabitating		0.36***	0.40***	0.30**
Level of education[1]				
Secondary school		0.28*	0.25*	0.19
Higher education		0.31**	0.30**	0.28**
Age at acute poliomyelitis infection			–0.01	–0.09
Number of years before onset of late effects of polio			0.30**	0.30**
Self-rated disability[2]				
Moderate				0.35**
Mild				0.37**
Significance	0.14	<0.001	<0.001	<0.001
R2 Adj	0.02	0.22	0.29	0.37
R2 change	0.05	0.22	0.08	0.09
F-ratio	2.05	5.86	5.89	6.45
F change	2.05	8.05	4.62	5.84
Sig F change	0.14	0.00	0.01	0.00

[1] Level of education was transformed to dummy variables with primary school as the reference category. [2] Self-rated disability was transformed to dummy variables with severe disability as the reference category.

Correlation is significant at the 0.05 level (*), at the 0.01 level (**) and at the 0.001 level (***)

Table 11. Results of the hierarchical regression analysis with SOC-13 as dependent variable. Standardised beta coefficients are presented.

	SOC-13			
Gender (female)	-0.06	-0.07	-0.07	-0.05
Age	0.23*	0.30**	0.28**	0.20*
SIPP		-0.54***	-0.30**	-0.18*
Daily functioning			0.11	0.10
Perceptions of Self			0.44***	0.23*
SWLS				0.41***
Significance	0.10	<0.001	<0.001	<0.001
R2 Adj	0.03	0.32	0.51	0.60
R2 change	0.06	0.28	0.20	0.08
F-ratio	2.39	13.48	18.09	20.93
F change	2.39	33.66	16.81	16.60
Sig F change	0.10	0.00	0.00	0.00

Correlation is significant at the 0.05 level (*), at the 0.01 level (**) and at the 0.001 level (***)

Table 12. Result of the three individual linear regression (model 1; Problem focused coping, model 2; Emotion focused coping, model 3; Less useful coping) with SOC-13 as the dependent variable. Standardised beta coefficients are presented.

	SOC-13		
	Model 1	Model 2	Model 3
Gender (female)	-0.09	-0.04	0.13
Age	0.22	0.23	0.18
Problem focused coping[1]	0.18		
Emotion focused coping[2]		-0.14	
Less useful coping[3]			-0.59***
Significance	0.09	0.08	0.00
R2 Adj	0.04	0.05	0.34
R2 change	0.08	0.09	0.36
F-ratio	2.26	2.31	15.48

Correlation is significant at the 0.001 level (***)

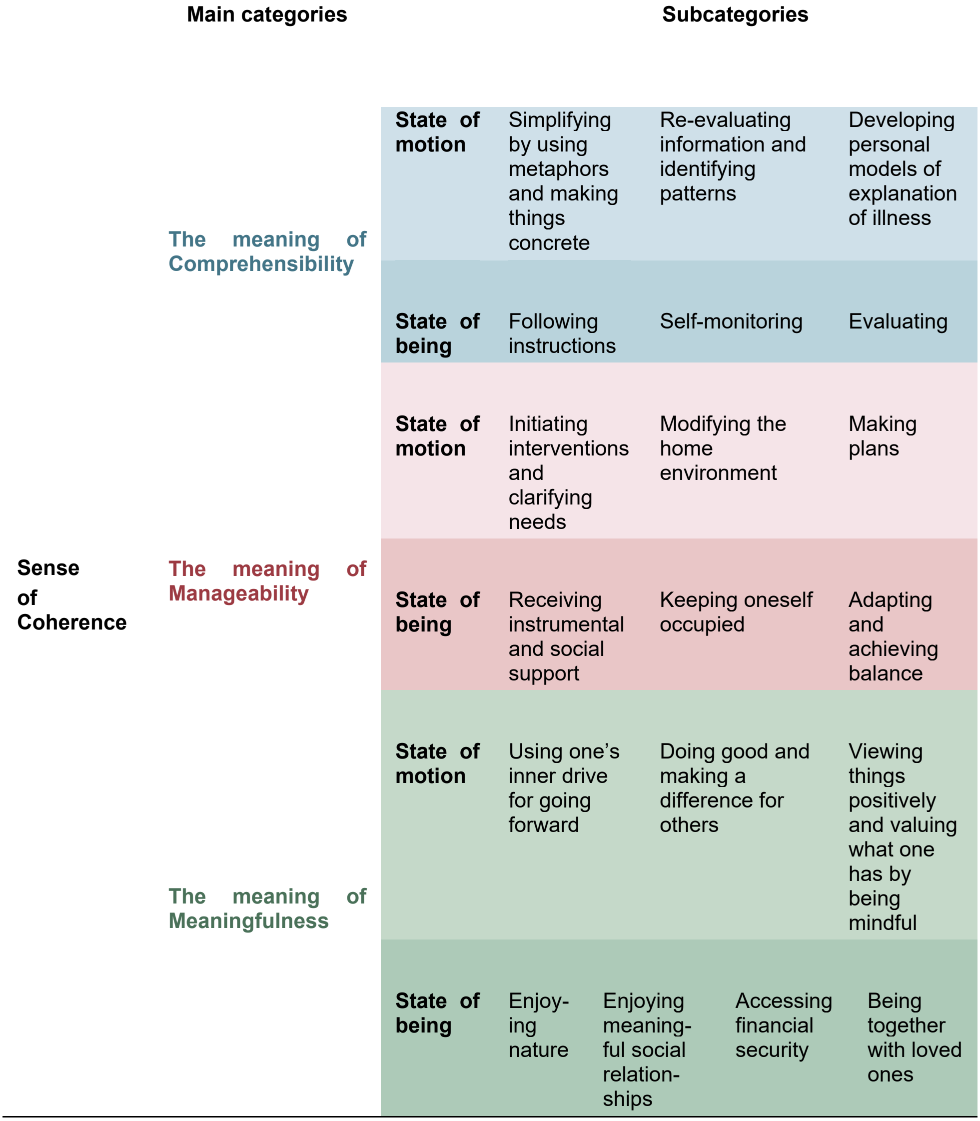
The meaning of SOC (Study IV)

Characteristics of the participants

Men and women were equally represented among the 14 participants. The mean age was 73 years (SD 5, range 65-84). Most were married or cohabitating (12 people, 86%). All had an education level of secondary school (8 people, 57%) or higher education (6 people, 43%).

The meaning of SOC

Each main category of SOC (comprehensibility, manageability and meaningfulness) contained common themes that were condensed into codes (step 3 in the analysis) and sorted into subcategories (step 4 in the analysis), covering the meaning of comprehensibility, manageability and meaningfulness. An overview of the findings is presented in Figure 4.



Main categories			Subcategories			
Sense of Coherence	**The meaning of Comprehensibility**	**State of motion**	Simplifying by using metaphors and making things concrete	Re-evaluating information and identifying patterns	Developing personal models of explanation of illness	
		State of being	Following instructions	Self-monitoring	Evaluating	
	The meaning of Manageability	**State of motion**	Initiating interventions and clarifying needs	Modifying the home environment	Making plans	
		State of being	Receiving instrumental and social support	Keeping oneself occupied	Adapting and achieving balance	
	The meaning of Meaningfulness	**State of motion**	Using one's inner drive for going forward	Doing good and making a difference for others	Viewing things positively and valuing what one has by being mindful	
		State of being	Enjoying nature	Enjoying meaningful social relationships	Accessing financial security	Being together with loved ones

Figur 4. An overview of the meaning of SOC in people with LEoP. Each main category of SOC (comprehensibility, manageability and meaningfulness) exists in a *state of motion* and a *state of being*. Subcategories covering the meaning of comprehensibility, manageability and meaningfulness are presented next to the states of motion and being in each main category.

The states of motion and being

Two overarching themes were revealed in the analysis (step 5): SOC among people with LEoP existed in a *state of motion* and in a *state of being*, visible in all three categories of SOC.

The state of motion was a process aiming to attain stronger comprehensibility, manageability and meaningfulness, and the state of being was the comprehensibility, manageability and meaningfulness that the people currently experienced.

Interaction between main categories, the states of motion and being and the subcategories

The main categories, the states of motion and being and the subcategories were closely intertwined. The subcategories could show elements of comprehensibility, manageability and meaningfulness (the three main categories), although belonging predominately to one main category of SOC. For example, one subcategory in manageability was **keeping oneself occupied.** This was placed into manageability, because having something to do was a way to manage daily life. However, some hobbies were undertaken through a genuine interest and were giving meaning, so the subcategory does also cover aspects of meaningfulness.

One person was engaged in voluntary work, which both increased manageability by keeping the person occupied, and meaningfulness by the feeling of doing good for others:

> *"...started to do volontary work at Erikshjälpen and help out... I think it's both important and pleasant at the same time" (P5)*

Moreover, each subcategory could have elements of both motion and being. For example, **adapting and achieving balance** was placed in the state of being, since that was a common way to manage everyday life with LEoP and part of the participants daily routines. However, there was also a motion in this category towards better manageability and also a trace of meaningfulness, since adapting and achieving balance could mean that you preserved energy and were thus able to do things you otherwise would not be able to. One common way of balancing was taking breaks during the activity:

> *"I can work for a while, sometimes I get a bit hot when I do it.... And when I have rested for a while, I can carry on" (P4)*

Furthermore, there were close interactions between subcategories. For example, **Receiving instrumental and social support** was placed in manageability, since support was a common way to manage daily life. One person described the support received from grandchildren like this:

> *“They help and support me when I need help and see that something needs to be carried in or out, for example. There is immediately someone who takes care of it. So, I get assistance with things they know I find difficult.” (P2)*

However, the other side of the coin is to *give support*, which is part of the subcategory **Doing good and making a difference for others**, which was increasing the participants’ sense of meaningfulness. This can be illustrated by a citation from the same person cited above:

> *”We are helping out by crocheting tiny dolls or animals that we give to the children’s hospital or to the ambulance service. They are for the children. I have made a lot of them.”* (P2)

The distinctions were thus not clear cut and the main categories, the states of motion and being and the subcategories were closely intertwined.

Barriers for SOC

Barriers for comprehensibility and manageability were identified. The identified barriers in comprehensibility were **uncertainty regarding where to turn for assistance for their LEoP**, and **uncertainty regarding the right amount of physical activity** in order to avoid either being inactive or risking overload. One person expressed the uncertainty of not knowing where to turn like this:

> *”Where do I turn? I haven´t received any information about that.... I know where to turn for the (orthopedic) shoes, I’ve got their phone number. But otherwise, I don´t know…” (P11)*

A barrier to manageability was **experiencing rigid bureaucracy**.

> *“I wish there were less bureaucracy… When I wanted to visit my daughter, I suggested that I could drive to (her hometown) and the stair climber could meet me there. But that was impossible… I had to go from (participant’s hometown) with the transportation service... And I mean, it would have been a saving for everyone if I could use my own car.” (P9)*

Another barrier for manageability was **not being allowed to define your own needs**, ie; when health care staff determined the type of aid/assistance required, or that no aid/assistance was needed.

Barriers for meaningfulness were not identified in the present study, but many participants expressed worries that a further decline in their health would threaten meaningful activities.

Discussion

Salutogenesis is a core feature of living a good life despite having a disability. This is a concept that has been of great interest since Antonovsky developed his salutogenic model. However, the model and the concept salutogenesis are still not completely understood.

I had encountered people with LEoP in my clinical work and had found that many of them appeared to be very content with their lives. In essence, they understood the core of salutogenesis in their situation, while others were less satisfied and needed support to live a good life.

I wanted to investigate in my thesis what is important for salutogenesis in people with LEoP. The findings from the four studies will be discussed in chronological order, followed by a salutogenic approach in rehabilitation and methodological considerations.

SOC and associated factors

Sense of Coherence in people with Late Effects of Polio (Study I)

When I started working on this thesis there was no knowledge at all about SOC in people with LEoP. The first step was thus to gain a basic knowledge of SOC in this population in terms of their general level of SOC, and an investigation of SOC in relation to gender, age, marital status and educational level. Moreover, since people with LEoP have various degrees of disabilities, and this could potentially be related to SOC, I thus included self-rated disability and number of years prior to onset of LEoP in the analyses.

The level of SOC

The level of SOC was generally as high, or even higher, as SOC in people in the general population and of the same age. However, there was a great variability, indicating that some people may need support in understanding, managing and finding meaning in their situation.

The high level of SOC in people with LEoP could have several explanations. Although the condition is progressive, the progression is very slow, which could give the person a greater sense of control and might not be as threatening as conditions with a more rapid progression. The level of SOC was similar to that found in people with stroke (55, 56) and spinal cord injury (60), both being stable conditions, and higher in comparison to people with Parkinson's disease (57, 58), which usually has a faster progression. Moreover, LEoP does not primarily affect the brain, which might contribute to higher SOC scores. Lower SOC scores have been found in people with traumatic brain injury (59).

The high scores for people with LEoP might also partly be explained by their childhood polio experience and that they have learnt from an early age to overcome difficulties. Adaptation is not new to them, which might generate a sense of acceptance and control of the new disabilities.

Another explanation might be a social comparison (89). When they were children, they compared themselves to healthy counterparts who could take part in school gymnastics and be very physically active (Picture 4). In older age, people without LEoP might have other health issues, and many of them also use walking devices such as rollators. Those with LEoP might thus feel that they are closer to being the "normal" person now, compared to when they were children.

Picture 4. "Wonder why my parents didn´t give me Salk shots". Picture: Tom Little, 1956. Britannica Image Quest.

Finally, all the people in the studies had at some point taken part in rehabilitation, where they could have learnt skills and ways for managing their disability, which could also contribute to higher SOC scores.

Gender

Gender was not associated with the level of SOC in people with LEoP, which is in accordance with other studies where no gender differences were reported (53, 61). However, some studies found slightly higher SOC scores for men (50, 52, 54). One study found a higher SOC score for men aged 60 to 70 years, but no differences in other age groups (62). The gender differences found in these studies were small – only 1-2 points – and it is questionable whether such small differences have any practical relevance. Given the non-existing or small differences it appears as if gender itself is not important for SOC. However, if gender leads to different stressors, expectations and possibilities in daily life, and the individual perceives these as important, one cannot exclude an influence on SOC.

Age

Age was not associated with SOC in this study, although SOC is generally found to be higher with increasing age (50, 52-54, 62). In general, it may be that daily life when older and retired becomes more manageable with grown-up children and a decreased workload, which might strengthen SOC. Indeed, there are studies where it is suggested that increased manageability promotes a stronger SOC (90, 91). Moreover, older people gain more experiences from their lifetime, and these experiences could help them to learn how to cope with issues in life and to prioritize what gives them value. The reason why a difference was not found in this study may be due to the vast majority of the participants being older.

Being married/cohabitating

Being married or cohabitating contributed to higher SOC scores. This is not surprising, since having a partner means that you are not alone, and that you have someone to share the joys and hassles of everyday life with. Furthermore, the financial situation might be better for people in shared households, thus providing opportunities for, for example, purchasing some services not provided by society.

The result in this study is also in agreement with several studies reporting that having close relationships and social support are associated with a strong SOC (52, 53, 64-66, 92, 93). A longitudinal study of people with spinal cord injury reported that a change in marital status from single to having a partner was the only explanatory factor for a positive change in SOC (60).

One can imagine, that having a partner helps to make one’s life situation more manageable, as you can easily get support in daily life. Furthermore, having close relationships means that you also give support and are needed by someone, which might enhance meaningfulness. According to Antonovsky, the fact that you are needed by someone is indeed of great importance for meaningfulness.

Level of education

Having an educational level higher than primary school was associated with a stronger SOC. There are other studies finding a positive association with higher education (63-65), but also studies reporting no, or very small differences (52, 53, 66).

The differing results could suggest that education itself is not important for SOC. However, the higher level of social status and the financial benefits that often go with higher education might be important. This is in agreement with Antonovsky's statement, that having a role in society that is socially valued is important for SOC. Moreover, having a good economy is a GRR, since it gives safety and better opportunities to do what you want and the ability to pay for assistance not obtained from society etc.

Perception of disability

Perceiving one's disability as mild or moderate was associated with higher SOC scores. Moreover, the number of years prior to the onset of LEoP, was of importance; more years before the onset of LEoP contributed to a higher SOC. A more detailed account of disability and the association with SOC will be discussed related to the findings in Study II.

Summary of Study I and progression to Study II

The first study showed that people with LEoP generally had a strong SOC. There was no difference between men and women, and no significant association with age. Contributing factors to higher SOC-scores were being married/cohabiting and having an education level above primary school. Moreover, perceiving the disability as mild or moderate and having more years prior to the onset of LEoP contributed to higher SOC-scores. Accordingly, it seemed as if factors related to the persons' disability were of importance. This was further investigated in the second study of my thesis.

Sense of Coherence and the Association with Socio-demographics and Disability Related Factors in People with Late Effects of Polio (Study II)

The aim of this study was to further investigate SOC in relation to disability-related factors. I used the SIPP scale, assessing self-perceived symptoms of LEoP. The RNL-I was also used, which can be divided into two sub-scales: ”Daily functioning”, assessing activities and participation in daily life, and ”Perceptions of

Self", assessing comfort with self. Furthermore, the variable life satisfaction was added and rated with the SWLS, which is a commonly used self-report scale.

Self-rated disability

The SIPP scale, assessing self-reported impairments, contributed negatively to SOC, i.e. perceiving more symptoms of LEoP was associated with lower SOC scores. This concurs with several studies (47, 52, 53), reporting that a strong SOC is associated with perceived good health. However, the association with objective health parameters is weaker. SOC was not correlated with impairments or medical characteristics in a study of people with Parkinson's disease (67). Another study (53) found no difference in people with no disease and people with an identified disease (such as stroke or myocardial infarction).

Why is there a difference in the association between SOC and subjective and objective health or disability? Perhaps the life situation as a whole is more important for SOC than the actual disability. If you have a social network, sufficient support and positive attitudes from society, the disability itself may not be seen as negative for the individual. Moreover, when using perceived symptoms as a parameter, one must keep in mind that different people could rate the same symptoms very differently. SOC is associated with positive aspects such as self-esteem and optimism (47), and people who possess these traits might not be as bothered by different symptoms of LEoP as people with low self-esteem and a more pessimistic attitude.

Activity limitations and participation restrictions

The RNL-I is used to assess both self-perceived as well as objective indicators of physical, psychological and social capabilities (76). The sub-scale "Daily functioning", which focuses on activity and participation in daily life, was not associated with SOC in people with LEoP. This is in agreement with a study of people with spinal cord injury (69), where it was reported that SOC did not contribute to the total sum score of RNL-I. However, contradicting results have also been presented. Virues-Ortega and colleagues found that SOC could protect against disability and dependence in elderly people in Spain, assessed as having difficulties in activities and participation (94). Another study (68) found synchronous effects between SOC and body function, activity and participation, i.e. SOC enhances participation, and participation enhances SOC. Furthermore, participation has been related to life satisfaction in people with LeoP (95) which in turn, is strongly related to SOC (see below). The findings are thus somewhat contradicting, and there is a need to clarify the relationship between participation and SOC in further studies.

The RNL-I sub-scale "Perceptions of Self" was significantly associated with a strong SOC. According to my knowledge, the subscale "Perceptions of Self" has not previously been investigated in relation to SOC, making comparisons difficult. However, as positive aspects such as comfort with self are focused on in the subscale, the result is in line with studies reporting strong associations with positive characteristics, such as self-esteem (47). Moreover, when considering the three items of this sub-scale, in addition to comfort with self, comfort in personal relationships and confidence in being able to deal with things are assessed. Personal relationships appear to be important for SOC as previously mentioned (see discussion Study I). Moreover, confidence in being able to deal with things is almost the exact definition of manageability. Face validity alone thus supports the positive association between this sub-scale and SOC.

Life satisfaction

SOC was strongly related to life satisfaction in this study, people with a strong SOC also rated a high life satisfaction. This is in agreement with other studies reporting a similar relationship (58, 59) (70, 96). The strong association with SOC suggests that if you can understand, manage and find meaning in your situation, you will be satisfied with your life as a whole.

Summary of Study II and progression to Study III

The second study in my thesis showed that subjective disability, assessed with the SIPP scale, was associated with lower SOC scores, whereas more objective disability, assessed with the subscale “Daily functioning” of the RNL-I, was not associated with SOC. The subscale “Perceptions of Self” of the RNL-I, as well as life satisfaction, were associated with higher SOC scores.

One interpretation of this, is that psychological characteristics could be more important for SOC in people with LEoP than the actual disability. One concept within psychology and rehabilitation that is often mentioned together with SOC is “coping”. An investigation of how coping relates to SOC in people with LEoP was performed in the third study of my thesis.

Sense of coherence and coping behaviours in people with late effects of polio (Study III)

The associations between SOC and the three broader coping categories of problem focused, emotion focused and less useful coping were assessed in order to find out how coping relates to SOC in people with LEoP.

Problem focused and emotion focused coping

Neither problem focused nor emotion focused coping had any association with SOC in the people with LEoP. This is in line with Antonovsky’s statement that SOC is not associated with any specific coping behaviour. Instead, people with a strong

SOC have a wide resource of different coping behaviours and are able to choose the most appropriate behaviour from this resource depending on the situation (44). Being able to be flexible in the choice of coping behaviours has been described as important when ageing with LEoP (14, 15, 97). It is likely that the people in this study have this flexibility which is reflected in the result, i.e. SOC is not significantly associated to any specific useful behaviours, but the people with a strong SOC use them all and are able to choose the most constructive behaviour for the situation.

The use of problem focused coping has been found to be positively associated with SOC in the general population (61). Another study of people with spinal cord injury (71) found a strong association with the emotion focused behaviour acceptance. This could be seen as contradicting Antonovsky's statement, and also the result of this study. However, there might not be a contradiction since this might instead reflect the most appropriate behaviour for the situation. People in the general population might have a better chance of solving the situation, problem focused coping is thus adaptive. The situation might more often have to be endured in people with spinal cord injury, acceptance is thus adaptive. One could argue that people with LEoP also have disabilities as people with spinal cord injury have and thus also have to endure their situation. This is true, and a positive association with acceptance would not have been surprising.

Less useful coping

People with LEoP with lower values of SOC more often used less useful coping behaviours, i.e. behaviours that are seen as destructive and could worsen the situation if used for longer periods. This relationship has also been found in other populations. People with a strong SOC with Parkinson's disease (67) did not use depressive coping nor dissimulation and wishful thinking. Nahlen and colleagues found that SOC was negatively associated with the venting of emotions and self-blame in people with chronic heart failure (98). SOC was negatively associated with coping styles such as daydreaming, expecting the worse, and blaming someone else in a study of peoples with renal failure (99). In summary, it seems that people who do not understand, manage or find meaning in their situation also tend to use less useful coping behaviours and thus lack the ability to deal with stressors in a constructive way.

Summary of Study III and progression to Study IV

SOC was not significantly associated with problem focused or emotion focused coping, but people with lower values of SOC tended to rely on less useful coping.

All studies of SOC and associated factors were performed by using rating scales, and thus a deeper understanding of SOC, which can be obtained by explanations and clarifications from the participants, was not possible. To gain a more in-depth understanding of SOC, I wanted people with LEoP to describe in their own words what comprehensibility, manageability and meaningfulness mean to them. This was explored in the fourth study of my thesis.

The meaning of SOC

The meaning of Sense of Coherence (SOC) in people with Late Effects of Polio (Study IV)

When people with LEoP described what comprehensibility, manageability and meaningfulness meant to them in their own words, it was revealed that SOC existed in a state of motion and a state of being. Moreover, the three main categories of SOC, the states of motion and being and the sub-categories (found in the main categories) were all closely intertwined. Furthermore, barriers for SOC were identified.

According to my knowledge, this is the first study identifying the state of motion and state of being in SOC. Studies investigating the in-depth meaning of SOC are very rare and thus comparisons with other studies are very difficult to do. One similar study of people with limb-girdle muscular dystrophy (a neuromuscular disease with some similarities with LEoP) (74) has findings that can be applied to some of the results in the present study.

The state of motion

The state of motion was a process aiming to reach higher comprehensibility, manageability and meaningfulness, and was characterized by active approaches, choices and actions. Most participants in this study did not appear to be particularly interested in the exact mechanisms of LEoP. By simplifying information, re-evaluating it and identifying patterns, they made their own personal model of explanation of their illness. Contributory factors were also taken into account in their own personal model, such as age. One reflection on this is that comprehensibility is not always dependent on actual knowledge. Instead, what is important is that the people themselves must have a feeling that it makes sense to them.

The participants were inventive in increasing manageability, and sometimes great efforts and clever interventions were made, such as designing their own houses and gardens. One can assume that the people in our study generally have a high SOC (see Study I), which might reflect that they know what to do to increase manageability. Moreover, their earlier polio experience might play a part. Great efforts to increase manageability have previously been described in people with LEoP (15), and might be due to the fact that people with LEoP are accustomed to struggling with difficulties since childhood (13).

Viewing things positively was an active choice, which enhanced meaningfulness. Being positive seems to be important for SOC, since this was also a finding in a study of older people with a high SOC (100).

The state of being

The state of being in people with LEoP entailed understanding the demands of being a person with LEoP (comprehensibility), accepting dependency (manageability) and, among other things, enjoying nature and meaningful social relationships (meaningfulness).

Comprehensibility included following instructions from rehabilitation professionals. This helped them to be active on an appropriate level and to avoid exhaustion and pain. Furthermore, they understood that they themselves had to work to find the appropriate level of activities, through self-monitoring and evaluation. One can assume, that the need for self-monitoring and evaluation is due to the "appropriate" level of activity changing over time. This is also reflected in the manageability category; adapting and achieving balance was part of the person's daily routines.

Life with LEoP thus seems to require continuous adaptation. The participants with muscular dystrophy in the study by Aho and colleagues (74) also described that the progressive nature of the illness required continuous adaptation and caused mental distress and sometimes depression. This mental distress was not a major finding in this qualitative study, although some participants expressed worries that a further decline in function could threaten meaningful activities. The participants in the study of muscular dystrophy were much younger (18-30 years) than the participants with LEoP, and age could thus be an explanatory factor. The decline in physical functioning in those who are older might not be as threatening as for young people, since older people might have achieved a lot of their goals and what they want to do in life (such as education, work, family), which younger people still have not. The social comparison (described in *The level of SOC*, Study I) might also play a role.

Close relationships were a source of meaningfulness for the participants and seemed to be very important for their sense of living a good life. They often rounded off with a phrase like: "So, without doubt, I lead a good life" when they described their closest relationships.

This concurs with the findings in a study of people with Parkinson's disease (101), where social belonging was the main concern for achieving life satisfaction. Having close relationships has been found important for adaptation and experiencing health despite a disability (102-104) and a change in marital status, going from single to having a partner, was the only explanatory factor for a positive change in SOC in a longitudinal study of older adults ageing with spinal cord injury (60).

Interaction in the categories, the states of motion and being, and the subcategories

The main categories (comprehensibility, manageability, and meaningfulness), the state of motion and the state of being, and the subcategories were closely intertwined, and often interacted. This interaction was positive for SOC. For example, using one's inner drive to move forward was placed in meaningfulness, as this drive was the motivation, which is in the essence of meaningfulness. However, it was important for all aspects of SOC, as this drive facilitated positive change in all categories of SOC.

An example of interactions in the state of motion and the state of being is the subcategory accepting support, placed in the state of being. There was also a motion in this, since accepting support enabled the people to manage better and thereby reach higher autonomy and independence.

Receiving social support from spouses, family and close friends was a subcategory enhancing manageability. This was also a finding in the study by Aho and colleagues (74). However, the other side of the coin is to *give* support and to be needed by someone else (i.e. the subcategory doing good and making a difference for others), which increased meaningfulness. This is an example of close interactions in the subcategories.

The close interactions support Antonovsky's statement that comprehensibility, manageability, and meaningfulness are closely intertwined (44).

Barriers for SOC

Barriers for SOC could also be identified. Examples of barriers were not knowing where to turn for assistance regarding their LEoP (comprehensibility) and experiencing rigid regulations and bureaucracy (manageability). Aho and colleagues have described a similar struggle for people with limb-girdle muscular dystrophy (74). Barriers for meaningfulness were not clearly identified, but considering the importance of close relationships to SOC, one conclusion is that loneliness could be a barrier to meaningfulness.

The people in the present study expressed a wish for an "open door" to a rehabilitation clinic specialized in LEoP, which would enhance both comprehensibility (knowing where to turn) and manageability (support with areas in daily life that have become demanding). This need was also expressed by those with muscular dystrophy. It is most likely that all people with progressive conditions would benefit from having contact with a clinic specialized in their condition, and many worries and uncertainties could be avoided.

Summary of Study IV

SOC existed in a state of motion, aiming to reach higher level of comprehensibility, manageability and meaningfulness, and a state of being, reflecting the comprehensibility, manageability and meaningfulness the people currently experienced. The main categories, the states of motion and being and the subcategories were closely intertwined.

Salutogenesis in rehabilitation

It appears, that people with LEoP who live a good life focus on aspects that give them value in life, for example, their personal relationships, social contexts, and nature (Study IV). They find ways to maintain such valuable aspects despite their disability (Study II) by a rich source of constructive coping behaviours that they use flexibly (Study III). Adaptation for people with LEoP is an ongoing process (Study IV). This leads us to general resistance resources (GRRs), and our role as rehabilitation professionals. We can improve our support of people with LEoP in the adaptation process, by a salutogenic approach in rehabilitation.

The stability of SOC that Antonovsky proposed, has been questioned and contradicted (70, 93, 105). SOC can perhaps indeed be strengthened, but in my opinion, SOC is rather to be seen as a tool/an orientation, than a goal in itself. The gained knowledge of this thesis adds to our existing knowledge of salutogenesis, and a salutogenic approach in rehabilitation will be discussed in this section.

First, in order to apply salutogenesis in rehabilitation, I believe the workplace must be salutogenic for the staff working there. A salutogenic workplace should, according to the definition of SOC, be a place where the staff have a common perception of the goals and missions of their workplace, know which activities and interventions are carried out by others, have a clear definition of their own duties and work assignments, and know where to turn for assistance. A scheduled, thorough introduction to new staff, as well as a mentor would benefit this comprehensibility. Moreover, to make the work manageable for the staff, there should be a balance in overload-underload with sufficient time for recreation. Communication is beneficial to obtain this balance, as well as the existence of a climate of flexibility, where the people at the workplace support each other when needed. Finally, being part of when decisions are to be taken would increase meaningfulness. To achieve this, I believe flexibility at the workplace that is increasing the person’s influence on his or her work situation is important, such as scheduling one’s own workday, having the possibility to do some work from home etc. The education of key members of staff has been suggested as a way to enable the development of a salutogenic workplace (106).

The person in rehabilitation should be greatly involved throughout the rehabilitation process, by formulating their own goals and taking responsibility for them (107). This is important, as a meaningful goal is highly individual, and must be defined by the person him/herself. An individualized, goal-oriented interdisciplinary rehabilitation program has previously been described and could entail a positive turning point for people with LEoP (37).

One way to support SOC could be by helping the person to identify SRRs and GRRs. It could be done by introducing the person to patient organizations and different types of assets within healthcare, but also by helping the person reflect upon which resources he or she has in their daily life, in their surroundings and in their personal abilities. For example, access to an environment that is a source of recreation could be seen as a GRR (43). This seems to be the nature for many people with LEoP (Study IV), although this, of course, could differ between individuals. Rehabilitation staff could help the person to identify which kind of environment that is recreational for the person, and then he/she could try to bring elements of that environment into his/her daily life.

Comprehensibility is more dependent on the person’s feeling that “it makes sense” than on actual knowledge, as described in Study IV. The person’s pre-understanding should thus be taken into account when giving information and this should be individualized to meet the needs and wishes of the person. It can be a delicate and not always easy task, neither giving too much information nor withholding it. However, I believe that by carefully listening to the person and giving him or her time to speak, and ask questions, we can come close to the desired level.

We know that people with a weaker SOC deal with stressors in a less useful way (Study III). Study IV showed, that accepting dependency was constructive and could in fact lead to greater independence and manageability. Acceptance and Commitment Therapy (ACT) could thus be used, since this therapy has been proven beneficial for adaptation in other lifelong conditions (108).

Due to the importance of close relationships and being part of a social context (Studies I and IV), interventions that prevent isolation and non-wanted loneliness could be beneficial. One way to do this, could be to initiate regular group activities for people with LEoP, which could provide a sense of social belonging. Interventions that bring together people with similar experiences have been proven to be beneficial for health (43).

The people with LEoP emphasized the great value of contact with a team specialized in their condition (Study IV). By providing such continuity, a barrier for SOC could be reduced, and the people need not to spend time and energy on searching to solve issues regarding their LEoP. Regular follow-up meetings would also ensure, that people in need of interdisciplinary rehabilitation are identified.

Methodological considerations

SOC and associated factors

The strengths of the studies were the high response rate (75%), and the use of valid and reliable rating scales that cover important aspects of the ICF-model and have been extensively used in research. The number of participants (93 people) is sufficient to make reliable correlation analyses. The respondents did not differ from the non-respondents in terms of age, gender, or number of years before onset of LEoP, so the sample is likely to be representative of Swedish people with LEoP with a mild – moderate disability level.

There were also some limitations. The conclusions should be restricted to people with LEoP who do not have a major disability as only ambulant people with LEoP were included. Furthermore, we cannot make any causal conclusions as all the studies were cross-sectional. Longitudinal studies assessing SOC and other variables over time would be beneficial for gaining a better understanding of cause and effect. The Brief Cope scale is an ordinal scale, yet data have been analyzed with conventional statistics. Analyses of the construct validity and the uni-dimensionality of the scale, applying the Rasch method would be advantageous for future use in people with LEoP.

The meaning of SOC

A strength of the study is the variety of the people who were interviewed, assuring credibility. Men and women were equally represented, their age range of 65-84 years covers most people with LEoP in the western world, and their disability level ranged from walking to using a wheelchair as their main mode of transportation. The varying professional background of the authors is also considered a strength, providing different approaches when discussing and interpreting the result. Furthermore, the participants had no previous relation to the interviewer, minimizing the risk of them providing inaccurate answers in order to "please" the interviewer.

There is always a subjective interpretation from the person doing the analysis in qualitative studies. Being aware of this, all authors had access to the full transcripts of the interviews and discussed the interpretation of the result until consensus was achieved. Furthermore, citations from participants were added when presenting the result in the journal in order to make the interpretation as objective as possible and assure confirmability.

The study process was described in sufficient detail to assure dependability so that the work can be repeated.

One limitation was that all participants had, at some point, taken part in an interdisciplinary rehabilitation program. They might thus have been provided with tools to manage their LEoP, and they might thus be more adapted to their condition than the average person with LEoP. Furthermore, all the participants were of Swedish origin and had an educational level higher than primary school. Transferability to people who have not taken part in rehabilitation, from other origins, having lower education levels and of younger age is thus limited.

One of the interviews was very short (10 min), which could also be seen as a limitation. However, this shorter interview was one of the last interviews, and themes came up that were already presented by previous participants. This short interview thus became more confirmatory. In summary, rich information about the participants' experiences of SOC was received.

Conclusions

The conclusions of this thesis are:

- People with LEoP generally have a strong SOC irrespective of age and gender, but some people with LEoP score very low on SOC.
- Married/cohabitating people with LEoP and people with an educational level above primary school generally have higher SOC scores.
- People with LEoP who assess their disability as more severe have lower SOC scores.
- People with LEoP with a positive Perception of Self and who are satisfied with their lives have a high SOC.
- People with LEoP and a high SOC are not generally using any particular coping behaviour, but people with LEoP and a low SOC are more likely to rely on less useful coping.
- SOC exists in a state of motion in people with LEoP, aiming to attain a higher level of comprehensibility, manageability and meaningfulness, and a state of being, reflecting the comprehensibility, manageability and meaningfulness the people currently experience.
- Comprehensibility, manageability, meaningfulness, as well as the states of motion and being are closely intertwined.

Clinical implications

A summary of clinical implications is provided in this section. For a more thorough description, see *Salutogenesis in rehabilitation*.

- The person should be greatly involved in his or her own rehabilitation throughout the rehabilitation process, by writing their own goals and taking responsibility for them.
- SOC could be supported by helping the person to identify SRRs and GRRs.
- The person’s pre-understanding should be taken into account when giving information and this should be individualized to meet the needs and wishes of the person.
- Acceptance and Commitment Therapy (ACT) could be used to facilitate adaptation.
- Regular group activities for people with LEoP could be initiated to prevent non-wanted loneliness and provide a sense of social belonging.
- Regular follow up with a team specialized in LEoP would be beneficial for SOC and ensure that people in need of interdisciplinary rehabilitation are identified.

Future perspectives

To further explore Living with LEoP from a salutogenic perspective, the following studies are suggested:

- Longitudinal studies of SOC and associated factors would give a better understanding of cause and effect, as well as the stability or development of SOC in this population.
- The factors in the multivariate analyses did not fully explain the variance in SOC. Similar studies conducted with SOC and additional associated factors (such as depressive symptoms) would thus further explain the variance in SOC.
- The role of participation in relation to SOC showed differing results in studies of other populations. Further studies investigating different domains of participation in relation to SOC would thus be beneficial.
- Psychometric testing of the rating scales in people with LEoP are lacking (except for the SIPP scale and RNL-I) and would be beneficial when conducting research in this population.
- ACT is suggested for people using less useful coping behaviours, since this is proven to facilitate adaptation in other disability groups. However, it has not previously been used in a rehabilitation program for people with LEoP. An intervention study of the use of ACT in people with LEoP would be beneficial for insights in the applicability of ACT for people with LEoP.
- Valuable insights in the in-depth meaning of SOC were gained. However, since this is a complex phenomenon there is still a lot to be explored. Further qualitative studies with a somewhat different approach would give further valuable insights of the meaning of SOC in people with LEoP and other disabilities.
- The study participants were all of Swedish origin and had at some point taken part in interdisciplinary rehabilitation. Further studies of SOC in people with LEoP with different ethnic backgrounds, also including people who have not taken part in rehabilitation, would make comparisons possible and provide a better understanding of the generalizability of the findings.

Afterword

When I think again of the person that I first met at the rehabilitation medicine department, I now know that this person must have had high levels of comprehensibility, manageability, and meaningfulness. I have learned a great deal in my research. I am pleased to be able to add one piece of knowledge to the existing knowledge of SOC and our understanding of why many people with LEoP can live a good life despite their disability, and why others are still struggling decades after their acute polio infection.

I have also learned that there is no simple answer to anything, and that all answers do not apply to everyone. I thus think it is important to keep asking naïve questions like *"How does he do it?"* and investigate this in different populations and contexts.

My PhD-project has come to an end, but I will carry on asking naïve questions, and keep trying to find an answer.

Populärvetenskaplig sammanfattning

De sista stora polioepidemierna i Sverige var på 1950-talet, då mer än 5000 personer insjuknade i akut polio med förlamning. Flera decennier efter insjuknandet har många fått nya symptom, som muskelsvaghet, muskulär uttröttbarhet, allmän trötthet och smärta från muskler och leder i vila och vid aktivitet, så kallad postpolio (PPS) eller sena effekter av polio. Tillståndet, som ofta medför olika funktionsnedsättningar, kan leda till stora förändringar i vardagen och påverka personens delaktighet i sin livssituation vilket i sin tur kan minska livstillfredsställelsen. Forskning har visat att många personer med PPS är nöjda med sina liv, medan andra är mindre nöjda och upplever svårigheter och begränsningar. För att kunna hjälpa personer med PPS, behöver vi förstå vad som är viktigt för känslan av att leva ett gott liv med PPS.

En faktor som har betydelse för känslan av att leva ett gott liv hos en person med en livslång funktionsnedsättning är vilket förhållningssätt man har till sin funktionsnedsättning. I detta är begrepp som salutogenes och känsla av sammanhang centrala. Salutogenes betyder ”hälsans ursprung” och representerar ett skifte från faktorer som orsakar sjukdom eller funktionsnedsättning till faktorer som ger hälsa och välbefinnande. Aaron Antonovsky, en amerikansk-israelisk forskare som intresserade sig för hälsans ursprung, kom fram till att en mycket avgörande faktor var en stark ”känsla av sammanhang”, KASAM, bestående av komponenterna begriplighet, hanterbarhet och meningsfullhet. KASAM har visat sig höra ihop med upplevd hälsa, livstillfredsställelse och framgångsrik anpassning till sin funktionsnedsättning, men kunskap om KASAM hos personer med PPS saknades helt innan studierna i denna avhandling påbörjades.

Denna avhandling syftar till att öka kunskapen om KASAM hos personer med PPS. Avhandlingen består av tre studier där olika frågeformulär använts för att skatta KASAM och associerade faktorer hos 93 personer med PPS, och en kvalitativ studie som studerat innebörden av KASAM hos 14 personer med PPS med hjälp av djupintervjuer.

Studierna visade, att personer med PPS generellt har höga värden på KASAM-skalan och därmed god förmåga att förstå, hantera och finna mening i sin situation. Samtidigt var det en stor spridning på KASAM-nivå. En del personer hade mycket låga värden och kan därför behöva stöd i adaptations-processen. Att vara gift/sammanboende, högre utbildning, god självkänsla och hög livstillfredsställelse var förknippat med högre värden på KASAM, medan mer symptom på PPS samt att använda bemästringsstrategier som anses vara mindre användbara var förknippat med lägre värden på KASAM. Intervjustudien visade, att KASAM hos personer med PPS existerar i två övergripande teman; en rörelse, som syftar till att få högre begriplighet, hanterbarhet och meningsfullhet, och ett varande, som är den begriplighet, hanterbarhet och meningsfullhet personerna upplever i sitt dagliga liv. Den kvalitativa studien visade också, att rörelsen och varandet, samt begriplighet, hanterbarhet och meningsfullhet interagerar och är tätt sammanlänkade med varandra.

Tillsammans ger studierna en djupare och bredare förståelse av att leva med PPS från ett salutogent perspektiv. Den sammantagna kunskapen kan hjälpa rehabiliteringspersonal i deras kliniska arbete och ge dem verktyg för att stödja personer och de faktorer som är viktiga för KASAM. Detta kan öka möjligheten för personer med PPS att leva ett gott liv trots sin livslånga funktionsnedsättning.

Tack till

Jag vill börja med att tacka **de personer som deltagit i min studier**, och som delat med sig av sina erfarenheter och upplevelser. Er medverkan har möjliggjort den här avhandlingen, och gett mig kunskap och erfarenhet som jag kommer ha nytta av både som person, forskare och läkare.

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References

1. World Health Organization. The International Classification of Functioning, Disability and Health (ICF). 2001: Geneva.
2. Lazarus RS, Folkman S. Stress, appraisal, and coping. New York: Springer; 1984.
3. Pavot W, Diener E. Review of the satisfaction with life scale. Assessing well-being: Springer; 2009. p. 101-17.
4. Global Polio Eradication Initiative, cited 2022. Available from: https://polioeradication.org.
5. Li Hi Shing S, Chipika RH, Finegan E, Murray D, Hardiman O, Bede P. Post-polio syndrome: more than just a lower motor neuron disease. Frontiers in Neurology. 2019:773.
6. World Health Organization. Health-topics: poliomyelitis, cited 2022. Available from: https://www.who.int/health-topics/poliomyelitis.
7. The magazine of Harvard medical school, cited 2022. Available from: https://hms.harvard.edu/magazine/artificial-intelligence/backstory.
8. Trevelyan B, Smallman-Raynor M, Cliff AD. The spatial dynamics of poliomyelitis in the United States: from epidemic emergence to vaccine-induced retreat, 1910–1971. Annals of the Association of American Geographers. 2005;95(2):269-93.
9. Axelsson P. Höstens spöke: de svenska polioepidemiernas historia: Carlsson; 2004.
10. Statistiska centralbyrån. Historisk statistik för Sverige Del 1. Befolkning. Allmänna Förlaget, 1969.
11. Folkhälsomyndigheten. Smittskydd-beredskap: vaccinationer, cited 2022. Available from : https://www.folkhalsomyndigheten.se/smittskydd-beredskap/vaccinationer/vacciner-a-o/polio.
12. Personskadeförbundet RTP. Om oss, historia, cited 2022. Available from: https://rtp.se/om-oss/historia.
13. Yelnik A, Laffont I. The psychological aspects of polio survivors through their life experience. Annals of Physical and Rehabilitation Medicine. 2010;53(1):60-7.
14. Bruno RL, Frick NM. The psychology of polio as prelude to post-polio sequelae: behavior modification and psychotherapy. Orthopedics; 1991. p. 1185-93.
15. Sjödahl Hammarlund C, Lexell J, Brogårdh C. Growing up with a disability following paralytic poliomyelitis: experiences from persons with late effects of polio. Disability and rehabilitation. 2021;43(7):960-6.

16. Gensowski M, Nielsen TH, Nielsen NM, Rossin-Slater M, Wüst M. Childhood health shocks, comparative advantage, and long-term outcomes: Evidence from the last Danish polio epidemic. Journal of health economics. 2019;66:27-36.
17. Bruno RL, Frick NM. Stress and" Type A" behavior as precipitants of Post-Polio Sequelae. Research and Clinical Aspects of the Late Effects of Poliomyelitis White Plains: March of Dimes Research Foundation. 1987:145-55.
18. March of dimes, cited 2022. Available from: https://www.marchofdimes.org/mission/a-history-of-the-march-of-dimes.
19. World Health Organization. History of polio vaccination, 2022. Available from: https://www.who.int/news-room/spotlight/history-of-vaccination/history-of-polio-vaccination.
20. University of Michigan. 1955 Polio Vaccine Trial Announcement, cited 2022. Available from: https://sph.umich.edu/polio.
21. Raymond M, Charcot J. Paralysie essentielle de l'enfance, atrophie musculaire consecutive. Gaz Med Paris. 1875;226.
22. Gawne AC, Halstead LS. Post-polio syndrome: historical perspective, epidemiology and clinical presentation. NeuroRehabilitation. 1997;8(2):73-81.
23. Farbu E, Gilhus N, Barnes M, Borg K, De Visser M, Driessen A, et al. EFNS guideline on diagnosis and management of post-polio syndrome. Report of an EFNS task force. European Journal of Neurology. 2006;13(8):795-801.
24. Lo JK, Robinson LR. Postpolio syndrome and the late effects of poliomyelitis. Part 1. pathogenesis, biomechanical considerations, diagnosis, and investigations. Muscle & nerve. 2018;58(6):751-9.
25. Lexell J. Postpoliomyelitis syndrome. In: WR SJ Frontera TRJ, editor. Essentials of physical medicine and rehabilitation. 4th ed ed: Elsevier; 2019. p. 834-40.
26. Gonzalez H, Khademi M, Borg K, Olsson T. Intravenous immunoglobulin treatment of the post-polio syndrome: sustained effects on quality of life variables and cytokine expression after one year follow up. Journal of neuroinflammation. 2012;9(1):1-12.
27. Huang Y-H, Chen H-C, Huang K-W, Chen P-C, Hu C-J, Tsai C-P, et al. Intravenous immunoglobulin for postpolio syndrome: a systematic review and meta-analysis. BMC neurology. 2015;15(1):1-9.
28. Halstead LS, Rossi CD. New problems in old polio patients: results of a survey of 539 polio survivors. Orthopedics; 1985. p. 845-50.
29. Brogårdh C, Lexell J, Lundgren-Nilsson Å. Construct validity of a new rating scale for self-reported impairments in persons with late effects of polio. PM&R. 2013;5(3):176-81.
30. Stolwijk-Swüste JM, Beelen A, Lankhorst GJ, Nollet F, Group CS. The course of functional status and muscle strength in patients with late-onset sequelae of poliomyelitis: a systematic review. Archives of physical medicine and rehabilitation. 2005;86(8):1693-701.
31. Zwarts M, Bleijenberg G, Van Engelen B. Clinical neurophysiology of fatigue. Clinical neurophysiology. 2008;119(1):2-10.
32. Östlund G. Aspects of fatigue in post-polio: Karolinska Institutet; 2010.

33. Boshuis EC, Melin E, Kristian B. Pain in Post-Polio Syndrome: A Separate Pain Entity? Journal of Rehabilitation Medicine-Clinical Communications. 2022;5.
34. Halstead LS. Assessment and differential diagnosis for post-polio syndrome. Orthopedics; 1991. p. 1209-17.
35. Gawne AC, Halstead LS. Post-polio syndrome: pathophysiology and clinical management. Critical Reviews™ in Physical and Rehabilitation Medicine. 1995;7(2).
36. Brogårdh C, Lexell J. Falls, fear of falling, self-reported impairments, and walking limitations in persons with late effects of polio. PM&R. 2014;6(10):900-7.
37. Larsson Lund M, Lexell J. A positive turning point in life: How persons with late effects of polio experience the influence of an interdisciplinary rehabilitation programme. Journal of Rehabilitation Medicine. 2010;42(6):559-65.
38. Trojan DA, Cashman NR. Post-poliomyelitis syndrome. Muscle & Nerve: Official Journal of the American Association of Electrodiagnostic Medicine. 2005;31(1):6-19.
39. Tiffreau V, Rapin A, Serafi R, Percebois-Macadré L, Supper C, Jolly D, et al. Post-polio syndrome and rehabilitation. Annals of Physical and Rehabilitation Medicine. 2010;53(1):42-50.
40. Lexell J, Brogårdh C. The use of ICF in the neurorehabilitation process. NeuroRehabilitation. 2015;36(1):5-9.
41. Lexell J, Brogårdh C. Life satisfaction and self-reported impairments in persons with late effects of polio. Annals of Physical and Rehabilitation Medicine. 2012;55(9-10):577-89.
42. Ryan RM, Deci EL. On happiness and human potentials: A review of research on hedonic and eudaimonic well-being. Annual review of psychology. 2001;52:141.
43. Mittelmark MB, Bauer GF, Vaandrager L, Pelikan JM, Sagy S, Eriksson M, et al. The handbook of salutogenesis. Springer; 2022.
44. Antonovsky A. Unraveling the mystery of health: How people manage stress and stay well. 1st ed. San Francisco, CA, USA: Jossey-bass; 1987.
45. Antonovsky A. A somewhat personal odyssey in studying the stress process. Stress medicine. 1990;6(2):71-80.
46. Antonovsky A. Health, stress, and coping. New perspectives on mental and physical well-being. 1979:12-37.
47. Eriksson M, Lindström B. Antonovsky's sense of coherence scale and the relation with health: a systematic review. Journal of epidemiology & community health. 2006;60(5):376-81.
48. Sagy S, Antonovsky H. The development of the sense of coherence: A retrospective study of early life experiences in the family. The international journal of aging and human development. 2000;51(2):155-66.
49. Antonovsky A. The structure and properties of the sense of coherence scale. Social science & medicine. 1993;36(6):725-33.
50. Eriksson M, Lindström B. Validity of Antonovsky's sense of coherence scale: a systematic review. Journal of Epidemiology & Community Health. 2005;59(6):460-6.

51. Naaldenberg J, Tobi H, van den Esker F, Vaandrager L. Psychometric properties of the OLQ-13 scale to measure Sense of Coherence in a community-dwelling older population. Health and quality of life outcomes. 2011;9(1):1-9.
52. Larsson G, Kallenberg KO. Sense of coherence, socioeconomic conditions and health: Interrelationships in a nation-wide Swedish sample. The European Journal of Public Health. 1996;6(3):175-80.
53. Nilsson B, Holmgren L, Westman G. Sense of coherence in different stages of health and disease in northern Sweden: gender and psychosocial differences. Scandinavian journal of primary health care. 2000;18(1):14-20.
54. Nilsson KW, Leppert J, Simonsson B, Starrin B. Sense of coherence and psychological well-being: improvement with age. Journal of Epidemiology & Community Health. 2010;64(4):347-52.
55. Tistad M, Tham K, von Koch L, Ytterberg C. Unfulfilled rehabilitation needs and dissatisfaction with care 12 months after a stroke: an explorative observational study. BMC neurology. 2012;12(1):1-7.
56. Ekstam L, Johansson U, Guidetti S, Eriksson G, Ytterberg C. The combined perceptions of people with stroke and their carers regarding rehabilitation needs 1 year after stroke: a mixed methods study. BMJ open. 2015;5(2):e006784.
57. Gison A, Rizza F, Bonassi S, Dall'Armi V, Lisi S, Giaquinto S. The sense-of-coherence predicts health-related quality of life and emotional distress but not disability in Parkinson's disease. BMC neurology. 2014;14(1):1-6.
58. Rosengren L, Brogårdh C, Jacobsson L, Lexell J. Life satisfaction and associated factors in persons with mild to moderate Parkinson's disease. NeuroRehabilitation. 2016;39(2):285-94.
59. Jacobsson L, Westerberg M, Malec J, Lexell J. Sense of coherence and disability and the relationship with life satisfaction 6–15 years after traumatic brain injury in northern Sweden. Neuropsychological Rehabilitation. 2011;21(3):383-400.
60. Jörgensen S, Lennman E, Lexell J. Sense of coherence and changes over six years among older adults aging with long-term spinal cord injury. Spinal Cord. 2021;59(12):1278-84.
61. Pallant JF, Lae L. Sense of coherence, well-being, coping and personality factors: Further evaluation of the sense of coherence scale. Personality and individual differences. 2002;33(1):39-48.
62. Lindmark U, Stenström U, Gerdin EW, Hugoson A. The distribution of ''sense of coherence''among Swedish adults: A quantitative cross-sectional population study. Scandinavian journal of public health. 2010;38(1):1-8.
63. Jueng R-N, Tsai D-C, Chen I-J. Sense of coherence among older adult residents of long-term care facilities in Taiwan: A cross-sectional analysis. PloS one. 2016;11(1):e0146912.
64. Giglio RE, Rodriguez-Blazquez C, de Pedro-Cuesta J, Forjaz MJ. Sense of coherence and health of community-dwelling older adults in Spain. International Psychogeriatrics. 2015;27(4):621-8.
65. Silverstein M, Heap J. Sense of coherence changes with aging over the second half of life. Advances in Life Course Research. 2015;23:98-107.

66. Holmberg S, Thelin A, Stiernström E-L. Relationship of Sense of Coherence to Other Psychosocial Indices. European Journal of Psychological Assessment. 2004;20(4):227.
67. Pusswald G, Fleck M, Lehrner J, Haubenberger D, Weber G, Auff E. The “Sense of Coherence” and the coping capacity of patients with Parkinson disease. International psychogeriatrics. 2012;24(12):1972-9.
68. Veenstra M, Moum T, Røysamb E. Relationships between health domains and sense of coherence: a two-year cross-lagged study in patients with chronic illness. Quality of Life Research. 2005;14(6):1455-65.
69. Geyh S, Nick E, Stirnimann D, Ehrat S, Michel F, Peter C, et al. Self-efficacy and self-esteem as predictors of participation in spinal cord injury—an ICF-based study. Spinal cord. 2012;50(9):699-706.
70. Snekkevik H, Anke AG, Stanghelle JK, Fugl-Meyer AR. Is sense of coherence stable after multiple trauma? Clinical rehabilitation. 2003;17(4):443-53.
71. Kennedy P, Lude P, Elfström M, Smithson E. Sense of coherence and psychological outcomes in people with spinal cord injury: Appraisals and behavioural responses. British Journal of Health Psychology. 2010;15(3):611-21.
72. Jörgensen S, Ginis KA, Iwarsson S, Lexell J. Depressive symptoms among older adults with long-term spinal cord injury: Associations with secondary health conditions, sense of coherence, coping strategies and physical activity. Journal of rehabilitation medicine. 2017;49(8):644-51.
73. Bauer GF, Roy M, Bakibinga P, Contu P, Downe S, Eriksson M, et al. Future directions for the concept of salutogenesis: a position article. Health Promotion International. 2020;35(2):187-95.
74. Aho AC, Hultsjö S, Hjelm K. Young adults’ experiences of living with recessive limb-girdle muscular dystrophy from a salutogenic orientation: An interview study. Disability and rehabilitation. 2015;37(22):2083-91.
75. Brogårdh C, Lexell J. Test-retest reliability of the self-reported impairments in persons with late effects of polio (SIPP) rating scale. PM&R. 2016;8(5):399-404.
76. Wood-Dauphinee S, Opzoomer M, Williams JI, Marchand B, Spitzer WO. Assessment of global function: The Reintegration to Normal Living Index. Archives of physical medicine and rehabilitation. 1988;69(8):583-90.
77. Perenboom RJ, Chorus AM. Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). Disability and rehabilitation. 2003;25(11-12):577-87.
78. Bourget N, Deblock-Bellamy A, Blanchette AK, Batcho CS. Use and psychometric properties of the reintegration to normal living index in rehabilitation: a systematic review. Annals of physical and rehabilitation medicine. 2018;61(4):262-9.
79. Andersson N, Lexell J, Brogårdh C. Test-Retest Reliability of the Reintegration to Normal Living Index (RNL-I) to Assess Perceived Participation in Adults With Late Effects of Polio. PM&R. 2020;12(2):147-53.
80. Diener E. Review of the Satisfaction With Life Scale. Psychological Assessment. 1993;5(2):164-72.

81. Carver CS. You want to measure coping but your protocol's too long: Consider the brief cope. International journal of behavioral medicine. 1997;4(1):92-100.
82. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. Journal of personality and social psychology. 1989;56(2):267.
83. Altman DG. Practical statistics for medical research: CRC press; 1990.
84. Armitage P, Berry G, Matthews JNS. Statistical methods in medical research: John Wiley & Sons; 2008.
85. Field A. Discovering statistics using IBM SPSS statistics: sage; 2013.
86. IBM Corporation, Armonk, New York, United States.
87. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. Qualitative health research. 2005;15(9):1277-88.
88. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. Jama. 2013;310(20):2191-4.
89. Festinger L. A theory of social comparison processes. Human relations. 1954;7(2):117-40.
90. Langeland E, Riise T, Hanestad BR, Nortvedt MW, Kristoffersen K, Wahl AK. The effect of salutogenic treatment principles on coping with mental health problems: A randomised controlled trial. Patient education and counseling. 2006;62(2):212-9.
91. Heggdal K, Lovaas BJ. Health promotion in specialist and community care: how a broadly applicable health promotion intervention influences patient's sense of coherence. Scandinavian Journal of Caring Sciences. 2018;32(2):690-7.
92. Read S, Aunola K, Feldt T, Leinonen R, Ruoppila I. The relationship between generalized resistance resources, sense of coherence, and health among Finnish people aged 65-69. European Psychologist. 2005;10(3):244.
93. Krantz G, Östergren P-O. Does it make sense in a coherent way? Determinants of sense of coherence in Swedish women 40 to 50 years of age. International Journal of Behavioral Medicine. 2004;11(1):18-26.
94. Virues-Ortega J, Vega S, Seijo-Martinez M, Saz P, Rodriguez F, Rodriguez-Laso A, et al. A protective personal factor against disability and dependence in the elderly: an ordinal regression analysis with nine geographically-defined samples from Spain. BMC geriatrics. 2017;17(1):1-10.
95. Lund ML, Lexell J. Relationship between participation in life situations and life satisfaction in persons with late effects of polio. Disability and Rehabilitation. 2009;31(19):1592-7.
96. Anke AG, Fugl-Meyer AR. Life satisfaction several years after severe multiple trauma–a retrospective investigation. Clinical rehabilitation. 2003;17(4):431-42.
97. Maynard FM, Roller S. Recognizing typical coping styles of polio survivors can improve re-rehabilitation. American Journal of Physical Medicine & Rehabilitation. 1991;70(2):70-2.
98. Nahlén C, Saboonchi F. Coping, sense of coherence and the dimensions of affect in patients with chronic heart failure. European Journal of Cardiovascular Nursing. 2010;9(2):118-25.

99. Klang B, Björvell H, Cronqvist A. Patients with chronic renal failure and their ability to cope. Scandinavian Journal of Caring Sciences. 1996;10(2):89-95.

100. Söderhamn U, Dale B, Söderhamn O. Narrated lived experiences of self-care and health among rural-living older persons with a strong sense of coherence. 2011.

101. Rosengren L, Forsberg A, Brogårdh C, Lexell J. Social belonging as the main concern for achieving life satisfaction when adapting to parkinson's disease. International Journal of Environmental Research and Public Health. 2021;18(16):8653.

102. Andersson T, Falk K, Bjerså K, Forsberg A. Health is belonging: lived experiences during recovery after pancreaticoduodenectomy. International Scholarly Research Notices. 2012;2012.

103. Forsberg A, Cavallini J, Fridh I, Lennerling A. The core of social function after solid organ transplantation. Scandinavian Journal of Caring Sciences. 2016;30(3):458-65.

104. Forsberg A, Karlsson V, Cavallini J, Lennerling A. The meaning of social adaptation after solid organ transplantation. Nordic Journal of Nursing Research. 2016;36(2):62-7.

105. Smith PM, Breslin FC, Beaton DE. Questioning the stability of sense of coherence. Social Psychiatry and Psychiatric Epidemiology. 2003;38(9):475-84.

106. Eriksson M. Salutogenes: om hälsans ursprung-från forskning till praktisk tillämpning: Liber; 2015.

107. Lexell EM, Lexell J, Larsson-Lund M. The rehabilitation plan can support clients' active engagement and facilitate the process of change–experiences from people with late effects of polio participating in a rehabilitation programme. Disability and rehabilitation. 2016;38(4):329-36.

108. Kuba K, Weißflog G. Acceptance and Commitment Therapy in the Treatment of Chronic Disease. Psychother Psychosom Med Psychol. 2017;67(12):525-36.

Appendix

KÄNSLA AV SAMMANHANG

Livsfrågeformulär
Här är några frågor som berör skilda områden i livet. Varje fråga har 7 möjliga svar. Markera den siffra som bäst passar in på ditt svar. Siffran 1 eller 7 är svarens yttervärden. Om du instämmer i det som står under 1, så ringa in 1:an, om du instämmer i det som står under 7, så ringa in 7:an. Om du känner annorlunda, ringa in den siffra som bäst överensstämmer med din känsla. Ge endast ett svar på varje fråga.

1. Har du en känsla av att du inte riktigt bryr dig om vad som händer runt omkring dig?

1	2	3	4	5	6	7
mycket sällan eller aldrig						mycket ofta

2. Har det hänt att du blev överraskad av beteendet hos personer som du trodde du kände väl?

1	2	3	4	5	6	7
har aldrig hänt						har ofta hänt

3. Har det hänt att människor som du litade på har gjort dig besviken?

1	2	3	4	5	6	7
har aldrig hänt						har ofta hänt

4. Hittills har ditt liv:

1	2	3	4	5	6	7
helt saknat mål och mening						genomgående haft mål och mening

5. Känner du dig orättvist behandlad?

1	2	3	4	5	6	7
mycket ofta						mycket sällan/ aldrig

6. Har du en känsla av att du befinner dig i en obekant situation och inte vet vad du skall göra?

1	2	3	4	5	6	7
mycket ofta						mycket sällan/ aldrig

7. Är dina dagliga sysslor en källa till:

1	2	3	4	5	6	7
glädje och djup tillfredsställelse						smärta och leda

8. Har du mycket motstridiga känslor och tankar?

1	2	3	4	5	6	7
mycket						mycket sällan/
ofta						aldrig

9. Händer det att du har känslor inom dig som du helst inte vill känna?

1	2	3	4	5	6	7
mycket						mycket
sällan/						
ofta						aldrig

10. Även en människa med stark självkänsla kan ibland känna sig som en ”olycksfågel”. Hur ofta har du känt det så?

1	2	3	4	5	6	7
aldrig						mycket ofta

11. När något har hänt, har du vanligen funnit att:

1	2	3	4	5	6	7
du över-						du såg
eller under-						saken i dess
värderade						rätta
dess betydelse						proportioner

12. Hur ofta känner du att det inte är någon mening med de saker du gör i ditt dagliga liv?

1	2	3	4	5	6	7
mycket						mycket sällan/
ofta						aldrig

13. Hur ofta har du känslor som du inte är säker på att du kan kontrollera?

1	2	3	4	5	6	7
mycket						mycket sällan/
ofta						aldrig

SJÄLVSKATTADE FUNKTIONSNEDSÄTTNINGAR HOS PERSONER MED POSTPOLIO

- De följande frågorna efterfrågar hur mycket du påverkats av din postpolio under de senaste två veckorna
- För varje påstående, ringa in den siffra som bäst beskriver din situation

Under de senaste två veckorna, hur mycket har du besvärats av…	Inte alls	Litet grand	Ganska mycket	Oerhört mycket
1. Nedsatt kraft i musklerna?	1	2	3	4
2. Uttröttbarhet i musklerna	1	2	3	4
3. Smärta i leder eller muskler när du går, står eller rör dig?	1	2	3	4
4. Smärta i leder eller muskler i vila?	1	2	3	4
5. Andningsproblem i vila?	1	2	3	4
6. Andningsproblem vid ansträngning?	1	2	3	4
7. Svårt att tåla kyla?	1	2	3	4
8. Känselnedsättning?	1	2	3	4
9. Allmän trötthet?	1	2	3	4
10. Sömnsvårigheter?	1	2	3	4
11. Koncentrationssvårigheter?	1	2	3	4
12. Minnesproblem?	1	2	3	4
13. Humörförändringar (irritabilitet, ängslan, oro eller nedstämdhet)?	1	2	3	4

Kolla att du har ringat in EN siffra för VARJE fråga

UPPLEVD AKTIVITET OCH DELAKTIGHET

1 = Beskriver inte min situation
2 = Beskriver i viss mån min situation
3 = Beskriver för det mesta min situation
4 = Beskriver till fullo min situation

Ringa in den siffra som bäst passar in på Din situation

1. Jag förflyttar mig runt i min bostad i den mån jag känner är nödvändigt. (Rullstol, annan utrustning eller annan hjälp kan användas).	1	2	3	4
2. Jag förflyttar mig runt i samhället i den mån jag känner är nödvändigt. (Rullstol, annan utrustning eller annan hjälp kan användas).	1	2	3	4
3. Jag kan resa bort från hemorten i den mån jag känner är nödvändigt. (Rullstol, annan utrustning eller annan hjälp kan användas).	1	2	3	4
4. Jag är nöjd med hur mina behov i personlig vård (påklädning, matsituation, toalettbesök, badning) tillgodoses. (Hjälpmedel, handledning och/eller assistans kan användas).	1	2	3	4
5. Jag tillbringar mesta delen av mina dagar i ett arbete eller en sysselsättning som är nödvändigt eller viktig för mig. (Arbete kan vara en betald anställning, hushållsarbete, frivilligarbete, skola. Hjälpmedel, handledning och / eller assistans kan användas).	1	2	3	4
6. Jag kan delta i fritidsaktiviteter (hobby, hantverk, sport, läsning, TV, spel, datorer etc.) som jag vill. (Hjälpmedel, handledning och / eller assistans kan användas).	1	2	3	4
7. Jag deltar i sociala aktiviteter med min familj, vänner och/eller affärsbekanta som är nödvändiga eller önskvärda för mig. (Hjälpmedel, handledning och/eller assistans kan användas.)	1	2	3	4
8. Jag har en roll i min familj som tillgodoser mina och andra familjemedlemmars behov. (Med familj avses människor med vilka du lever och/ eller släkt du inte lever med, men träffar regelbundet. Hjälpmedel, handledning och/eller assistans kan användas).	1	2	3	4
9. I allmänhet är jag tillfreds med mina personliga relationer.	1	2	3	4
10. I allmänhet är jag tillfreds med mig själv när jag är i sällskap med andra.	1	2	3	4
11. Jag känner att jag kan hantera händelser i livet när de uppstår.	1	2	3	4

LIVSTILLFREDSTÄLLELSE

Här nedan finns fem påståenden som du kan instämma i eller inte. För varje påstående ringa in en siffra från 1 till 7 där 1 betyder ”instämmer absolut inte” och 7 betyder ”instämmer helt och hållet. Var så ärlig som möjligt i dina svar.

Skalan:

1= Instämmer absolut inte

2= Instämmer inte

3= Instämmer oftast inte

4= Instämmer varken eller/neutral

5= Instämmer delvis

6= Instämmer

7= Instämmer helt och hållet

Påståendena:

1. I de flesta avseenden är mitt liv så nära det ideala

1 2 3 4 5 6 7

2. Mina levnadsförhållanden är utomordentliga

1 2 3 4 5 6 7

3. Jag är nöjd och tillfreds med mitt liv

1 2 3 4 5 6 7

4. Hittills har jag uppnått det viktigaste jag önskat i mitt liv

1 2 3 4 5 6 7

5. Om jag kunde leva om mitt liv skulle jag nästan inte ändra någonting

1 2 3 4 5 6 7

STRATEGIER FÖR ATT BEMÖTA SVÅRIGHETER

Hur brukar du i allmänhet göra när du stressas av problem?

Ringa in den siffra som passar bäst in på ditt svar

Så gör jag:

Svarsskalan: 1=mycket sällan, 2=ganska sällan, 3=ganska ofta, 4=mycket ofta

1. Jag arbetar eller gör andra saker för att inte tänka på problemet.
   1 2 3 4
2. Jag anstränger mig för att göra något åt min situation.
   1 2 3 4
3. Jag säger till mig själv ”detta är inte sant”.
   1 2 3 4
4. Jag använder alkohol eller andra droger för att känna mig bättre.
   1 2 3 4
5. Jag får känslomässigt stöd från andra.
   1 2 3 4
6. Jag ger upp mina försök att klara av det.
   1 2 3 4
7. Jag agerar för att försöka förbättra situationen.
   1 2 3 4
8. Jag vägrar inse att det har hänt.
   1 2 3 4
9. Jag uttrycker mig verbalt för att ge utlopp för mina obehagliga känslor.
   1 2 3 4
10. Jag får hjälp och råd från andra människor.
    1 2 3 4
11. Jag tar alkohol eller andra droger till hjälp för att ta mig igenom situationen.
    1 2 3 4
12. Jag försöker se det i ett annat ljus för att få det att verka mer positivt.
    1 2 3 4
13. Jag är kritisk mot mig själv.
    1 2 3 4
14. Jag försöker komma på en strategi för vad jag ska göra.
    1 2 3 4
15. Jag får tröst och förståelse från någon annan person.
    1 2 3 4
16. Jag ger upp mina försök att hantera situationen.
    1 2 3 4
17. Jag försöker finna något bra i det som sker.
    1 2 3 4

18. Jag skämtar om det.
    1 2 3 4
19. Jag går på bio, tittar på tv, läser, dagdrömmer, sover, handlar eller gör något annat för att slippa tänka på situationen.
    1 2 3 4
20. Jag accepterar det faktum att det hänt.
    1 2 3 4
21. Jag ger uttryck för mina negativa känslor.
    1 2 3 4
22. Jag försöker finna tröst i min religion eller andliga tro.
    1 2 3 4
23. Jag försöker få råd eller hjälp från andra människor om vad jag ska göra.
    1 2 3 4
24. Jag lär mig leva med det.
    1 2 3 4
25. Jag tänker noga på vilka åtgärder jag kan vidta.
    1 2 3 4
26. Jag anklagar mig själv för saker som hänt.
    1 2 3 4
27. Jag ber eller mediterar.
    1 2 3 4
28. Jag skojar om situationen.
    1 2 3 4

Intervjuguide

Övergripande inledande frågor:

Vill du berätta hur ditt liv ser ut? (När fick du polio? Hur drabbad var du? Hur länge har du haft post-polio? Hur ser ditt liv ut för övrigt? Hur ser din hemsituation ut? Är du aktiv inom något yrke/förening/hobby?)

Frågor om begriplighet:

Vill du berätta hur du förstår din post-polio och varför du har de besvär du har idag?

Hur påverkas ditt dagliga liv av post-polion?

Hur tänker du kring framtiden?

Finns det något som du vet idag som du önskar att du begripit tidigare?

Frågor om hanterbarhet:

Vill du berätta hur du hanterar din post-polio?

Hur upplever du att din omgivning och närstående hanterar den?

Finns det några rutiner/strategier/lösningar som du tycker fungerar bättre än andra eller som du är särskilt stolt över att ha tänkt ut?

Frågor om meningsfullhet:

Vad får dig att känna mening med tillvaron?

Finns det handlingar eller personer som påverkar din känsla av meningsfullhet?

Vill du berätta om dina livsmål utifrån där du befinner dig just nu i livet.

Exempel på följdfrågor: *Kan du ge exempel? Kan berätta mera? Kan du förklara vad du menar?*

Nu har jag fått ställa de frågor jag tänkt, *finns det något mer som du har reflekterat över och skulle vilja berätta om som inte framkommit i intervjun?*

Paper I

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Sense of Coherence in persons with late effects of polio

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Abstract.

BACKGROUND: Sense of Coherence (SOC) is important for successful adaptation and mental well-being in people with life-long medical conditions. Late effects of polio (LEoP) often lead to a life-long disability, but no study has assessed SOC in this population.

OBJECTIVE: To assess SOC in persons with LEoP and to explore the association between SOC, demographics (age, gender, marital status and level of education) and variables related to LEoP (age at polio onset, number of years from polio until onset of LEoP and self-rated disability).

METHOD: Ninety-three community-dwelling persons with clinically verified LEoP responded to a postal survey with the Sense of Coherence Scale (SOC-13). A hierarchical multiple regression analysis was performed to explore the associations with SOC.

RESULTS: SOC varied considerably among the participants. The mean and median SOC-13 total sum score was 71.8 and 76 points, which is similar to age-matched non-disabled people. The number of years before onset of LEoP and self-rated disability together with the participants' marital status and level of education explained 37% ($p < 0.001$) of the variance in SOC.

CONCLUSION: Persons with LEoP have a level of SOC indicating that they generally have the ability to understand, handle and being motivated when dealing with stressful events and problems arising in their lives as a result of their disability. Being married and having a higher education, living many years before onset of LEoP and perceiving a mild to moderate disability contributed to a strong SOC.

Keywords: Adaptation, psychological, disabled persons, Postpoliomyelitis syndrome, rehabilitation, Sense of Coherence

1. Introduction

During the first half of the 20th century, millions of people around the world acquired paralytic polio, also referred to as infantile paralysis (Williams, 2013). As mostly children were affected, polio turned out to be one of the most frightening infections at a time when many other infectious diseases were being successfully prevented. In 1955 the polio vaccine was introduced in the United States (Centers for Disease Control and Prevention, CDC, USA) and shortly thereafter general vaccination began in other parts of the world. In Sweden, one of the most affected countries in the world at that time, a government-supported vaccination program began in 1957 (Axelsson, 2004), which led to a rapid reduction in the number of new cases of polio. From 1988 and onwards, major efforts have been made worldwide to completely eradicate

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polio through a massive vaccination program, and in 2017 less than 100 new cases were reported (The Global Polio Eradication Initiative, Switzerland).

Even though the global initiative to combat polio has been very successful, the long-term consequences of the initial infection may remain well into the 21th century. Many persons who recovered from the acute paralytic polio infection can several decades later experience new symptoms, such as muscle weakness, muscle fatigability, general fatigue and pain during activities and at rest, referred to as late effects of polio (LEoP) or post-polio syndrome (PPS) (Lexell, 2014). It is estimated that up to 80% of those who acquired paralytic polio may develop LEoP (Farbu, Gilhus, Barnes, Borg, de Visser, Driessen, et al., 2006), making it one of the most common neuromuscular conditions.

LEoP may lead to a life-long disability, affecting many aspects of a person's daily life and mental well-being. Hence, living with LEoP requires life style changes and an adaptation to the disability (Thoren-Jönsson, 2001). These persons may therefore benefit from being in contact with a rehabilitation clinic specialized in LEoP (Lexell, 2014). Through interdisciplinary goal-oriented rehabilitation they can acquire new skills, which, over time, contribute to a sense of control, taking on a changed valued self, a look to the future with confidence and an overall adaptation to a new but good life (Larsson Lund & Lexell, 2010).

An important component for successful adaptation and mental well-being is the person's global approach towards his or her disability. The word "salutogenesis", meaning origin of health, was 1979 developed by Aaron Antonovsky (Antonovsky, 1987) and represents a shift in medical focus from factors making people ill to factors promoting health and well-being. According to Antonovsky, there are psychological elements that explain why some people stay healthy, despite the strains of illness-promoting stressors. Antonovsky found that a central factor for staying healthy was a strong Sense of Coherence (SOC), comprising 'comprehensibility', 'manageability' and 'meaningfulness'. Comprehensibility is a cognitive element and the perception that the environment and daily events make sense, manageability is a component involving problem solving and personal resources, and meaningfulness is an emotional element, giving motivation and the perception that challenges are worthy of investment. Hence, a strong SOC entails the ability to understand, handle and being motivated when dealing with stressful events and problems arising as a result of a medical condition.

According to Antonovsky, SOC develops during childhood and adolescence. Early experiences of the environment being predictable and structured develop the component comprehensibility. A balance between challenges and personal ability develops manageability. The component meaningfulness grows when the child or adolescent experiences being a person of importance and a part that matters for the result. According to Antonovsky, SOC is also strengthened by resources such as wealth, intelligence, social support and cultural stability (Antonovsky, 1987). He defined such resources as general resistance resources (GRRs); the presence of appropriate GRRs help reduce the tension when exposed to a stressor, which strengthen SOC and increases health.

Taken together, SOC indicates how well a person handles stress that is a result of having a disability (Kenne Sarenmalm, Browall, Persson, Fall-Dickson, & Gaston-Johansson, 2013). A person with a strong SOC will view stressful events less as a threat compared to people with a weak SOC (Kennedy, Lude, Elfström, & Smithson, 2010). Therefore, SOC is of great importance when rehabilitation professionals support people with lifelong disabilities, such as LEoP, towards successful adaptation.

To be able to assess a person's SOC, Antonovsky developed the Sense of Coherence-29 Scale and subsequently the shorter SOC-13 scale (Antonovsky, 1993), and both scales have been used extensively in clinical research (Eriksson & Lindström, 2005). SOC has been assessed in persons with various life-long neurological disabilities, such as traumatic brain injury (Jacobsson, Westerberg, Malec, & Lexell, 2011), stroke (Tistad, Tham, von Koch, & Ytterberg, 2012), spinal cord-injury (Shakeri, Yazdanshenas Ghazwin, Rakizadeh, Moshari, Sharbatdaralaei, Latifi, & Tavakoli, 2016) and Parkinson's disease (Rosengren, Brogårdh, Jacobsson, & Lexell, 2016), and found to be positively related to various aspects of health and well-being (Eriksson & Lindström, 2006). To the best of our knowledge, no study has assessed SOC in people with LEoP.

Thus, the aim of the present study is to assess SOC in persons with LEoP, and to explore the association between SOC, demographics (age, gender, marital status and level of education) and variables related to their LEoP (age at acute poliomyelitis infection, number of years before onset of LEoP and self-rated disability).

2. Methods

2.1. Participants

A convenience sample of 130 community-dwelling persons with LEoP participated in this postal survey. They were selected from a clinical database at a post-polio rehabilitation clinic in a university hospital in the south of Sweden. All participants had a confirmed history of acute poliomyelitis with full or partial recovery, and new symptoms after at least 15 years of functional stability. As part of the verification of prior polio, an electromyogram (EMG) had been recorded in both arms and legs, and all participants had EMG findings indicative of prior polio in at least one limb. The participants were all ambulatory with or without mobility devices and not using a wheelchair as the main mode of transportation. They were living in ordinary housing and able to understand verbal and written instructions in Swedish. An exclusion criterion was the presence of other major medical conditions (such as stroke, Parkinson's disease or severe joint problems). Of the 130 invited persons, 97 gave their informed consent to participate; four persons were excluded due to missing data on the SOC-13 Scale. Thus, the total sample comprised 93 participants.

2.2. Ethics

The principles of the Helsinki Declaration were followed and the study was approved by the Regional Ethical Review Board in Lund, Sweden (Dnr 2016/134).

2.3. Procedure

Each participant received an invitation letter with information about the study, a questionnaire about demographics (gender, age, marital status and educational level), the Sense of Coherence Scale (SOC-13), and a prepaid envelope to return the questionnaire and the SOC-13 Scale. The participants were also asked to rate their disability as mild, moderate or severe. Data on the participants' age at the acute poliomyelitis infection and the number of years before onset of LEoP were obtained from the database in the rehabilitation clinic.

2.4. Sense of Coherence Scale (SOC-13 scale)

The Swedish version of the SOC-13 scale was used in the present study (http://www.salutogenesis.hv.se). The scale consists of 13 items measuring the three dimensions of SOC: comprehensibility (5 items), manageability (4 items) and meaningfulness (4 items) (Antonovsky, 1987; Antonovsky, 1993). Respondents answer questions such as "Do you have the feeling that you are in an unfamiliar situation, and don't know what to do?" (comprehensibility); "Do you have the feeling that you are being treated unfairly?" (manageability); "Do you have the feeling that you don't really care about what goes on around you?" (meaningfulness). Responses are given on a 7-point Likert scale ranging from 'agree' to 'disagree', with statements at each end of the scale like 'very often' (1 point) and 'very seldom' or 'never' (7 points). According to Antonovsky, the responses representing the three dimensions (comprehensibility, manageability and meaningfulness) are highly integrated and should not be summed separately; instead, the responses on each item are used to calculate a total sum score that ranges from 13 to 91 points. A greater SOC-13 total sum score indicates a stronger SOC, yet there are no definite cut-off values defining a strong or a weak SOC. The SOC-13 scale has been found to be valid and reliable, with a Cronbach's α ranging from 0.70 to 0.92 (Antonovsky, 1993; Eriksson & Lindström, 2005). In a sample of 2003 Swedes, selected to be representative of the Swedish population, the mean SOC-13 total sum score was 65.1 points for men and 64.0 points for women (Larsson & Kallenberg, 1996).

2.5. Data and analyses

Means, medians, standard deviations, minimum and maximum values, and frequencies were used when appropriate. To examine differences between respondents and non-respondents, *t*-tests, Mann-Whitney U-tests and Chi square tests were used (Altman, 1990).

Bivariate analyses using the Spearman rank correlation coefficient (Spearman's rho) were performed to explore associations between SOC, demographics and variables related to LEoP. Thereafter, a hierarchical multiple regression analysis was performed with SOC as the dependent variable. All demographical variables and variables related to the participants' LEoP were included in the analyses as independent variables. The rationale was that previous studies (Larsson & Kallenberg, 1996; Eriksson & Lindström, 2005; Nilsson, Leppert, Simonsson, & Starrin, 2010; Lindmark, Stenström, Gerdin, & Hugoson, 2010; Nilsson, Holmgren, & Westman, 2000) have found that gender and age are associated with SOC. The age when the participants acquired their polio was also included in the analyses as SOC, according to Antonovsky, develops during childhood (Antonovsky, 1987). The two variables 'level of education' and 'self-rated disability' were represented by 3 response categories. Therefore, dummy variables for secondary school and university were created, with primary school as the reference category. Similarly, dummy variables for mild and moderate disability were created, with severe disability as the reference category.

The independent variables were added stepwise in 4 steps: 1) gender and age; 2) marital status and level of education; 3) variables related to LEoP (age at the acute poliomyelitis infection and number of years before onset of LEoP); and 4) self-rated disability. There was no indication of multicollinearity, as the strongest bivariate correlation was below 0.6 and no variable had a variance inflation factor above 2.0 or tolerance below 0.2 (Armitage, Berry, & Matthews, 2008; Field, 2013).

All analyses were performed using the IBM SPSS statistics version 22 (IBM Corporation, Armonk, New York, United States). Throughout, significance levels less than 0.05 were considered statistically significant.

3. Results

3.1. Characteristics of the participants

Data on the characteristics of the 93 participants are presented in Table 1. There were 45 men (48%) and 48 women (52%) with a mean age of 73.7 years. Almost 60% were married or cohabiting and the level of education varied equally between primary school, secondary school and higher education. The mean age at the acute poliomyelitis infection was 6.4 years and the mean number of years before onset of LEoP was 45.6 years. A majority of the participants (58%) rated themselves as having a moderate disability. Among the non-respondents, 18 were men (55%) and 15 were women (46%), with a mean age of 72.9 years. There were no significant differences between respondents and non-respondents regarding gender, age, age at the acute poliomyelitis infection and number of years before onset of LEoP.

3.2. Sense of Coherence

The mean SOC-13 total sum score was 71.8 points (SD 14.5) and the median 76 points (range 26-90, Q1 64.5, Q3 82.0).

Table 1
Characteristics of the 93 participants with late effects of polio

Gender	
Men, *n* (%)	45 (48)
Women, *n* (%)	48 (52)
Age (years)	
Mean (SD, range)	73.7 (8.3; 41–91)
Marital status	
Single, *n* (%)	36 (39)
Married/cohabiting, *n* (%)	54 (58)
Level of education	
Primary school (≤9 years), *n* (%)	31 (33)
Secondary school (10–12 years), *n* (%)	31 (33)
Higher education (≥13 years), *n* (%)	29 (31)
Age at acute poliomyelitis infection (years)	
Mean (SD)	6.4 (5.8)
Number of years before onset of late effects of polio	
Mean (SD)	45.6 (9.0)
Self-rated disability	
Mild, *n* (%)	18 (19)
Moderate, *n* (%)	54 (58)
Severe, *n* (%)	20 (22)

3.3. Bivariate analyses

In Table 2, the associations between the SOC-13 total sum score, gender, age, marital status, level of education, age at the acute poliomyelitis infection, number of years before onset of LEoP and self-rated disability are presented. SOC was significantly correlated with marital status, level of education and number of years before onset of LEoP and self-rated disability, but not with gender, age or age at the acute poliomyelitis infection. The strongest significant correlation was between SOC and self-rated disability (rho = –0.34; $p < 0.01$); greater SOC-13 scores were associated with less severe self-rated disability. There were also significant correlations between some of the independent variables. The strongest of these was between age and age at the acute poliomyelitis infection (rho = 0.45, $p < 0.01$); higher age was associated with higher age at the acute poliomyelitis infection.

3.4. Hierarchical multiple regression analysis

In Table 3, the results of the hierarchical multiple regression analysis with the SOC-13 total sum score as the dependent variable are presented. In the first step, gender and age were included but were not significant. In the second step, marital status and level of education were included, resulting in a significant change in the model (Sig F change <0.001); in this step both marital status and level of education, together with age, were significantly con-

Table 2
Correlations between the different variables for the 93 participants with late effects of polio

	Gender	Age	Marital status	Level of education	Age at acute poliomyelitis infection	Number of years before onset of late effects of polio	Self-rated disability
SOC-13	–0.05	0.15	0.26*	0.25*	0.01	0.32**	–0.34**
Gender		–0.06	–0.16	0.11	0.03	–0.22*	0.07
Age			–0.12	–0.17	0.45**	0.26*	0.12
Marital status				0.09	–0.01	–0.07	–0.25*
Level of education					0.11	–0.11	–0.19
Age at acute poliomyelitis infection						–0.15	–0.09
Number of years before onset of late effects of polio							–0.03

SOC-13 = Sense of Coherence Scale (13 items). Correlations between variables were analyzed with the Spearman rank correlation coefficient (Spearmans rho). Correlation is significant at the 0.05 level (*) and at the 0.01 level (**).

Table 3
Results of the hierarchical multiple regression analyses for the 93 participants with late effects of polio with Sense of Coherence Scale (SOC-13) as dependent variable

	SOC-13			
Gender	–0.12	–0.09	–0.04	–0.05
Age	0.17	0.27**	0.18	0.22
Marital status		0.36***	0.40***	0.30**
Level of education[1]				
Secondary school		0.28*	0.25*	0.19
Higher education		0.31**	0.30**	0.28**
Age at acute poliomyelitis infection			–0.01	–0.09
Number of years before onset of late effects of polio			0.30**	0.30**
Self-rated disability[2]				
Moderate				0.35**
Mild				0.37**
Significance	0.14	0.00	0.00	0.00
R2 Adj	0.02	0.22	0.29	0.37
R2 change	0.05	0.22	0.08	0.09
F-ratio	2.05	5.86	5.89	6.45
F change	2.05	8.05	4.62	5.84
Sig F change	0.14	0.00	0.01	0.00

Standardised beta coefficients are presented. [1] Level of education was transformed to dummy variables with primary school as the reference category. [2] Self-rated disability was transformed to dummy variables with severe disability as the reference category. (For details see 2.5 Data and analyses.). Correlation is significant at the 0.05 level (*), at the 0.01 level (**) and at the 0.001 level (***).

tributing to the variance in SOC. In the third step, when the variables age at the acute poliomyelitis infection and number of years before onset of LEoP were included, both resulted in a significant change in the model (Sig F change = 0.01). In the fourth and final step, self-rated disability was also significantly changing the model (Sig F change <0.001). The final model explained 37% (R2 adj 0.37, $p < 0.001$) of the variance in SOC. The variables contributing significantly to the model were marital status, level of education, number of years before onset of LEoP, and self-rated disability; being married or cohabiting, having a higher level of education, having lived many years before experiencing LEoP and perceiving a mild or moderate disability, were associated with a greater SOC.

4. Discussion

This is, to the best of our knowledge, the first study that has assessed SOC in persons with LEoP and explored the association with demographics and variables related to their disability. The main findings were that SOC varied considerably among the participants with a mean and median SOC-13 total sum score of 71.8 and 76 points, which is similar or even greater than in non-disabled people. From the multiple regression analysis, the participants' marital status and level of education, together with the number of years before onset of LEoP and self-rated disability contributed significantly to the variance in SOC.

4.1. SOC in people with late effects of polio

The mean SOC-13 total sum score in the present study is greater than the sample of 2003 persons (65.1 points for men and 64.0 points for women) selected to be representative of the Swedish population (Larsson & Kallenberg, 1996), and similar to cohorts of non-disabled people of similar age. Nilsson and co-workers (Nilsson et al., 2010) reported a mean SOC-13 total sum score of 72.1 points among a large group of men and women age 70–74 years, and Lindmark and co-workers (Lindmark et al., 2010) reported a mean SOC-13 total sum score of 72.7 points among 70 year old people.

When comparing with other lifelong disabilities, the participants in the present study have a similar or even greater SOC-13 total sum score. In cohorts of older people with stroke, Tistad and co-workers (Tistad et al., 2012) reported a median SOC-13 total sum score of 78 points (mean age 68 years) and Ekstam and co-workers (Ekstam, Johansson, Guidetti, Eriksson, & Ytterberg, 2015) a median of 79.5 points (median age 72.5 years). Two studies of older people with Parkinson's disease have found lower SOC-13 scores. Gison and co-workers (Gison, Rizza, Bonassi, Dall'Armi, Lisi, & Giaquinto, 2014) reported a mean SOC-13 total sum score of 53.7 points (mean age 67 years) and Rosengren and co-workers (Rosengren, Brogardh, Jacobsson, & Lexell, 2016) a mean total SOC-13 sum score of 65.8 points (mean age 70.1 years). The similarities and differences in the SOC-13 total sum score between these populations with life-long disabilities could be attributed to the diagnosis and the course of the disability, whether it is stable (stroke) or progressive (Parkinson's disease). In people with LEoP, there are only small deteriorations over a period of time, and, consequently, LEoP can be seen as a fairly stable disability (Stolwijk-Swuste, Beelen, Lankhorst, & Nollet, 2005; Flansbjer, Lexell & Brogårdh, 2017).

Taken together, ambulant persons with LEoP generally have a strong SOC, indicating that they have the ability to understand, handle and being motivated when dealing with stressful events and problems arising as a result of their disability. However, some people with LEoP have a weak SOC, inferring that they view stressful events more as a threat than people with a strong SOC and are less adapted to their disability. Antonovsky (Antonovsky, 1993) meant that this indicates poorer coping resources. However, Antonovsky did not relate SOC to any specific coping strategies. It would therefore be of interest in future studies to explore how SOC is related to specific coping strategies in people with LEoP as well as other lifelong disabilities.

4.2. SOC and the association with variables related to late effects of polio

The final regression model explained as much as 37% of the variance in SOC, and the number of years before onset of LEoP and the participants' self-rated disability were most strongly associated with SOC. This implies that a person who has lived several decades without experiencing LEoP and then perceives only mild or moderate disability has a strong SOC. It may be that people with a strong SOC, using appropriate coping strategies and adapting well, rate his or her disability as less severe than people with a weaker SOC. Alternatively, it may be that SOC develops as a result of a person's life situation and could be related to aspects such as activities of daily living, perceived participation and life satisfaction. In particular, life satisfaction, representing the degree to which an individual's aspirations and achievements are being met, has been found to be positively associated with SOC in other life-long disabilities, such as Parkinson's disease (Rosengren et al., 2016) and traumatic brain injury (Jacobsson et al., 2011). Further studies are needed to understand what factors are related to SOC in people with LEoP.

4.3. SOC and the association with marital status and level of education

Participants that were married or cohabiting rated a stronger SOC. Several studies of both disabled and non-disabled people report that having close relations and sufficient social support is related to a strong SOC (Holmberg, Thelin, & Stiernström, 2004; Giglio, Rodriguez-Blazquez, de Pedro-Cuesta, & Forjaz, 2015; Read, Aunola, Feldt, Leinonen, & Ruoppila, 2005; Nilsson et al., 2000; Silverstein & Heap, 2015; Krantz & Östergren, 2004; Larsson & Kallenberg, 1996). Moreover, a longitudinal study (Nilsson, Holmgren, Stegmayr, & Westman, 2003) reported that decreased social support was associated with a weaker SOC. It is reasonable to assume that close relations and social support makes the environment more manageable and meaningful, thereby contributing to a stronger SOC.

Participants with a higher level of education also rated a stronger SOC. Some studies have reported an association between SOC and the level of education (Jueng, Tsai, & Chen, 2016; Giglio et al., 2015; Silverstein & Heap, 2015), whereas other studies have reported no or very limited difference in SOC in relation to the level of education (Larsson & Kallenberg, 1996; Nilsson et al., 2000; Holmberg et al., 2004). Education clearly makes the environment more comprehensible, which would strengthen the ability to handle stressful events. Furthermore, higher education is often accompanied with better economy and higher social status, both being GRRs that strengthens SOC (Antonovsky, 1987).

4.4. SOC and the association with gender, age and age at the acute infection

The multiple regression analysis revealed that the participants' gender was not associated with SOC. Some studies have found that SOC is greater for men than women (Larsson & Kallenberg, 1996; Nilsson et al., 2010). Generally, though, most studies report no difference in SOC between men and women (Antonovsky, 1997; Eriksson & Lindström, 2005).

We also found that the participants' age was not associated with SOC. This is consistent with Antonovsky's concept that SOC develops up to the age of 30, is thereafter stable and can only change if an adult person initiates a new pattern of life experiences (Antonovsky, 1987). However, several studies have in fact reported increases in SOC with advancing age, suggesting that SOC do continue to develop during a life-time (Larsson & Kallenberg, 1996; Eriksson & Lindström, 2005; Nilsson et al., 2010; Nilsson et al., 2000; Lindmark et al., 2010). This implies that SOC may not be as stable as Antonovsky originally proposed (Smith, Breslin, & Beaton, 2003; Snekkevik, Anke, Stanghelle, & Fugl-Meyer, 2003), and that specific interventions may affect SOC in a positive direction. Further longitudinal studies are needed to elucidate if SOC changes with advancing age also in people with LEoP.

Finally, SOC was not related to the participants' age at the acute poliomyelitis infection. Thus, when during childhood one acquired polio did not affect SOC several decades later. This is consistent with a study exploring the influence of childhood and adult life experiences on SOC, indicating that SOC is more dependent on the present life situation than on childhood experiences (Krantz & Östergren, 2004).

4.5. Clinical implications and future research

Given the importance of SOC and the possible association with factors related to a person's life situation (Eriksson & Lindström, 2006), it has been suggested that SOC may serve as a tool to identify those who are at risk of poorer quality of life and in need of supportive care (Mendel, Bergenius, & Langius, 2001). Thus, SOC could be used as a screening tool to identify people with LEoP in need of rehabilitation. Further studies are, however, needed to explore the association between SOC and other factors of importance for persons' with LEoP and their life situation. Here, qualitative interviews of people with LEoP and different levels of SOC may be of value. Through in-depth interviews we could enhance our understanding of their comprehensibility, manageability and meaningfulness in daily life. This could assist us in determining the use of SOC as a potential screening tool.

The question then remains if rehabilitation for people with LEoP, in particular those with low SOC scores, could make their life situation more comprehensible, more manageable and more meaningful. It has been shown that SOC can improve through interventions (Lindström & Eriksson, 2005; Tan, Chan, Wang, & Vehvilainen-Julkunen, 2016; Weissbecker, Salmon, Studts, Floyd, Dedert, & Sephton, 2002; Valtonen, Raiskila, Veijola, Laksy, Kauhanen, Kiuttu, et al., 2015), at least in a short-term perspective. For people with LEoP, interdisciplinary goal-oriented rehabilitation is described as a turning point in life (Larsson Lund & Lexell, 2010). Following such a rehabilitation program people with LEoP described that they adapted to a new but good life. During the program, the participants were taught to write their own rehabilitation plan. This forced them to reflect on their life and their difficulties in managing daily activities. This, in turn, made their situation clearer and assisted them to describe their difficulties and needs to the rehabilitation professionals. The participants described that this increased their awareness of the necessary changes in their daily life and their own responsibility to accomplish these changes.

Thus, much of what we know of the effects of rehabilitation for persons with LEoP is linked to SOC and potential improvements in SOC. It is possible that a structured program including the use of a rehabilitation plan can support their overall adaptation towards an enhanced comprehensibility, manageability and meaningfulness. An important area for future research is therefore to establish if and how interdisciplinary goal-oriented rehabilitation for people with LEoP and the use of a rehabilitation plan based on the International Classification of Functioning, Disability and Health (ICF) (Lexell & Brogårdh, 2015) can strengthen their SOC.

4.6. Strengths and limitations

A strength of the study was the high (75%) response rate. There were also some limitations. As we only included ambulant persons with LEoP the conclusions should be limited to those who are not severely restricted by their disability. Moreover, the cross-sectional design does not allow us to make any causal inferences. Longitudinal studies assessing SOC and other variables over time would provide a better understanding of the cause and effect.

5. Conclusion

Persons with LEoP have a level of SOC that is similar to age-matched non-disabled people. Thus, persons who in their childhood acquired acute poliomyelitis and later in life experience new symptoms and a gradually worsening disability, generally have the ability to understand, handle and being motivated when dealing with problems arising in their lives as a result of their disability. The participants' marital status and level of education together with variables related to their LEoP were contributing to a strong SOC. Further cross-sectional as well as longitudinal studies are needed to understand how SOC is associated with other factors in persons with LEoP, how SOC changes over time as the disability progresses, and if SOC can be strengthened through rehabilitation.

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Conflict of interest

None to report.

References

Altman, D. G. (1990). *Practical statistics for medical research*: CRC press.

Antonovsky, A. (1987). *Unraveling the mystery of health: How people manage stress and stay well*: Jossey-Bass.

Antonovsky, A. (1993). The structure and properties of the sense of coherence scale. *Social Science & Medicine*, *36*(6), 725-733.

Armitage, P., Berry, G., & Matthews, J. N. S. (2008). *Statistical methods in medical research*: John Wiley & Sons.

Axelsson, P. (2004). The history of polio in Sweden – from infantile paralysis to polio vaccine (In Swedish). *Svensk Medicinsk Tidskrift*, *8*(1), 57-66.

Centers for Disease Control and Prevention, CDC, USA. Retrieved from http://www.cdc.gov. Accessed 13 march 2017.

Ekstam, L., Johansson, U., Guidetti, S., Eriksson, G., & Ytterberg, C. (2015). The combined perceptions of people with stroke and their carers regarding rehabilitation needs 1 year after stroke: A mixed methods study. *BMJ Open*, *5*(2), 1-8.

Eriksson, M., & Lindström, B. (2005). Validity of Antonovsky's sense of coherence scale: A systematic review. *Journal of Epidemiology & Community Health*, *59*(6), 460-466.

Eriksson, M., & Lindström, B. (2006). Antonovsky's sense of coherence scale and the relation with health: A systematic review. *Journal of Epidemiology & Community Health*, *60*(5), 376-381.

Farbu, E., Gilhus, N. E., Barnes, M. P., Borg, K., de Visser, M., Driessen, A., et al. (2006). EFNS guideline on diagnosis and management of post-polio syndrome. Report of an EFNS task force. *European Journal of Neurology*, *13*(8), 795-801.

Field, A. (2013). *Discovering statistics using IBM SPSS statistics*: Sage.

Flansbjer, U. B., Lexell, J., & Brogårdh, C. (2017) Predictors of changes in gait performance over 4 years in persons with late effects of polio. *NeuroRehabilitation*, *41*(2), 403-411.

Giglio, R. E., Rodriguez-Blazquez, C., de Pedro-Cuesta, J., & Forjaz, M. J. (2015). Sense of coherence and health of community-dwelling older adults in Spain. *International Psychogeriatrics*, *27*(4), 621-628.

Gison, A., Rizza, F., Bonassi, S., Dall'Armi, V., Lisi, S., & Giaquinto, S. (2014). The sense-of-coherence predicts health-related quality of life and emotional distress but not disability in Parkinson's disease. *BMC Neurol*, *14*, 193.

Hollingsworth, L., Didelot, M. J., & Levington, C. (2002). Post-polio syndrome: Psychological adjustment to disability. *Issues in Mental Health Nursing*, *23*(2), 135-156.

Holmberg, S., Thelin, A., & Stiernström, E.-L. (2004). Relationship of sense of coherence to other psychosocial indices. *European Journal of Psychological Assessment*, *20*(4), 227-236.

Jacobsson, L. J., Westerberg, M., Malec, J. F., & Lexell, J. (2011). Sense of coherence and disability and the relationship with life satisfaction 6-15 years after traumatic brain injury in northern Sweden. *Neuropsychological Rehabilitation*, *21*(3), 383-400.

Jueng, R. N., Tsai, D. C., & Chen, I. J. (2016). Sense of Coherence among Older Adult Residents of Long-Term Care Facilities in Taiwan: A Cross-Sectional Analysis. *PLoS One*, *11*(1).

Kenne Sarenmalm, E., Browall, M., Persson, L. O., Fall-Dickson, J., & Gaston-Johansson, F. (2013). Relationship of sense of coherence to stressful events, coping strategies, health status, and quality of life in women with breast cancer. *Psychooncology*, *22*(1), 20-27.

Kennedy, P., Lude, P., Elfström, M. L., & Smithson, E. (2010). Sense of coherence and psychological outcomes in people with spinal cord injury: Appraisals and behavioural responses. *British Journal of Health Psychology*, *15*(Pt 3), 611-621.

Kling, C., Persson, A., & Gardulf, A. (2000). The health-related quality of life of patients suffering from the late effects of polio (post-polio). *Journal of Advanced Nursing*, *32*(1), 164-173.

Krantz, G., & Östergren, P. O. (2004). Does it make sense in a coherent way? Determinants of sense of coherence in Swedish women 40 to 50 years of age. *International Journal of Behavioral Medicine*, *11*(1), 18-26.

Larsson, G., & Kallenberg, K. O. (1996). Sense of coherence, socioeconomic conditions and health. *The European Journal of Public Health*, *6*(3), 175-180.

Larsson Lund, M., & Lexell, J. (2010). A positive turning point in life–how persons with late effects of polio experience the influence of an interdisciplinary rehabilitation programme. *Journal of Rehabilitation Medicine*, *42*(6), 559-565.

Lexell, J. (2014). *Postpoliomyelitis syndrome* (W. Frontera Ed.). Philadelphia: Elsevier Saunders.

Lexell, J., & Brogårdh, C. (2015). The use of ICF in the neurorehabilitation process. *NeuroRehabilitation*, *36*(1), 5-9.

Lindmark, U., Stenström, U., Gerdin, E. W., & Hugoson, A. (2010). The distribution of "sense of coherence" among Swedish adults: A quantitative cross-sectional population study. *Scandinavian Journal of Public Health*, *38*(1), 1-8.

Lindström, B., & Eriksson, M. (2005). Salutogenesis. *Journal of Epidemiology & Community Health*, *59*(6), 440-442.

Mendel, B., Bergenius, J., & Langius, A. (2001). The sense of coherence: A tool for evaluating patients with peripheral vestibular disorders. *Clinical Otolaryngology and Allied Science*, *26*(1), 19-24.

Nilsson, B., Holmgren, L., Stegmayr, B., & Westman, G. (2003). Sense of coherence–stability over time and relation to health, disease, and psychosocial changes in a general population: A longitudinal study. *Scandinavian Journal of Public Health*, *31*(4), 297-304.

Nilsson, B., Holmgren, L., & Westman, G. (2000). Sense of coherence in different stages of health and disease in northern Sweden – gender and psychosocial differences. *Scandinavian Journal of Primary Health Care*, *18*(1), 14-20.

Nilsson, K. W., Leppert, J., Simonsson, B., & Starrin, B. (2010). Sense of coherence and psychological well-being: Improvement with age. *Journal of Epidemiology & Community Health*, *64*(4), 347-352.

The Global Polio Eradication Initiative, Geneva, Switzerland. Retrieved from http://www.polioeradication.org. Accessed 13 March 2017.

Read, S., Aunola, K., Feldt, T., Leinonen, R., & Ruoppila, I. (2005). The relationship between generalized resistance resources, sense of coherence, and health among Finnish people aged 65-69. *European Psychologist*, *10*(3), 244-253.

Rosengren, L., Brogårdh, C., Jacobsson, L., & Lexell, J. (2016). Life satisfaction and associated factors in persons with mild to moderate Parkinson's disease. *NeuroRehabilitation*, *39*(2), 285-294.

Shakeri, J., Yazdanshenas Ghazwin, M., Rakizadeh, E., Moshari, A., Sharbatdaralaei, H., Latifi, S., & Tavakoli, S. A. (2016). Do spinal cord-injured individuals with stronger sense of coherence use different psychological defense styles? *Spinal Cord*, *54*(10), 843-848.

Silverstein, M., & Heap, J. (2015). Sense of coherence changes with aging over the second half of life. *Advances in Life Course Research*, *23*, 98-107.

Smith, P. M., Breslin, F. C., & Beaton, D. E. (2003). Questioning the stability of sense of coherence–the impact of socio-economic status and working conditions in the Canadian population. *Social Psychiatry and Psychiatric Epidemiology*, *38*(9), 475-484.

Snekkevik, H., Anke, A. G., Stanghelle, J. K., & Fugl-Meyer, A. R. (2003). Is sense of coherence stable after multiple trauma? *Clinical Rehabilitation*, *17*(4), 443-453.

Stolwijk-Swuste, J. M., Beelen, A., Lankhorst, G. J., & Nollet, F. (2005). The course of functional status and muscle strength in patients with late-onset sequelae of poliomyelitis: A systematic review. *Archives of Physical Medicine & Rehabilitation*, *86*(8), 1693-1701.

Tan, K. K., Chan, S. W., Wang, W., & Vehvilainen-Julkunen, K. (2016). A salutogenic program to enhance sense of coherence and quality of life for older people in the community: A feasibility randomized controlled trial and process evaluation. *Patient Education and Counseling*, *99*(1), 108-116.

Thoren-Jonsson, A. L. (2001). Coming to terms with the shift in one's capabilities: A study of the adaptive process in persons with poliomyelitis sequelae. *Disability & Rehabilitation*, *23*(8), 341-351.

Tistad, M., Tham, K., von Koch, L., & Ytterberg, C. (2012). Unfulfilled rehabilitation needs and dissatisfaction with care 12 months after a stroke: An explorative observational study. *BMC Neurol*, *12*, 40.

Valtonen, M., Raiskila, T., Veijola, J., Laksy, K., Kauhanen, M. L., Kiuttu, J., et al. (2015). Enhancing sense of coherence via early intervention among depressed occupational health care clients. *Nordic Journal of Psychiatry*, *69*(7), 515-522.

Weissbecker, I., Salmon, P., Studts, J. L., Floyd, A. R., Dedert, E. A., & Sephton, S. E. (2002). Mindfulness-based stress reduction and sense of coherence among women with fibromyalgia. *Journal of Clinical Psychology in Medical Settings*, *9*(4), 297-307.

Williams, G. (2013). *Paralysed with fear: The story of polio*: Springer.

Paper II

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Original Research

Sense of Coherence and the Association with Sociodemographics and Disability Related Factors in Persons with Late Effects of Polio

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Abstract

Background: Sense of Coherence (SOC) is important for successful adaptation in persons with life-long disabilities. A previous study has shown that persons with Late Effects of Polio (LEoP) have a level of SOC indicating that they generally have the ability to understand, handle, and have the motivation to deal with stressful events and problems arising in their lives. However, no study has explored the associations between SOC, sociodemographics, and disability-related factors in persons with LEoP.
Objective: To explore the associations between SOC, sociodemographics, and disability-related factors in persons with LEoP.
Design: A cross-sectional design.
Setting: University hospital outpatient clinic.
Study Participants: Ninety-three persons (mean age 74 years, 52% women) with LEoP.
Main Outcome Measurements: Swedish versions of the Sense of Coherence scale (SOC-13), Self-reported Impairments in Persons with Late Effects of Polio (SIPP) scale, Reintegration to Normal Living Index (RNL-I) (subscales “Daily Functioning” and “Perceptions of Self”), and Satisfaction With Life Scale (SWLS).
Methods: The participants responded to a postal survey with background information and the four rating scales. To determine factors associated with SOC, a hierarchical regression analysis was performed with SOC as the dependent variable.
Results: Higher age, less bothered by symptoms of LEoP, better perceptions of self, and higher life satisfaction were significantly associated with a greater SOC score. The final model explained 60% of the variance in the SOC (R^2 Adj = 0.60, $P < .001$).
Conclusions: The strong association between SOC, higher age, and disability-related factors is important to consider in the rehabilitation of persons with LEoP. This knowledge can assist rehabilitation professionals to plan interventions that enable people with LEoP to develop strategies to better manage their daily life.
Level of Evidence: III.

Introduction

In persons who have had paralytic poliomyelitis during childhood or adolescence, new symptoms may arise after several decades of stability, a condition referred to as Late Effects of Polio (LEoP) or post-polio syndrome.[1] Impairments commonly seen in persons with LEoP include muscle weakness, general fatigue, and pain during activities and at rest.[1] These impairments may lead to limitations in daily activities and cause restrictions in participation,[2,3] which can impede life satisfaction.[4,5] Even though there is no cure, persons with LEoP can benefit from an individualized goal-oriented, interdisciplinary rehabilitation program.[6] With a variety of targeted interventions, they can go through a process of change and thereby adapt to a different but good life.

An essential component in successful adaptation is a person’s overall approach toward stressors in life. As an estimate of the ability to manage stressors, the concept Sense of Coherence (SOC), developed by Aaron Antonovsky,[7] is often used. Persons with a strong SOC are able to understand and handle stressful situations in a positive way and have the motivation to deal with them, whereas those with a weak SOC can be considered to have difficulties to manage the situation of living with a

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lifelong disability. A strong SOC has therefore been linked to successful adaptation after an injury or a disease.[8,9]

In a recent study[10] we explored, for the first time, SOC in persons with LEoP. We found that they have similar levels of SOC as nondisabled persons indicating that they generally have the ability to understand, handle, and have the motivation to deal with stressful events and problems arising in their lives. However, SOC varied considerably and persons experiencing a more severe disability had a weaker SOC than those experiencing mild or moderate disability. This indicates that factors in a person's present life situation can be associated with SOC. Therefore, knowledge of factors associated with SOC could increase our understanding of the life situation among persons with LEoP and how rehabilitation professionals could plan interventions that support their adaptation process with this lifelong disability.

Thus, the objective of this study is to explore the associations between SOC, sociodemographics, and disability-related factors in persons with LEoP.

Material and Methods

Study Design

This study is part of a larger project investigating SOC and associated factors in persons with LEoP. Data describing SOC have been presented in an earlier study.[10] In the present cross-sectional study, we explored the associations between SOC, age and gender, and some components of the International Classification of Functioning, Disability and Health (ICF) model,[11] namely self-reported impairments, activity limitation and participation restrictions, and life satisfaction.

Study Participants

A convenience sample of 130 persons with LEoP was selected from a database in a post-polio rehabilitation clinic in a university hospital in southern Sweden. All participants were community dwelling and able to walk indoors, with or without walking devices, and were not using a wheelchair as their main mode of transportation. They had a verified history of acute poliomyelitis in their childhood or adolescence, a period of stability of at least 15 years and subsequently new symptoms that had remained for at least 1 year. An electromyogram (EMG) had been recorded in the upper and lower limbs as part of the verification of prior polio, and the EMG findings were in agreement with prior polio in at least one limb. The exclusion criteria were presence of other major medical conditions, such as stroke or Parkinson disease and inability to understand verbal and written instructions in Swedish. Of the invited 130 persons, 97 gave their written informed consent to take part in the study (response rate 75%); four persons were excluded due to missing data on the SOC-13 scale. Accordingly, the total sample comprised 93 persons.

Ethical Considerations

The principles of the Helsinki Declaration were followed and the study was approved by the Regional Ethical Review Board in Lund, Sweden (Dnr 2016/134).

Procedure

Each potential participant received by mail an invitation letter with information about the study, a questionnaire about sociodemographics (gender, age, marital status, and educational level) and Swedish versions of four rating scales: (1) the Sense of Coherence scale (SOC-13), (2) the Self-reported Impairments in Persons with Late Effects of Polio (SIPP) scale, (3) the Reintegration to Normal Living Index (RNL-I) and (4) the Satisfaction With Life Scale (SWLS).

Rating Scales

In the present study, we used the shorter form of the Sense of Coherence scale, SOC-13, developed by Antonovsky.[7] The scale consists of 13 items measuring the components comprehensibility (five items), manageability (four items), and meaningfulness (four items). Comprehensibility is the perception to understand daily stressors. Manageability is the ability to handle stressors by yourself or by using other resources. Meaningfulness is the motivation and the will to take on the challenges stressors induce. The respondent answers on a 7-point Likert scale anchored to statements describing different situations (eg, Doing the things you do every day is: a source of deep pleasure and satisfaction/a source of pain and boredom). The total score ranges from 13 to 91 points. A greater score indicates stronger SOC, but there are no exact cutoff values defining a strong or weak SOC. The SOC-13 scale has been found to be valid and reliable with a Cronbach's α ranging from 0.70 to 0.92.[12] In a Swedish reference sample, the mean SOC-13 total scores were 65 points for men and 64 points for women.[13]

As ratings of LEoP-related impairments, we used the SIPP scale.[14] The scale was developed to specifically describe self-reported impairments, as defined by the ICF, in persons with LEoP. It consists of 13 items assessing the degree the respondent has been bothered, during the past 2 weeks, by various impairments directly or indirectly related to LEoP. The 13 items cover muscle weakness, muscle fatigue, muscle and/or joint pain during physical activity and at rest, sensory disturbance, breathing difficulties during physical activity and at rest, cold intolerance, general fatigue, sleep disturbances, concentration difficulties, memory difficulties, and mood swings. There are four response options, ranging from 1 (not at all) to 4 (extremely). The sum score for all items ranges from 13 to 52 points. Greater scores indicate that the person is more bothered by impairments associated with LEoP. SIPP has been Rasch analyzed and is unidimensional,[14] and it has also been examined for test-retest reliability with an intraclass correlation coefficient of 0.88.[15]

The RNL-I[16] is a rating scale of self-perceived activity limitations and participation restrictions in a person's life situation. Being reintegrated means "the reorganization of physical, psychologic, and social characteristics so that the individual can resume well-adjusted living after incapacitating illness or trauma".[16] The RNL-I has been shown to adequately assess participation according to ICF criteria.[17] It is composed of 11 items. The first eight items belong to the subscale Daily Functioning (ie, mobility, activities in daily life, self-care, occupation) with statements such as "I move around my community as I feel necessary." The last three items belong to the subscale Perceptions of Self (ie, personal relationships, comfort with self, coping skills) with statements like "In general I am comfortable with myself when I am in the company of others." Each statement is followed by a 4-point Likert scale anchored to the statements 1 (does not describe my situation) and 4 (fully describes my situation). The subscale Daily Functioning ranges from 8 to 32 points and the subscale Perceptions of Self from 3 to 12 points, yielding a total score of 11 to 44 points. For both subscales greater scores indicate better reintegration. The RNL-I has been found to be valid and reliable with Cronbach's α values between 0.73-0.97.[18]

Life satisfaction was rated with the SWLS, which is used as an overall summation of a person's life situation.[19] SWLS describes a person's subjective well-being and covers his or her estimation of having an ideal life, satisfaction with goals achieved, and a wish for change. The scale consists of five questions rated on a 7-point Likert scale ranging from "strongly disagree" to "strongly agree." This yields a total score of 5 to 35 points, where a greater score represents higher life satisfaction. A score of 20 points is considered the midpoint between satisfied and dissatisfied.[19] The SWLS has been widely used in research and clinical work. The scale demonstrates good convergence with other scales of life satisfaction and has a Cronbach's alpha value exceeding 0.80.[19]

Data and Analyses

All analyses were performed using the IBM SPSS statistics version 22.[20] Means, medians, standard deviations, and minimum and maximum values were used when appropriate. To examine differences between the participants (ie, respondents) and nonrespondents, independent sample *t*-tests, Mann-Whitney U-tests and chi-square tests were used.[21]

To investigate factors associated with SOC, a hierarchical regression analysis was performed with SOC as the dependent variable. The total sum scores of SIPP, the two subscales of RNL-I, and SWLS were added consecutively as independent variables. Age and gender were also included as independent variables because previous studies have shown that these factors are associated with SOC.[12,13,22-24] The independent variables were entered in four steps with age and gender in the first step, SIPP in the second step, the two subscales of RNL-I in the third step, and SWLS in the fourth step. There were no residual outliers in the model. All variables had a variance inflation factor far below 10 and a tolerance well above 0.1, indicating that there was no multicollinearity.[25] Significance levels <.05 were considered statistically significant.

Results

Participant Characteristics

Data on the 93 participants are presented in Table 1. There were 48 women (52%) and the mean age of the participants was 74 years (median 75, SD 8, range 41-91 years). Most of the participants (58%) were married or cohabitating. Eighty-one persons (87%) were retired. A majority (70 persons, 75%) was using assistive devices. Among the nonrespondents, there were 18 men (55%) and 15 women (45%) with a mean age of 73 years. There

Table 1
Characteristics of the 93 participants with Late Effects of Polio (LEoP) and the nonrespondents

	Participants	Nonrespondents
Gender, n (%)		
Men	45 (48%)	18 (55%)
Women	48 (52%)	15 (45%)
Age (y)		
Mean (SD)	74 (8)	73 (9)
Range	41-91	39-87
Age at polio onset		
Mean (SD)	6 (6)	6 (6)
Marital status		
Single	36 (39%)	
Married/cohabiting	54 (58%)	
Living situation		
House	53 (57%)	
Apartment	38 (41%)	
Vocational status		
Working	8 (9%)	
Old age pension/disability pension	81 (87%)	
Sick leave	2 (2%)	
Assistive devices		
No device	22 (24%)	
Indoor device	1 (1%)	
Outdoor device	23 (25%)	
Both indoor and outdoor devices	46 (50%)	
Walking ability		
<100 m	28 (30%)	
100-1000 m	37 (40%)	
≥1000 m	28 (30%)	

NB: A few of the participants did not respond to some questions so the number of responses is not always 93.

Table 2
Summary of the rating scales

	Mean	Median	SD	Min	Max
SOC-13 (n = 93)	71.8	76	14.5	26	90
SIPP (n = 87)	28.2	27	7.7	14	47
RNL-I					
Daily Functioning (n = 90)	24.8	26	6.4	9	32
Perceptions of Self (n = 93)	10.1	10	2.0	5	12
SWLS (n = 92)	24.7	26	6.9	5	35

SOC-13 = Sense of Coherence scale; SIPP = Self-reported Impairments in Persons with Late Effects of Polio scale; RNL-I = Reintegration to Normal Living Index; SWLS = Satisfaction With Life Scale.
The numbers in parentheses indicate the number of responses.

were no significant differences between the participants and nonrespondents regarding age or gender.

Data for the Rating Scales

In Table 2, data from the four rating scales are presented. The mean SOC-13 score was 71.8 points (SD 14.5) and the mean SIPP score 28.2 points (SD 7.7), respectively. The mean RNL-I score was 24.8 points (SD 6.4) for the subscale Daily Functioning and 10.1 points (SD 2.0) for the subscale Perceptions of Self. The mean SWLS score was 24.7 points (SD 6.9).

Hierarchical Regression Analysis

In Table 3, the results from the hierarchical regression analysis are presented. In the first step, with age and gender as independent variables, the model did not reach significance. In the second step, when SIPP was included, the model reached significance and explained 32% (R^2 Adj = 0.32) of the variance in SOC-13; both age and SIPP contributed significantly to the variance of SOC-13. In the third step, when the subscales of RNL-I were entered, this also resulted in a significant change ($P < .001$), but only the subscale Perceptions of Self together with age and SIPP contributed significantly to the variance in SOC-13. In the fourth and final step, the added variable SWLS contributed significantly to the model (Sig F change <.001); this final model explained 60% of the variance in SOC-13 (R^2 Adj = 0.60, $P < .001$).

Table 3
Results of the hierarchical regression analyses for the 93 participants with LEoP with Sense of Coherence Scale (SOC-13) as dependent variable

	SOC-13			
Gender	−0.06	−0.07	−0.07	−0.05
Age	0.23*	0.30**	0.28**	0.20*
SIPP		−0.54***	−0.30**	−0.18*
RNL-I				
Daily Functioning			0.11	0.10
Perceptions of Self			0.44***	0.23*
SWLS				0.41***
F-ratio	2.39	13.48	18.09	20.93
P value	.10	.00	.00	.00
R2 Adj	0.03	0.32	0.51	0.60
R2 change	0.06	0.28	0.20	0.08
F change	2.39	33.66	16.81	16.60
P value	.10	.00	.00	.00

Standardized beta coefficients are presented.
Correlation is significant at the .05 level (*), at the .01 level (**) and at the .001 level (***).

Discussion

Increased knowledge of factors associated with SOC, a determinant of successful adaptation following a lifelong disability, may enhance our understanding of the long-term life situation for people with LEoP. In this study, our main findings were that higher age, being less bothered by LEoP-related impairments, better perceptions of self, and a higher life satisfaction were associated with a stronger SOC, and together these variables explained as much as 60% of the variance in SOC-13.

SOC, Age and Gender

The hierarchical multiple regression analysis revealed that age, but not gender, contributed to the variance in SOC, with higher age being associated with a stronger SOC. This is consistent with several reports of greater SOC in older age.[12,13,22-24] The reason SOC is greater in older age is, however, not clear. Increasing age may generally lead to better self-awareness, deeper knowledge, and more life experiences, which potentially could strengthen SOC. Increasing age may also lead to better manageability, as children being grown up and retirement diminish one's everyday workload.

Previous studies have reported greater SOC scores for men,[13,22] but no gender differences in the normal population have also been presented.[23] One study[24] reported no gender differences in the total population, but greater SOC scores for men aged 60-70 years. When looking at the actual SOC scores, the differences between men and women[13,22] are small, only 1 or 2 points, and may therefore not have any real clinical importance. Moreover, these studies have explored SOC in nondisabled persons and no study has included people with a lifelong disability. Taken together, age seems to be of importance for SOC whereas further studies are needed to clarify the importance of gender for SOC in persons with disabilities.

SOC and SIPP

The mean value of SIPP indicates that the participants were mildly to moderately bothered by LEoP-related impairments, which is similar to other studies of ambulatory persons with LEoP.[26,27] SIPP contributed significantly to SOC in the analysis, indicating that being more bothered by LEoP-related impairments was associated with a lower level of SOC. This result differs somewhat from studies of other disability groups where SOC was not associated with the degree of symptoms. For example, in persons with Parkinson disease, SOC did not correlate significantly with Parkinson disease–related impairments or medical characteristics.[28] In another study,[23] there was no significant difference in persons with an identified disease (eg, heart infarct, stroke, and diabetes) and persons with no disease, but SOC was negatively correlated with perceived health.

These differences may be due to the type of rating scales used and whether the impairments are assessed in an objective or subjective way. SIPP is used to describe self-reported impairments, as defined by the ICF, in persons with LEoP and is not an objective measure. It could be that a person with a strong SOC who experiences, for example, muscle fatigue, pain in muscles and joints, and cold intolerance does not feel that he or she is particularly bothered by these impairments. In other words, a person with a strong SOC understands and could have learned to manage these LEoP-related impairments in a constructive way and thereby rate low on SIPP. Alternatively, the perception of symptoms does indeed influence a person's level of SOC and thereby indicates that SOC, as opposed to Antonovsky's suggestion,[7] is not stable. Further studies are needed to explore the extent to which SOC is in fact associated with a more positive perception of LEoP-related impairments.

SOC and the Subscales of RNL-I

The hierarchical regression analysis also revealed that the subscale Perceptions of Self in the RNL-I contributed significantly to SOC. In a study of persons with spinal cord injury,[29] SOC was not significantly contributing to the total sum score of RNL-I. In another study of elderly persons in Spain,[30] SOC was found to be a protective factor against disability and dependence, assessed as difficulties in performing activities and participation. In persons with chronic illnesses,[31] significant synchronous effects were found between SOC and body function, activity and participation, suggesting that SOC enhances participation and conversely, participation enhances SOC. As the items in this RNL-I subscale are related to personal relationships, comfort with self and coping skills, this implies that a person's psychological characteristics are more important for SOC than his or her actual physical disability. Further studies investigating different domains of participation in relation to SOC are needed to clarify those associations.

SOC and SWLS

The mean score of SWLS (24.7 points) was higher than the midpoint (20 points) between dissatisfied and satisfied with life and close to the range "high score" (25-29 points), described by Diener.[32] This means that the participants in the present study were generally satisfied with their lives. SWLS, as a representation of life satisfaction, was also the strongest contributor to the variance of SOC, where the final model explained as much as 60% of the variance in SOC. Thus, participants who were satisfied with their lives also had a strong SOC.

As this is the first study investigating the association between SOC and SWLS in people with LEoP, there are no studies to compare with. However, the result is in agreement with studies of people with traumatic brain injury,[33] multiple trauma,[34,35] and Parkinson disease,[36] where similar patterns have been described. Accordingly, our study adds to the existing literature that a strong SOC is associated with higher life satisfaction. Because a strong SOC indicates that a person understands and manages difficult situations in a successful way and perceives life meaningful, it makes sense that this is also associated with a higher life satisfaction.

SOC and Rehabilitation

Our overall finding in people with LEoP of an association between SOC and self-reported impairments, perceptions of self, and life satisfaction is important to consider in the rehabilitation of these persons. In a previous qualitative study, it was described how persons with LEoP experienced the influence of participating in an individualized, goal-oriented, comprehensive interdisciplinary rehabilitation program.[6] The rehabilitation program was experienced as a turning point in their lives. Before rehabilitation they felt they were on a downward slope without control. Rehabilitation was the start of a process of change where they acquired new skills, which, over time, contributed to a different but good life. After approximately a year, they had a sense of control and had accepted life with LEoP.

Much of the findings in this qualitative study[6] may be related to SOC. Rehabilitation apparently had provided the participants with an increased comprehension of LEoP. Also, rehabilitation was the start of a process of change where their perception of self had changed and they were able to manage life with LEoP, which, over time, contributed to a different but good life. Through this adaptation the participants had established new habits and could look to the future with confidence, in line with an improved meaningfulness in life.

Thus, rehabilitation interventions that improve someone's overall ability to cope with one's situation and understand and confront the stressors that arises due to a disability, may thereby strengthen SOC and lead to a more stable long-term situation. If so, the question then remains what specific coping behaviors persons with LEoP use to manage well. Additional studies investigating the associations between SOC and specific coping behaviors are needed to further clarify what factors and behaviors underlie a strong SOC.

Implications for Rehabilitation Professionals

Our results have implications for rehabilitation professionals. Knowledge of a person with LEoP and his/her SOC can assist in the planning of interventions. In particular, identifying persons with a low SOC could reveal those most in need of rehabilitation. Interventions may strengthen the persons' ability to understand and manage the consequences of LEoP, as well positively influence their self-perception and lead to an active and meaningful life. Whether this actually contributes to an improved SOC remains to be elucidated. According to Antonovsky,[7] SOC develops up to the age of 30 and is thereafter stable. However, Antonovsky also stated that SOC can, in fact, change if an adult person initiates a new pattern of life experiences. It may be that a rehabilitation program leading to a process of change could initiate such a new pattern.

Strengths and Limitations

A strength of the study is the high response rate and the use of valid and reliable rating scales, which enabled us to make detailed inferences. A limitation is the cross-sectional design, which does not allow us to make any causal inferences. Longitudinal studies following SOC and other variables over time are therefore needed. In this study, persons using a wheelchair as their main mode of transportation were not included. Until studies of those being more severely disabled due to LEoP are pursued, the results and conclusions should be limited to those with mild to moderate LEoP-related disability.

Conclusion

The strong association between SOC, higher age, self-reported impairments, perceptions of self, and life satisfaction indicates that these variables are important to consider in the rehabilitation of persons with LEoP. This knowledge can assist rehabilitation professionals to provide targeted interventions that enable people with LEoP to develop new strategies to better manage their daily life.

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References

1. Lexell J. Postpoliomyelitis syndrome. In: Frontera W, Silver J, Rizzo J, eds. *Essentials of Physical Medicine and Rehabilitation*. Philadelphia, PA: Elsevier Saunders; 2014:775-781.
2. Hammarlund CS, Lexell J, Brogårdh C. Perceived consequences of ageing with late effects of polio and strategies for managing daily life: a qualitative study. *BMC Geriatr*. 2017;17:179.
3. Lund ML, Lexell J. Perceived participation in life situations in persons with late effects of polio. *J Rehabil Med*. 2008;40:659-664.
4. Lund ML, Lexell J. Relationship between participation in life situations and life satisfaction in persons with late effects of polio. *Disabil Rehabil*. 2009;31:1592-1597.
5. Lexell J, Brogårdh C. Life satisfaction and self-reported impairments in persons with late effects of polio. *Ann Phys Rehabil Med*. 2012;55:577-589.
6. Lund ML, Lexell J. A positive turning point in life–how persons with late effects of polio experience the influence of an interdisciplinary rehabilitation programme. *J Rehabil Med*. 2010;42:559-565.
7. Antonovsky A. *Unraveling the Mystery of Health: How People Manage Stress and Stay Well*. San Fransisco, CA: Jossey Bass; 1987.
8. Livneh H, Martz E. Coping strategies and resources as predictors of psychosocial adaptation among people with spinal cord injury. *Rehabil Psychol*. 2014;59:329-339.
9. Lustig DC, Rosenthal DA, Strauser DR, Haynes K. The relationship between sense of coherence and adjustment in persons with disabilities. *Rehabil Couns Bull*. 2000;43:134-141.
10. Nolvi M, Brogårdh C, Jacobsson L, Lexell J. Sense of coherence in persons with late effects of polio. *NeuroRehabilitation*. 2018;42:103-111.
11. World Health Organization. *Towards a Common Language for Functioning, Disability and Health: ICF*; 2002. http://www.who.int/classifications/icf/en/. Accessed November 14, 2018.
12. Eriksson M, Lindström B. Validity of Antonovsky's sense of coherence scale: a systematic review. *J Epidemiol Community Health*. 2005;59:460-466.
13. Larsson G, Kallenberg KO. Sense of coherence, socioeconomic conditions and health: interrelationships in a nation-wide Swedish sample. *Eur J Public Health*. 1996;6:175-180.
14. Brogårdh C, Lexell J, Lundgren-Nilsson Å. Construct validity of a new rating scale for self-reported impairments in persons with late effects of polio. *PM&R*. 2013;5:176-181.
15. Brogårdh C, Lexell J. Test-retest reliability of the self-reported impairments in persons with late effects of polio (SIPP) rating scale. *PM&R*. 2016;8:399-404.
16. Wood-Dauphinee SL, Opzoomer MA, Williams JI, Marchand B, Spitzer WO. Assessment of global function: the reintegration to normal living index. *Arch Phys Med Rehabil*. 1988;69:583-590.
17. Perenboom RJ, Chorus AM. Measuring participation according to the international classification of functioning, disability and health (ICF). *Disabil Rehabil*. 2003;25:577-587.
18. Bourget N, Deblock-Bellamy A, Blanchette AK, Batcho CS. Use and psychometric properties of the reintegration to Normal living index in rehabilitation: a systematic review. *Ann Phys Rehabil Med*. 2018;61:262-269.
19. Pavot W, Diener E. Review of the satisfaction with life scale. *Psychol Assess*. 1993;5:164-172.
20. *SPSS. IBM Corporation*. Armonk, NY.
21. Altman DG. *Practical Statistics for Medical Research*. London, England: Chapman & Hall; 1991.
22. Nilsson KW, Leppert J, Simonsson B, Starrin B. Sense of coherence and psychological well-being: improvement with age. *J Epidemiol Community Health*. 2010;64:347-352.
23. Nilsson B, Holmgren L, Westman G. Sense of coherence in different stages of health and disease in northern Sweden: gender and psychosocial differences. *Scand J Prim Health Care*. 2000;18:14-20.
24. Lindmark U, Stenström U, Gerdin EW, Hugoson A. The distribution of "sense of coherence" among Swedish adults: a quantitative cross-sectional population study. *Scand J Public Health*. 2010;38:1-8.
25. Hair JF, Black WC, Babin BJ, Anderson RE, Tatham RL. *Multivariate Data Analysis*. 6th ed. Upper Saddle River, NJ: Pearson Prentice Hall, cop; 2006.

26. Brogårdh C, Lexell J. How various self-reported impairments influence walking ability in persons with late effects of polio. *NeuroRehabilitation*. 2015;37:291-298.
27. Winberg C, Brogårdh C, Flansbjer UB, Carlsson G, Rimmer J, Lexell J. Physical activity and the association with self-reported impairments, walking limitations, fear of falling, and incidence of falls in persons with late effects of polio. *J Aging Phys Act*. 2015; 23:425-432.
28. Pusswald G, Fleck M, Lehrner J, Haubenberger D, Weber G, Auff E. The "Sense of Coherence" and the coping capacity of patients with Parkinson disease. *Int Psychogeriatr*. 2012;24:1972-1979.
29. Geyh S, Nick E, Stirnimann D, et al. Self-efficacy and self-esteem as predictors of participation in spinal cord injury—an ICF-based study. *Spinal Cord*. 2012;50:699.
30. Virues-Ortega J, Vega S, Seijo-Martinez M. et al; Spanish Epidemiological Studies on Ageing Group. A protective personal factor against disability and dependence in the elderly: an ordinal regression analysis with nine geographically-defined samples from Spain. *BMC Geriatr*. 2017;17:42.
31. Veenstra M, Moum T, Røysamb E. Relationships between health domains and sense of coherence: a two-year cross-lagged study in patients with chronic illness. *Qual Life Res*. 2005;14:1455-1465.
32. Diener, E. *Understanding the SWLS Scores*; 2006. http://labs.psychology.illinois.edu/~ediener/Documents/Understanding%20SWLS%20Scores.pdf. Accessed November 29, 2018.
33. Jacobsson LJ, Westerberg M, Malec JF, Lexell J. Sense of coherence and disability and the relationship with life satisfaction 6–15 years after traumatic brain injury in northern Sweden. *Neuropsychol Rehabil*. 2011;21:383-400.
34. Snekkevik H, Anke AG, Stanghelle JK, Fugl-Meyer AR. Is sense of coherence stable after multiple trauma? *Clin Rehabil*. 2003;17: 443-453.
35. Anke AG, Fugl-Meyer AR. Life satisfaction several years after severe multiple trauma–a retrospective investigation. *Clin Rehabil*. 2003; 17:431-442.
36. Rosengren L, Brogårdh C, Jacobsson L, Lexell J. Life satisfaction and associated factors in persons with mild to moderate Parkinson's disease. *NeuroRehabilitation*. 2016;39:285-294.

Disclosure

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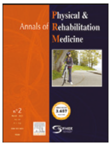

Original article

Sense of coherence and coping behaviours in persons with late effects of polio

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ABSTRACT

Background: Sense of coherence (SOC), comprising "comprehensibility", "manageability" and "meaningfulness", is important for successful adaptation in persons with late effects of polio (LEoP) and can be used as an estimate of the ability to cope with stressors. Coping behaviours are the actions a person performs to reduce stress and can be divided into problem-focused coping, emotion-focused coping and less useful coping. Our knowledge is very limited of what coping behaviours persons with LEoP use to manage their life situation as well as the association between SOC and coping behaviours.
Objective: The aims of this cross-sectional study were to assess coping behaviours and to explore the association between SOC and coping behaviours in persons with LEoP.
Methods: In total, 93 ambulant persons (52% women, mean [SD] age 74 [8] years) with clinically and electromyographically verified LEoP responded to a postal survey with the Sense of Coherence Scale 13 items (SOC-13) and the Brief Cope Scale. Three linear regression analyses were used to explore the association between SOC and problem-focused coping, emotion-focused coping and less useful coping, controlling for age and sex.
Results: The most-used coping behaviours belonged to the categories problem-focused and emotion-focused coping. We found a significant negative association between SOC and less useful coping; less useful coping explained 34% of the variance of SOC (adj R2 = 0.34, $p < 0.001$), whereas age and sex were not significant in the analyses.
Conclusions: Persons with LEoP primarily use problem-focused and emotion-focused coping behaviours, which suggests that generally they have adapted well to their disability. Regardless of age and sex, persons with lower SOC scores use less useful coping behaviours, which suggests that they are not as well adapted. These results can facilitate the development of rehabilitation interventions that help persons with LEoP adapt to their situation with a life-long disability.

Introduction

Late effects of polio (LEoP), also called post-polio syndrome, is a chronic progressive condition that can arise decades after an initial acute poliomyelitis infection [1]. The condition often leads to different impairments that slowly but gradually increase over time. This situation can give rise to worries and anxiety [2] and challenges in everyday life [3], such as walking limitations [4] and participation restrictions [5], which, in turn, can lead to reduced life satisfaction [6]. To be able to live a satisfactory life, many persons with LEoP need to make lifestyle changes and adapt to their lifelong disability [7]. An interdisciplinary goal-oriented rehabilitation program can help these persons take control and accept life with LEoP, establish new habits, taking on a changed valued self and look to the future with confidence [8].

An important component in this adaptation process is the psychological concept "sense of coherence" (SOC). SOC, comprising "comprehensibility", "manageability" and "meaningfulness", was developed 1979 by Aaron Antonovsky [9] and reflects a person's ability to maintain health despite external stressors. SOC can be perceived as the appraisal of stressors, after evaluating resources available to deal with it [10]. In Antonovskys own words, SOC is a "global orientation", and as such, a personality factor focusing on a person's healthy aspects, often referred to as "salutogenesis". Persons with a strong SOC can understand and handle stressors in a successful way and are motivated to deal with them. Hence, they view stressful events as less of a threat than persons with a weak SOC. Previous research has also shown that SOC is positively associated with

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successful adaptation to a lifelong disability [11]. Therefore, knowledge of SOC and factors underlying SOC is one way to understand the adaptation process in persons with LEoP.

We have initiated a project aiming to investigate SOC and associated factors in persons with LEoP. In the first study [12], we described that SOC in persons with LEoP is generally similar to the non-disabled population. In the second study [13], we showed that perceptions of self and life satisfaction, both related to a person's psychological characteristics, were more strongly associated with SOC than the actual LEoP-related physical disability. This indicates that different approaches toward a disability, such as mental attitudes and specific behaviours, could be important in the adaptation process.

One behaviour that could be important is "coping". Coping is the action a person performs to reduce stress [14]. It can be divided into 2 major positive categories: "problem-focused coping", which attempts to solve or reduce the problem, and "emotion-focused coping", trying to regulate stressful emotions evoked from the problem [14]. A third category is "less useful coping", which includes behaviours that are not constructive and that could make the situation even worse [15]. Generally, how a person copes with stressors is considered essential whether the tension of the stressors is released or not. Antonovsky meant that stressors are always present and that they can be both destructive and constructive. He also meant that SOC is a global trait-like coping resource [9], reducing the tension and preserving health. Moreover, the stress buffering effect of SOC has been suggested to originate from the choice of coping behaviours [16].

A few studies, published more than 20 years ago, have used different rating scales and assessed coping behaviours in persons with LEoP [17–19]. However, these studies did not reveal a particular pattern in coping behaviours. Moreover, no study has investigated the association between SOC and coping behaviors in persons with LEoP. Detailed knowledge of coping behaviours and the association with SOC could facilitate the development of rehabilitation interventions that help persons with LEoP adapt to their situation with a life-long disability.

Thus, the aims of this cross-sectional study were to assess coping behaviours and to explore the association between SOC and coping behaviours in persons with LEoP.

Material and methods

Participants

A convenience sample of 130 community-dwelling persons with verified LEoP was invited to take part in the study. Participants were recruited from a post-polio clinic at the Department of Rehabilitation Medicine at Skåne University Hospital, Lund, Sweden, and were randomly selected from 325 persons who met the inclusion criterion of being ambulatory with or without mobility devices.

All participants had a verified history of polio in their childhood or youth and new symptoms after a period of stability of at least 15 years, meeting the criteria of post-polio syndrome [1]. In the verification process of prior polio, an electromyogram (EMG) had been recorded for all 4 limbs, and the EMG findings indicated prior polio in at least one limb in all participants (for further details see [6]). Persons who had other major medical conditions (such as stroke or Parkinson's disease) that could contribute to their disability were excluded from the study.

Of the 130 persons invited, 97 accepted the invitation to participate in the study. Owing to missing data on the Sense of Coherence Scale 13 items (SOC-13) scale, 4 persons were excluded. Therefore, the total sample comprised 93 persons.

Ethics

All participants gave their written informed consent and the principles of the Helsinki Declaration were followed. The study was approved by the Regional Ethical Review Board in Lund, Sweden (Dnr 2016/134).

Procedure

An invitation letter with information about the study, the rating scales and a prepaid envelope for returning the rating scales were sent to potential participants. The rating scales were the Swedish versions of the SOC-13 and the Brief Cope Scale (see below). All responses were returned within 2 months.

Rating scales

SOC-13 scale

The short form of the SOC scale, SOC-13, developed by Aaron Antonovsky, was used in the present study [9]. The participants responded to 13 questions comprising the components comprehensibility (5 questions), manageability (4 questions) and meaningfulness (4 questions). They rated to what extent they agreed with different statements in a general context. For example: "Do you have the feeling that you are being treated unfairly?" Responses are given on a Likert scale ranging from 1, "very often" (1 point) to 7, "very seldom or never" (7 points). According to Antonovsky, the 3 components of SOC are highly integrated and should not be presented separately. The total score ranges from 13 to 91; a higher score is consistent with a stronger SOC, but there is no definite or cut-off score defining a strong or weak SOC.

The SOC-13 scale has been used in many studies, for example in persons with traumatic brain injury [20], spinal cord-injury [21], Parkinson's disease [22], and recently in persons with LEoP [12, 13]. The scale is valid and reliable, with a Cronbach's α ranging from 0.70 to 0.92 [23]. In a representative sample of the Swedish population (N = 2003) [24], the mean SOC-13 scores were 65 for men and 64 for women.

Brief cope scale

The Brief Cope Scale [25] is a shorter and revised version of the original 60-item Cope Scale [15]. In the Brief Cope Scale, the participants consider 28 statements about how they normally react in stressful situations, with response options ranging from 1 (not at all) to 4 (exactly right). The 28 items can be divided into 14 subscales, each representing a specific coping behavior. The 14 subscales, in turn, belong to one of 3 broader categories [15]: 1) problem-focused coping, 2) emotion-focused coping, and 3) less useful coping. Problem-focused coping comprises the subscales active coping (actively trying to remove or ameliorate a stressor, increasing one's efforts), instrumental support (seeking assistance or advice) and planning (thinking about how to handle the problem in the best way). Emotion-focused coping comprises the subscales acceptance (acknowledging the presence of the stressor), religion (finding comfort and trust in religion, praying, seeking God's help), humor (jokes, making fun of the situation), emotional support (getting sympathy or understanding), positive reframing (seeing the positive aspects) and denial (refusing the reality of the stressor or acting as if it doesn't exist). Less useful coping comprises the subscales self-distraction (conducting activities such as immersion in TV, daydreaming), substance use (overuse of alcohol or drugs), venting (dwelling on the distress and ventilating these feelings), self-blame (criticizing oneself, blaming the problem on oneself) and behavioral disengagement (reducing efforts to manage the stressor, giving up).

The Brief Cope Scale is multidimensional and the 14 subscales are often used separately to determine the association with other variables, and therefore, there is no total sum score for the entire scale. In this study, we analyzed the total sum scores of the 3 broader coping categories that Carver divided the subscales into [15]. Problem-focused coping (3 subscales) has a total score of 24, emotion-focused coping (6 subscales) a total score of 48, and less useful coping (5 subscales) a total score of 40. For interpreting the results, the higher the score of each subscale, the more a person uses that particular coping behaviour.

The Brief Cope Scale has been used in many studies, for example in persons with spinal cord injury [26] and stroke [27], but, to the best of our knowledge, it has never been used in persons with LEoP. The subscales in the Brief cope Scale have acceptable Cronbach's α values (ranging from 0.50-0.90) [25].

Statistical analyses

The data analyses involved using IBM SPSS 22 (IBM Corp.). For descriptive statistics, means (SD) and medians (range) were used. To explore differences between respondents and non-respondents, t tests, Mann-Whitney U tests and chi-square tests were used. To explore the associations between SOC and subscales of the Brief Cope Scale as well as between the variables used in regression analyses, bivariate correlations were first determined by using the Spearman rank correlation coefficient. Because of significant positive correlations between the 3 broader coping categories, with the strongest relation between problem-focused and emotion-focused coping (rho = 0.655, $p < 0.001$), the variables were not used in the same regression model. Instead, 3 linear regression analyses were used, with SOC as the dependent variable. We controlled for age and sex in the 3 linear regression analyses because these variables could be related to SOC [23, 24, 28, 29]. The first model included problem-focused coping, the second model emotion-focused coping, and the third model, less useful coping. There were no signs of multicollinearity in the models; the variance inflation factor was far below 10 and tolerance well above 0.1. There was one residual outlier in the model with emotion-focused coping; however, it had very little influence on the model because the maximum Cooks distance was far below 1. P <0.05 was considered statistically significant.

Results

Participant characteristics

Data on the 93 participants are presented in Table 1: 48 (52%) were women. The mean (SD) age was 74 (8) years. Most of the participants were married or cohabiting (58%), and almost all had an old age pension or disability pension (87%). All participants were ambulant and had mild to moderate walking limitations; 30% were able to walk >1000 m. The non-respondents (n=33) included 18 (55%) men. The mean age of respondents was 73 (9) years. Participants and non-respondents did not significantly differ in sex or age.

Table 1
Characteristics of participants with late effects of polio (LEoP) and non-respondents.

	Participants *n* = 93	Non-respondents *n* = 33
Sex		
Men	45 (48%)	18 (55%)
Women	48 (52%)	15 (46%)
Age (years), mean (SD), range	74 (8), 41-91	73 (9), 39-87
Age at polio onset (years), mean (SD)	6 (6)	6 (6)
Age at onset of LEoP (years), mean (SD)	52 (9)	50 (12)
Number of years with LEoP, mean (SD)	21 (9)	23 (12)

Of the 130 potential participants, 97 responded to the invitation and 4 were excluded due to missing data in the SOC-13 questionnaire. A total of 33 persons did not respond to the invitation (non-respondents).

Table 2
Summary of ratings on the Brief Cope Scale among persons with LEoP (*n* = 93).

	Mean (SD)	Median	Range
Problem-focused coping			
Active coping (91)	5.8 (1.6)	6	2-8
Instrumental support (91)	4.7 (1.6)	5	2-8
Planning (89)	5.7 (1.7)	6	2-8
Emotion-focused coping			
Acceptance (88)	5.9 (1.5)	6	2-8
Religion (87)	3.3 (2.0)	2	2-8
Humor (87)	4.3 (1.6)	4	2-8
Emotional support (90)	4.9 (1.8)	5	2-8
Positive reframing (90)	5.4 (1.4)	6	2-8
Denial (91)	3.4 (1.5)	3	2-8
Less useful coping			
Mental disengagement (88)	3.9 (1.4)	4	2-7
Substance use (92)	2.3 (0.7)	2	2-6
Venting of emotions (89)	4.4 (1.6)	4	2-8
Self-blame (90)	4.6 (1.7)	4	2-8
Behavioral disengagement (91)	3.0 (1.2)	3	2-6

Numbers in brackets represent number of complete rating scales.
Each subscale in the Brief Cope scale is represented by 2 items, yielding scores from 2 to 8.

Rating scales

The mean (SD) SOC-13 score was 71.8 (14.5) and median 76 (range 26–90).

Data from the Brief Cope Scale are presented in Table 2. The most-used coping behaviours belonged to the categories problem-focused coping (active coping and planning) and emotion-focused coping (acceptance and positive reframing). The least-used coping behaviours belonged to the categories less useful coping (substance use and behavioral disengagement) and emotion-focused coping (religion and denial).

Association between SOC and coping behaviours (Table 3)

We found a significant negative correlation between SOC-13 score and the less useful coping category (rho = -0.59, $p < 0.001$) as well as between SOC-13 score and the coping behaviors denial (rho = -0.34,

Table 3
Bivariate correlations between ratings on the SOC-13 scale, age, sex and coping behaviours for persons with LEoP (*n* = 93).

	Spearman's rho
Age	0.15
Sex (female)	-0.05
Problem-focused coping	0.17
Active coping (91)	0.11
Instrumental support (91)	0.05
Planning (89)	0.19
Emotion-focused coping	-0.18
Acceptance (88)	-0.05
Religion (87)	-0.16
Humor (87)	-0.11
Emotional support (90)	0.08
Positive reframing (90)	0.11
Denial (91)	-0.34 ($p = 0.001$)
Less useful coping	-0.59 ($p < 0.001$)
Self-distraction (88)	-0.38 ($p < 0.001$)
Substance use (92)	-0.15
Venting (89)	-0.17
Self-blame (90)	-0.46 ($p < 0.001$)
Behavioral disengagement (91)	-0.51 ($p < 0.001$)

Numbers in brackets represent number of complete rating scales.

$p = 0.001$), self-distraction, self-blame and behavioral disengagement (rho = -0.38 to -0.51, $p < 0.001$) but no significant correlation between SOC-13 score and any of the other coping behaviours.

Linear regression analysis of the association of coping with SOC (Table 4)

In the models with problem-focused coping and emotion-focused coping, significance was not reached but it was reached in the third model, with less useful coping ($p < 0.001$). In this model, SOC-13 score was significantly and negatively associated with less useful coping (standardized beta -0.59, $p < 0.001$), and the model explained 34% (adj R2 = 0.34, $p < 0.001$) of the variance in SOC-13 score. Age and sex were not significant in the models.

Discussion

The main findings in this study were that for persons with LEoP, the most-used coping behaviours belonged to the categories problem-focused and emotion-focused coping and the least-used coping behaviours belonged to the categories less useful coping and emotion-focused coping. Also, we found a significant negative correlation between SOC and less useful coping; less useful coping explained 34% of the variance in SOC-13 score, whereas age and sex were not significant in the analyses.

Coping behaviours in persons with LEoP

Problem-focused and emotion-focused coping is considered constructive when dealing with stressors and have been associated with successful adaptation to a disability [11]. These categories are also known to complement each other [14, 15, 30, 31]. Which category a person chooses depends on the situation and whether the situation is solvable (i.e., problem-focused coping) or not solvable (i.e., emotion-focused coping) [14]. The persons with LEoP in the present study mostly used behaviours from these 2 categories, which indicates that they generally handle stressors in their life situation constructively and have adapted well to their disability.

Behaviours belonging to the less useful coping category as well as the specific behaviours religion and denial from the emotion-focused category were not commonly used by our participants. When used for longer periods, less useful coping behaviours are likely to exacerbate distress, inhibit adjustment and adaptation, and distract the person from moving forward [15]. Consequently, a low use of less-useful coping indicates a low presence of the problems that those behaviours could induce.

The coping behaviour denial, belonging to the emotion-focused coping category, has been argued to be both a constructive and a destructive coping behaviour [15]. Carver suggested that denial could mostly be constructive in the beginning of a crisis but later is mostly destructive. Because our participants had lived with their LEoP for 21 years on average (Table 1), denial does not seem to have a role as a constructive behavior. The fact that religion was rarely used might reflect that religion generally takes a low role in everyday life among Swedish persons with LEoP.

Table 4
Results of the 3 individual linear regression analyses of factors associated with the SOC-13 score for persons with LEoP.

	SOC-13 score		
	Model 1	**Model 2**	**Model 3**
Sex (female)	-0.09	-0.04	0.13
Age	0.22	0.23	0.18
Problem-focused coping^1	0.18		
Emotion-focused coping^2		-0.14	
Less useful coping^3			-0.59 ($p < 0.001$)
Significance (p value)	0.09	0.08	0.00
Adj R2	0.04	0.05	0.34
R2 change	0.08	0.09	0.36
F-ratio	2.26	2.31	15.48

Data are standardised beta coefficients.
Independent variables were sex, age and problem-focused (model 1), emotion-focused (model 2) or less useful coping (model 3).

The most frequently used coping behaviours among the participants — acceptance, active coping, planning and positive reframing — were also the most-used coping behaviors among 63 persons with LEoP, assessed with the original Cope Scale [17]. The behaviours least used were also the same in that study and are those in the less useful category, as well as denial and religion from the emotion-focused category. These findings also agree with a qualitative study of 24 persons with LEoP [32]. The authors reported that a variety of coping behaviours were used in everyday life and that the behaviours used belonged to both the problem-focused and emotion-focused categories, such as acceptance and conscious problem-solving.

In the study by Westbrook and McIlwain [18], of 176 persons with LEoP, the most-used coping behaviours were resting, reducing physical activity, pacing oneself, and planning life more efficiently. Most of the items in the rating scale used in that study are not included in the Brief Cope Scale. However, planning agrees with our results, and the behaviours resting, reducing physical activity and pacing oneself could be related to acceptance.

Furthermore, in a study assessing coping behaviors in 119 persons with different types of neuromuscular disorders, including 40 persons with LEoP [19], problem-focused behaviours were not used extensively. These authors used a different rating scale, and the behaviours “devices and tricks”, “aids”, “own technical solutions”, “accept help” and “avoid[ance]” were considered to belong to the problem-focused coping category.

When compared to the normal population, in persons with LEoP, coping behaviours are fairly similar. In a Swedish sample [33], the behaviours mostly used were active coping, planning and emotional support. Acceptance, together with instrumental support, was the fourth most favoured behaviour.

In summary, the use of both problem-focused and emotion-focused coping behaviours among our participants with LEoP, together with the low use of less useful behaviours, suggests that persons with LEoP are generally well adapted and have the ability to cope in a constructive way with the stressors that arise from their disability.

Association between SOC and coping behaviours

Although problem-focused and emotion-focused coping behaviours were the most used, there was no significant correlation with SOC-13 score. This actually agrees with Antonovsky’s statement that a strong SOC is not associated with a specific coping behaviour (9). Instead, persons with a strong SOC have a wide repertoire of coping behaviours that they use appropriately and flexibly depending on the situation. When aging with a progressive condition, this flexibility is likely important in the adaptation process.

Being flexible in the choice of coping behaviours when aging with LEoP is important [34–36]. These studies highlighted the need to change coping behaviours learned during childhood, such as overachieving, because these behaviours are no longer adaptive when aging with LEoP. Instead, new behaviours, such as acceptance, were found adaptive.

Studies of other populations found significant positive associations between SOC and constructive coping behaviours. For example, in a study of 439 persons from the normal population [16], SOC was positively and significantly associated with active coping and planning, both problem-focused behaviours. Another study of 237 persons with spinal cord injury [37] found SOC strongly associated with emotion-focused behaviour acceptance. These associations might reflect a stable life situation in people other than persons with a progressive disability, such as LEoP, in which the most adaptive coping behaviours may change over time.

We found a significant negative correlation between SOC-13 score and the less useful coping behaviours and between SOC-13 score and the emotion-focused coping behaviour denial. This finding infers that persons with low SOC are less able to handle stressors successfully. It agrees with findings from other studies. In a study of 51 persons with Parkinson's disease [38], those with a strong SOC did not use depressive coping or dissimulation and wishful thinking. In a study of 80 persons with chronic heart failure [39], SOC score was negatively associated with venting of emotions and self-blame, and in a study of 48 persons with renal failure [40], SOC score was negatively associated with so-called emotive coping styles such as daydreaming, expecting the worse, and blaming someone else.

Thus, persons with LEoP and low SOC scores seem to cope in a less useful way and tend to rely on denial. They may lack the important flexibility in coping behaviours and the ability to deal with the stressors that arise in their life situation and could benefit from a rehabilitation program addressing aspects in their daily life they find demanding.

Strengths and limitations

The strengths of this study are the quite high response rate and the use of valid and reliable rating scales. A limitation is the cross-sectional design that does not allow us to infer a causal relation. Because only ambulant persons with LEoP were included in the study, the results should be restricted to persons with LEoP who do not have a major disability. The Brief Cope scale is an ordinal scale, and data have been analysed using conventional statistics. For future use in persons with LEoP, analyses of the construct validity and the uni-dimensionality of the scale, applying the Rasch method would be advantageous.

Conclusions

Persons with LEoP primarily use problem-focused and emotion-focused coping behaviours, which suggests that in general, they have adapted well to their disability. Regardless of age and sex, persons with low SOC scores use less useful behaviours, which suggests they are not as well adapted. These results can facilitate the development of rehabilitation interventions that help persons with LEoP adapt to their situation with a life-long disability.

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Conflict of interest

None declared.

References

[1] Boyer FC, Tiffreau V, Rapin A, Laffont I, Percebois-Macadré L, Supper C, et al. Post-polio syndrome: pathophysiological hypotheses, diagnosis criteria, drug therapy. Ann Phys Rehabil Med 2010;53:34–41.
[2] Yelnik A, Laffont I. The psychological aspects of polio survivors through their life experience. Ann Phys Rehabil Med 2010;53:60–7.
[3] Laffont I, Julia M, Tiffreau V, Yelnik A, Herisson C, Pelissier J. Aging and sequelae of poliomyelitis. Ann Phys Rehabil Med 2010;53:24–33.
[4] Brogårdh C, Lexell J. Falls,fear of falling, self-reported impairments, and walking limitations in persons with late effects of polio. PM R 2014;6:900–7.
[5] Lund ML, Lexell J. Relationship between participation in life situations and life satisfaction in persons with late effects of polio. Disabil Rehabil 2009;31:1592–7.
[6] Lexell J, Brogårdh C. Life satisfaction and self-reported impairments in persons with late effects of polio. Ann Phys Rehabil Med 2012;55:577–89.
[7] Lexell J. Postpoliomyelitis syndrome. In: Frontera WR SJ, Rizzo TDJr., editors. Essentials of physical medicine and rehabilitation. 4th ed Elsevier; 2019. p. 834–40.
[8] Larsson Lund M, Lexell J. A positive turning point in life—how persons with late effects of polio experience the influence of an interdisciplinary rehabilitation programme. J Rehabil Med 2010;42:559–65.
[9] Antonovsky A. Unraveling the mystery of health: how people manage stress and stay well. 1st ed. San Francisco, CA, USA: Jossey-bass; 1987.
[10] Braun-Lewensohn O, Mayer CH. Salutogenesis and coping: ways to overcome stress and conflict. Int J Environ Res Public Health 2020;17:6667.
[11] Livneh H, Martz E. Coping strategies and resources as predictors of psychosocial adaptation among people with spinal cord injury. Rehabil Psychol 2014;59:329–39.
[12] Nolvi M, Brogardh C, Jacobsson L, Lexell J. Sense of Coherence in persons with late effects of polio. NeuroRehabil 2018;42:103–11.
[13] Nolvi M, Brogårdh C, Jacobsson L, Lexell J. Sense of coherence and the association with sociodemographics and disability related factors in persons with late effects of polio. PM R 2020;12:154–60.
[14] Lazarus RS, Folkman S. Stress, appraisal, and coping. New York: Springer; 1984.
[15] Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. J Pers Soc Psychol 1989;56:267.
[16] Pallant JF, Lae L. Sense of coherence, well-being, coping and personality factors: further evaluation of the sense of coherence scale. Pers Individ Diff 2002;33:39–48.
[17] Schanke A-K. Psychological distress, social support and coping behaviour among polio survivors: a 5-year perspective on 63 polio patients. Disabil Rehabil 1997;19:108–16.
[18] Westbrook M, McIlwain D. Living with the late effects of disability: a five year follow-up survey of coping among post-polio survivors. Aust Occup Ther J 1996;43 (2):60–71.
[19] Nätterlund B, Ahlström G. Problem-focused coping and satisfaction with activities of daily living in individuals with muscular dystrophy and postpolio syndrome. Scand J Caring Sci 1999;13:26–32.
[20] Jacobsson LJ, Westerberg M, Malec JF, Lexell J. Sense of coherence and disability and the relationship with life satisfaction 6-15 years after traumatic brain injury in northern Sweden. Neuropsychol Rehabil 2011;21:383–400.
[21] Jorgensen S, Ginis KA, Iwarsson S, Lexell J. Depressive symptoms among older adults with long-term spinal cord injury: associations with secondary health conditions, sense of coherence, coping strategies and physical activity. J Rehabil Med 2017;49:644–51.
[22] Rosengren L, Brogardh C, Jacobsson L, Lexell J. Life satisfaction and associated factors in persons with mild to moderate Parkinson's disease. NeuroRehabil 2016;39:285–94.
[23] Eriksson M, Lindstrom B. Validity of Antonovsky's sense of coherence scale: a systematic review. J Epidemiol Commun Health 2005;59:460–6.
[24] Larsson G, Kallenberg KO. Sense of coherence, socioeconomic conditions and health: interrelationships in a nation-wide Swedish sample. Eur J Public Health 1996;6:175–80.
[25] Carver CS. You want to measure coping but your protocol'too long: consider the brief cope. Int J Behav Med 1997;4:92–100.
[26] Geyh S, Kunz S, Müller R, Peter C. Describing functioning and health after spinal cord injury in the light of psychological-personal factors. J Rehabil Med 2016;48:219–34.
[27] Minshall C, Ski CF, Apputhurai P, Thompson DR, Castle DJ, Jenkins Z, et al. Exploring the impact of illness perceptions, self-efficacy, coping strategies, and psychological distress on quality of life in a post-stroke cohort. J Clin Psychol Med Settings 2021;28:174–80.
[28] Nilsson KW, Leppert J, Simonsson B, Starrin B. Sense of coherence and psychological well-being: improvement with age. J Epidemiol Commun Health 2010;64:347–52.
[29] Nilsson B, Holmgren L, Westman G. Sense of coherence in different stages of health and disease in northern Sweden—gender and psychosocial differences. Scand J Prim Health Care 2000;18:14–20.
[30] Super S, Wagemakers MA, Picavet HS, Verkooijen KT, Koelen MA. Strengthening sense of coherence: opportunities for theory building in health promotion. Health Promot Int 2016;31:869–78.
[31] Kristofferzon ML, Engström M, Nilsson A. Coping mediates the relationship between sense of coherence and mental quality of life in patients with chronic illness: a cross-sectional study. Qual Life Res 2018;27:1855–63.
[32] Hansson B, Ahlström G. Coping with chronic illness: a qualitative study of coping with postpolio syndrome. Int J Nurs Stud 1999;36:255–62.
[33] Muhonen T, Torkelson E. Kortversioner av frågeformulär inom arbets- och hälsopsykologi - om att mäta coping och optimism. Nordisk Psykol 2005;57 (3):288–97.
[34] Sjödahl Hammarlund C, Lexell J, Brogårdh C. Growing up with a disability following paralytic poliomyelitis: experiences from persons with late effects of polio. Disabil Rehabil 2021;43:960–6.
[35] Maynard FM, Roller S. Recognizing typical coping styles of polio survivors can improve re-rehabilitation. A commentary. Am J Phys Med Rehabil 1991;70:70–2.
[36] Bruno RL, Frick NM. The psychology of polio as prelude to post-polio sequelae: behavior modification and psychotherapy. Orthopedics 1991;14:1185–93.
[37] Kennedy P, Lude P, Elfström ML, Smithson E. Sense of coherence and psychological outcomes in people with spinal cord injury: appraisals and behavioural responses. Br J Health Psychol 2010;15:611–21.
[38] Pusswald G, Fleck M, Lehrner J, Haubenberger D, Weber G, Auff E. The "Sense of Coherence" and the coping capacity of patients with Parkinson disease. Int Psychogeriatr 2012;24:1972–9.
[39] Nahlén C, Saboonchi F. Coping, sense of coherence and the dimensions of affect in patients with chronic heart failure. Eur J Cardiovasc Nurs 2010;9:118–25.
[40] Klang B, Björvell H, Cronqvist A. Patients with chronic renal failure and their ability to cope. Scand J Caring Sci 1996;10:89–95.

Paper IV

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Article

The Meaning of Sense of Coherence (SOC) in Persons with Late Effects of Polio—A Qualitative Study

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Abstract: Sense of Coherence (SOC), comprising comprehensibility, manageability and meaningfulness, is important for the sense of living a good life with Late Effects of Polio (LEoP). However, there is a lack of knowledge about the meaning of these three components. The aim of this study was to explore in-depth the meaning of SOC among persons living with LEoP, in terms of comprehensibility, manageability and meaningfulness. A directed content analysis was performed based on individual interviews with 7 men and 7 women with LEoP (mean age 73 years). SOC in persons with LEoP existed in two overarching themes that were closely intertwined: a state of motion and a state of being. The state of motion comprised active approaches, choices and actions, and was a process aimed at achieving a stronger comprehensibility, manageability and meaningfulness. The state of being comprised the comprehensibility, manageability and meaningfulness that the persons currently experienced. A profound understanding of SOC as both a state of motion and state being is essential for rehabilitation professionals when providing self-management support to persons living with LEoP. This understanding can increase their sense of living a good life and also be used in the rehabilitation of other life-long conditions.

Keywords: adaptation; psychological; disabled persons; post-poliomyelitis syndrome; qualitative research; rehabilitation; self-management; sense of coherence

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1. Introduction

Many persons who experienced paralytic polio in their childhood have adapted successfully to a life with a remaining disability. However, decades after their initial polio infection, they may develop new symptoms known as Late Effects of Polio (LEoP) or Post-polio syndrome [1]. Common symptoms among persons with LEoP are muscle weakness, general fatigue, pain during activities and at rest, cold intolerance and breathing difficulties [1]. This can affect their sense of control, their mobility and their manageability of meaningful activities in daily life [2], which may have a psychological impact and lead to a feeling of being on a downward slope without control [3]. Despite a gradual functional decline, studies have shown that persons with LEoP are generally satisfied with their lives [4,5]. Thus, many persons with LEoP have adapted successfully also to their new disability and continued to live good lives. In order to continuously support persons with LEoP, rehabilitation professionals need a deep and broad understanding of factors underlying this sense of living a good life.

One factor that is important for a sense of living a good life is "salutogenesis", introduced by Aaron Antonovsky [6]. Salutogenesis, meaning the origin of health, is focusing on factors promoting health and well-being, instead of focusing on illness and disease. Antonovsky found that the necessary elements in salutogenesis are "comprehensibility", "manageability" and "meaningfulness", which together make up the sense of coherence (SOC). Accordingly, persons with a strong SOC can understand and handle challenges, such as the stressors caused by a disability, and are motivated to deal with them. Among other factors, SOC has been related to mental health [7,8] and successful adaptation to a disability [9]. In persons with LEoP, we have shown that SOC is generally similar to that of the non-disabled population [10] and that SOC is more strongly related to life satisfaction and perceptions of self than the actual LEoP-related disability [11]. Recently, we also demonstrated that persons with LEoP who have a strong SOC avoid using maladaptive coping behaviors that might worsen the situation [12]. In summary, our findings suggest that persons with LEoP and a strong SOC can, despite a new disability, handle its inherent challenges and continue to live good lives.

Thus, SOC seems to be a key factor for persons with LEoP, their successful management of the stressors related to growing old with a disability and their sense of living a good life. However, there is a lack of knowledge about the in-depth meaning of comprehensibility, manageability and meaningfulness, the three components of SOC, expressed by persons living with LEoP. A deeper understanding of salutogenesis might be essential for targeted self-management support and possibly increasing the sense of living a good life. Thus, the aim of this study was to explore in-depth the meaning of SOC among persons living with LEoP in terms of comprehensibility, manageability and meaningfulness.

2. Materials and Methods

2.1. Research Design

This study has a qualitative research design and stems from the assumption that there are multiple subjective realities. Thus, we have adopted an interpretivist approach based on the participants' narratives guided by the SOC framework. Individual interviews and a directed content analysis [13] were used to explore the meaning of SOC in persons with LEoP. This design was chosen as we aimed to obtain a deeper and broader understanding of an existing framework—SOC—and add further knowledge to this concept.

2.2. Participants

The participants were recruited from a clinical database including persons with LEoP who had undergone interdisciplinary rehabilitation at a University Hospital in southern Sweden. They had all taken part in our previous studies of SOC and associated factors in persons with LEoP [10–12]. Inclusion criteria were verified LEoP and living in their own homes. Exclusion criteria were being unable to take part in an interview and having a clinically verified depression. The participants were selected to represent different gender, age, marital status and educational background. We aimed to achieve an equal gender distribution, an age range that covers most persons with LEoP, participants that were both single and married/cohabiting, had a different educational background, and had long-term experience of LEoP, were cognitively intact and not depressed, and thereby could provide rich narratives.

In total, 21 potential participants were contacted by letter. Five persons did not respond to the invitation. Among the 16 persons who volunteered to participate, two were excluded; one due to a hearing loss and clinical depression and the other as a result of a very late response when the other interviews had already been completed. Consequently, we included 7 men and 7 women with a mean age of 73 years (SD 5). All 14 participants had a confirmed history of acute poliomyelitis in their childhood and were experiencing new symptoms after a period of stability that had lasted for at least 15 years.

As part of the verification of previous polio, they had undergone an electromyogram (EMG) in all four limbs, and all participants had EMG findings indicative of previous polio in at least one limb. All participants lived in their own homes and at the time of the interview none were considered to have clinical depression or any major cognitive or physical impairment that would impede their participation.

Data on the 14 participants are presented in Table 1. Men and women were equally represented and the age range of 65–84 years covers most persons with LEoP, at least in the western world. Their disability level also varied; some persons were quite ambulatory, whereas others used a wheelchair as their main mode of transportation. Both married/cohabiting and single persons were included, providing a rich source of experiences.

Table 1. Characteristics of the 14 participants with Late Effects of Polio.

Gender	
Men, n (%)	7 (50)
Women, n (%)	7 (50)
Age (years)	
Mean (SD, range)	73 (5, 65–84)
Marital status	
Single, n (%)	2 (14)
Married/cohabitating, n (%)	12 (86)
Level of education	
Primary school ($\leq$9 years), n (%)	0 (0)
Secondary school (10–12 years), n (%)	8 (57)
Higher education ($\geq$13 years), n (%)	6 (43)

2.3. Procedure

Before inclusion, the participants received a letter with information about the study and gave their written informed consent, which they sent back in a prepaid envelope. They were informed that data could not be traced to any of them, and that they had the possibility to withdraw at any time and that this would not affect their right to receive rehabilitation or healthcare at a later stage. The first author, who also performed all interviews, contacted the participants by phone and arranged a time and a place for the interviews between May and July 2021. Eight interviews were performed face-to-face and the remaining six digitally. The face-to-face meetings were conducted in the participants' homes (n = 7) or at the office of the research team (n = 1). All interviews were performed individually, except for one where the participant's spouse was present during the interview but did not become involved.

2.4. Data Collection

Data were collected through semi-structured interviews. An interview guide was developed based on the SOC categories, i.e., comprehensibility, manageability and meaningfulness. The interview guide was pilot tested on the first three participants, which resulted in minor changes. The questions explored the meaning of SOC among the participants, such as: "Could you please tell me what you understand about post-polio and why you have your present symptoms?"; "Could you please tell me how you manage your post-polio?" and "What gives you meaning in your everyday life?". Follow-up questions were posed, such as "Could you please describe what you mean by..." and "Could you give examples...". The interviews lasted between 10 and 56 min (average 31 min). All interviews were recorded using a digital recorder, transcribed verbatim and the accuracy of the transcripts was checked against the audio files. After the 14th interview, we were convinced that we understood what we saw, could identify the relevant forms of the results, and that it appeared consistent. Thus, we decided that we had reached saturation and terminated the data collection.

2.5. Data Analysis

The directed content analysis [13] included a five-step procedure:

1. Achieving an overall impression of the content by reading all the interviews and obtaining a naïve understanding.
2. Text units involving comprehensibility, manageability or meaningfulness were identified and copied into an individual matrix sheet for each of the SOC categories.

3. In the matrix sheet, each text unit was analyzed and interpreted, after which the meaning units were condensed into codes.
4. Codes were sorted into subcategories, covering the meaning of comprehensibility, manageability and meaningfulness.
5. Identification of the two overarching themes.

The analysis and interpretation were mainly performed by the first author (MN) together with the second author (AF), who has long experience in qualitative research, and further validated by the third author (CB). All authors had access to the transcripts of the full interviews and the findings were discussed among all authors throughout the process.

3. Results

The analysis revealed two overarching themes that were closely intertwined: SOC among persons with LEoP existed in a ***state of motion*** and in a ***state of being***, visible in all three categories of SOC. The state of motion comprised active approaches, choices and actions, and was a process aimed at reaching stronger comprehensibility, manageability and meaningfulness. The state of being comprised the comprehensibility, manageability and meaningfulness that the persons currently experienced. SOC became profound when the person could feel certainty, act according to his or her own free will and enjoy participation and meaningful social interactions. The meaning of each main category of SOC is presented in subcategories indicated by bold italics in the text and summarized in Table 2. To add transparency and trustworthiness to our findings, quotations from the participants are also provided.

Table 2. An overview of the meaning of Sense of Coherence in persons with Late Effects of Polio.

Sense of Coherence	The meaning of Comprehensibility	State of motion	Simplifying by using metaphors and making things concrete	Re-evaluating information and identifying patterns		Developing personal models of explanation of illness
		State of being	Following instructions	Self-monitoring		Evaluating
	The meaning of Manageability	State of motion	Initiating interventions and clarifying needs	Modifying the home environment		Making plans
		State of being	Receiving instrumental and social support	Keeping oneself occupied		Adapting and achieving balance
	The meaning of Meaningfulness	State of motion	Using one's inner drive for going forward	Doing good and making a difference for others		Viewing things positively and valuing what one has by being mindful
		State of being	Enjoying nature	Enjoying meaningful social relationships	Accessing financial security	Being together with loved ones

3.1. The Meaning of Comprehensibility

The motion in comprehensibility occurred as a learning process of sense-making, i.e., understanding cause and effect, and how and why one's health condition was affected. The process of sense-making included various learning strategies. ***Simplifying by using***

metaphors and making things concrete meant breaking down difficult information into pieces that were easier to grasp, e.g., that the nervous system works like an electric system.

> "*It's about the electrical system that drives us. When I got polio, part of my spinal cord was shut down and all the electronic wires were out of current. They didn't work anymore. But they (rehabilitation professionals) told me that the body is remarkable as it makes different nerve cells replace the deficient ones. That is why some symptoms disappear after a while. However, because some parts of the nervous system become overloaded and lose their function you get post-polio, if I understand it correctly.*" (P1)

Another learning strategy was ***re-evaluating information and identifying patterns***. The participants considered some information they had received as young persons with polio no longer valid. A few had been advised not to participate in physical activities at school in contrast to newer advice about being active at an appropriate level. In addition, knowing that the condition is progressive and that their functioning could deteriorate further in the future meant that they continuously needed to re-evaluate the "appropriate level of activity". The participants experienced fatigue and pain, and identified patterns between these experiences and excessive activities, strained muscles and overweight. However, it was often difficult to distinguish whether the problems were due to LEoP or aging itself.

> "*Walking is getting harder and harder. I get far more tired and it takes longer to recover. I guess that's how I noticed it predominantly . . . . But it ´s hard to distinguish if it ´s due to old age or post-polio.*" (P3)

The strategies of simplifying, re-evaluating information and identifying patterns led to ***developing personal models of explanation of illness***. Based on the information they had and the patterns they could identify, they gained an understanding of their current condition.

> "*Since I ´ve got these arrangements (orthoses), I ´ve noticed that some tiny muscles don ´t need to work as before, which might have made them wither and led to an even more reduced muscularity in the leg, as I haven ´t had to use these muscles.*" (P3)

Comprehensibility as a state of being meant understanding the demands of being a person with LEoP. This was characterized by trusting rehabilitation professionals and ***following*** their ***instructions***. Rehabilitation professionals' instructions about how to avoid pain and exhaustion could be experienced as a limitation of meaningful activities. However, by accepting and adhering to the instructions their pain decreased.

> "*Then she (the physiotherapist) asked me, why are you running? I guess you run uphill as well? Stop doing that because it will harm you. You could either swim or ride a bike. So, I quit jogging immediately and got rid of the pain.*" (P7)

Being in a state of comprehensibility also meant actively paying attention to one's body through ***self-monitoring*** and ***evaluating*** various trial and error experiences. The participants kept track of the number of activities and number of steps during a day to find the optimum level of physical activity without becoming exhausted or having pain.

> "*I usually keep track of my walking, how many steps I take. Usually, I take between three and five thousand steps every day. That is what I manage before I get very tired.*" (P10)

A barrier to comprehensibility was uncertainty. In addition to the uncertainty about whether symptoms were due to LEoP or old age, many expressed uncertainties regarding where to turn for assistance for their LEoP. They sensed a general lack of knowledge among healthcare staff and had to approach different units instead of one that was specialized in the rehabilitation of LEoP. There were also doubts pertaining to how to be sufficiently physically active as they were uncertain about the right balance between being active and at the same time not risking overload. As one participant put it:

> "*First, I heard that I shouldn ´t exercise because it would harm my muscles. Then, I was told I should exercise to some extent. But what level should it be at? I would really like to know a bit more about that.*" (P13)

3.2. The Meaning of Manageability

Manageability was the interplay between the state of motion and the state of being. The state of motion in manageability was a process towards greater manageability, independence and autonomy. The state of being was the acceptance of dependency and the management of daily life. Both states involved active choices and the ability to switch between the states enhanced manageability. The change between the state of motion and state of being had a purpose, as accepting support enabled the person with LEoP to manage better and thereby experience independence and autonomy despite the need for assistance.

The motion towards greater manageability meant ***initiating interventions and clarifying needs***. The participants described many initiatives, such as self-referral to rehabilitation. Some services were paid for, e.g., ordering food for a dinner party instead of cooking themselves, which saved their energy for social interactions. There were also clever interventions, e.g., the development of a specialized wheelbarrow for the garden. ***Modifying the home environment*** was a significant part of their routines. Many had adapted their houses to facilitate various activities, e.g., installed a stair lift, toilet seats that could be adjusted to different heights, bathtubs made for sitting and adjustable tables and chairs.

> "*Climbing stairs is really difficult. And we have made it easier by simply installing a stair lift and I climb the stairs as little as possible, that's not something one really has to do.*" (P2)

Making plans was also important and involved different precautions, such as planning activities according to their abilities and thinking about their future when re-designing their houses or gardens.

> "*We built an outdoor room a few years ago, and I stood up for myself that there mustn ´t be any stairs, it must be on one level because I must be able to walk there with a rollator . . . So, we think ahead, my husband and I, when we do things, so that I can manage them later on. Yes, its ´s always present, facilitating for the future . . .* " (P11)

The state of being meant accepting dependency by ***receiving instrumental and social support***, such as assistance with everyday life chores and using various aids or devices. The various forms of instrumental support from society involved many different aids, e.g., orthopedic shoes, orthoses, crutches, disability-friendly alterations in the house, scooters, transportation services and home care services, enabling everyday life to function well.

> "*I got an electric scooter. Pure joy! It was the best thing that has happened to me. I am free now. My husband rides his bike and he and our grandchildren walk beside me when I use the scooter. Like the easiest thing in the world. It's great!*" (P11)

Social support, such as daily help with things they found demanding, was mainly provided by spouses, relatives and neighbors. This was most valued and seemed to be very important for the sense of living a good life.

> "*They (the grandchildren) help and support me when I need help and see that something needs to be carried in or out, for example. There is immediately someone who takes care of it. So, I get assistance with things they know I find difficult.*" (P2)

The state of being also involved managing daily life with a disability. ***Keeping oneself occupied*** meant that some hobbies and activities were undertaken to occupy themselves at times when they had nothing else to do. For some, quiet activities had replaced those that could not be managed anymore due to disability.

> "*After reading the newspaper I park myself at the computer, only taking a break for lunch and coffee. And basically, what I do is genealogy.*" (P1)

Adapting and achieving balance was important for ensuring that the strains of everyday life did not become too high.

> "*I have let go of the thought that I must be so good and do everything and have everything ready and so on. I can now think that, no, I have already done that, it's enough.*" (P4)

This also meant that they had to do things at their own speed, often with breaks during the activity.

> "*Mowing the lawn is quite difficult, but I manage anyways. I take breaks in between*" (P8)

A barrier to manageability seemed to be a lack of participation and not being allowed to define one's own needs. The participants did not always receive the support from society that they needed and unnecessary bureaucracy, rigid laws and regulations were sometimes experienced.

> "*I wish there were less bureaucracy . . . . When I wanted to visit my daughter, I suggested that I could drive to (her hometown) and the stair climber could meet me there. But that was impossible . . . . I had to go from (participant's home town) with the transportation service . . . . And I mean, it would have been a saving for everyone if I could use my own car.*" (P9)

Furthermore, frustration and resignation were expressed when healthcare staff decided that one was not in need of treatment or assistance or determined the type of aid/assistance required, which had a negative impact on manageability.

3.3. The Meaning of Meaningfulness

The motion towards more meaningfulness meant nurturing aspects that the participants found interesting and meaningful. This involved the actions of ***using one's inner drive for going forward*** *and* ***doing good and making a difference for others.*** In general, the participants seemed to have an inner drive that helped them to go forward towards their goals. This drive made them focus on possibilities instead of difficulties, confident that solutions could be found and willing to take on challenges.

> "*We have been used to drive through Europe quite a lot, but one starts to get older, so that with car . . . but there are other travel choices . . . . Train, for example, I like traveling on a train.*" (P5)

Doing good and making a difference for others was valuable for the participants, e.g., helping their spouse, letting others use their garden or doing voluntary work.

> "*We are helping out by crocheting tiny dolls or animals that we give to the children's hospital or to the ambulance service. They are for the children. I have made a lot of them.*" (P2)

The motion towards meaningfulness also included the active choice of ***viewing things positively and valuing what one has by being mindful***. To view things positively was, e.g., to choose not to spend too much time on things that had gone wrong.

> "*I don ´t bury myself very easily for different things and I ´m not a brooder either . . . . So that ´s why I ´m doing well, I guess that is helping me.*" (P5)

Being mindful, i.e., living in the moment, was another active choice.

> "*You know, it ´s so wonderful just to sit down outside and just watch . . . . And with some coffee and so on. It's not so bad. I can ´t say more than that, but I mean . . . I enjoy and I value it.*" (P6)

The state of being in meaningfulness involved ***enjoying nature*** as it made them happy and mindful. In particular, having a garden or summer house was much appreciated.

> "*Where I live, I have a great view, which promotes mental wellbeing. High trees. Look how beautiful they are, close to the water and so on. I am lucky.*" (P7)

Enjoying meaningful social relationships meant being part of a social context, which resulted in a sense of comfort. The participants appreciated various interactive activities, e.g., book circles, excursions, the table tennis club and sewing circles. The COVID-19 pandemic had acted as a barrier and they were looking forward to resuming their social activities. ***Accessing financial security*** meant freedom to choose a preferred lifestyle and to add a bit of luxury to their ordinary everyday life.

> “*We live a good life. Financially strong. It means a lot in our situation. We can allow ourselves certain things*”. (P4)

Being together with loved ones, e.g., spouses, children, grandchildren and close friends, was very important for many participants. It prevented isolation and loneliness by providing a secure social belonging.

> “*My life is good. I have my husband, children and grandchildren. Even great-grandchildren. We all keep in touch*”. (P14)

Many participants expressed that a decline in their health would threaten meaningful activities, e.g., going for a walk.

> “*I enjoy going for a walk in nature so much. I really hope I can continue with that for as long as possible*”. (P12)

Being able to participate in social events was very important, and they hoped for a stable physical condition in the future.

4. Discussion

To the best of our knowledge, this is the first study that has explored the meaning of SOC among persons with LEoP in-depth. The novelty primarily lies in the profound understanding of SOC as both motion and being. The findings will be essential for rehabilitation professionals when providing self-management support to persons living with LEoP. This understanding also enriches the approach towards other persons with life-long conditions.

During the analysis, it became clear that the state of motion and the state of being were closely intertwined. In most sub-categories, there were traces of the other overarching theme, even if they mainly belonged to either motion or being. Some of the sub-categories were also of relevance for more than one category of SOC. These findings support Antonovsky’s statement that the categories of SOC are highly integrated [6]. Because of the novelty of SOC as a state of motion and being, we have chosen to discuss the findings based on the two overarching themes.

4.1. The State of Motion

The state of motion was characterized by active approaches, choices and actions. One active approach to achieve higher comprehensibility was to simplify information from rehabilitation professionals and make things concrete and understandable related to the consequences of LEoP. Contributory factors, such as old age and comorbidities, were frequently considered in the participants’ explanatory models of their current condition. However, the exact mechanisms behind LEoP, or if their current condition was due to LEoP or old age, did not appear to be important for the majority of the participants. This has previously been described by Sjödahl Hammarlund et al. [14] and can be seen as a coping behavior aimed at achieving a sense of normality. By “blaming old age” for the current condition, you are not very different compared to other persons of the same age [14]. Another active approach that our participants described was to continuously re-evaluate and identify patterns (i.e., understand cause and effect), possibly because their condition had changed from the time when they had their polio until now when they lived with LEoP. This gave them a sense of comprehensibility and a personal model of explanation for their current situation. Doing good and making a difference for others was an active approach that increased the participants’ sense of meaning. This approach seems to be important for meaningfulness, as it provides social meaning and a higher purpose. The same has also been described in traffic victims [15], in whom altruism was a coping behavior that increased a person’s meaning in life. Furthermore, in a study of older persons with a high level of SOC [16], voluntary work and helping others were very much appreciated by the participants, as they sensed it gave so much value in return.

Moreover, our participants chose to view things positively and to value what they had in life. This was important for meaning making, as it enabled a focus on values that were positive for them. Our findings are also in line with another study [16], where older persons with a high SOC were described as being satisfied, positive and forward looking.

The action of taking their own initiatives to increase manageability was often used by our participants, who made great efforts and clever interventions to improve their functioning. For example, some had designed their house or garden in a disability-friendly way and modified their home environment by using their own solutions or inventions. Similar efforts have previously been described among persons with LEoP [17]. Since childhood, they have been accustomed to struggling to overcome difficulties, making efforts to function in society and not differ from others [18]. Although some participants now received instrumental support from society it was sometimes not enough. Therefore, they had to take their own measures in their homes. Making plans was also important, both thinking ahead and planning how to perform challenging everyday activities. This was intended to increase manageability, both in the present and in the future. Our findings are also in line with another study of persons with LEoP, where the participants described planning every move in challenging situations in order to manage better [14].

The findings in the state of motion comprised aspects that could be related to using one's inner drive for going forward. All the active approaches, choices and actions undertaken allowed the participants to go forward and focus on possibilities and aspects that gave them value in life. This is important for all categories of SOC and seems to be a fertilizer of the meaning making process, as it ultimately concerns the freedom to choose what one wants to do and to be able to do it. Similar findings have been described in a study of liver transplant recipients, where the freedom and ability to do what you want to do was found to be the meaning of health and quality of life [19].

4.2. The State of Being

The state of being included understanding and managing the demands of everyday life, as well as enjoying valued experiences and interactions. Listening to rehabilitation professionals' advice and following their instructions were considered important for knowing how best to live with LEoP and engage in the right amount of daily activity. However, many participants expressed frustration about not knowing where to turn for help regarding their LEoP and frustration about being unaware of the right level of activity. Therefore, continuous self-monitoring and evaluation were important, e.g., to assess the number of steps/day as part of the daily routine in order to avoid physical overload. Similar findings were reported in a study of physical activity in persons with LEoP [20]. In that study, the participants needed to find a balance and adjust their activities in order to avoid fatigue and pain. To obtain individualized support from rehabilitation professionals, our participants wished for an "open door" to a rehabilitation clinic specialized in LEoP. This need has also been described by persons with muscular dystrophy [21] and is most likely applicable to all life-long progressive conditions. Even if the persons have lived with a disability for most of their lives, the progressiveness, albeit slow, means that new issues may arise, for which they might need support.

Accepting dependency by receiving instrumental and social support, keeping oneself occupied as well as adapting and achieving balance made it easier to manage the demands of everyday life. The importance of accepting one's situation has also been described in persons with Parkinson's disease, where such acceptance was necessary for their adaptation and to achieve life satisfaction [22]. In the present study, the acceptance of dependency interplayed with the state of motion (i.e., choosing independency). This gave the participants higher manageability, as acceptance enabled them to choose appropriate leisure activities and obtain the assistance they needed, thereby leading to more independence and autonomy. Instrumental support was to a great extent provided by society, while support from spouses, family and close friends was both instrumental and social. However, a barrier to manageability was the bureaucracy that sometimes made it impossible to obtain the instrumental support they needed. Similar experiences of a struggle with regulations and laws have been described among persons with muscular dystrophy [21]. Although the

Swedish society welfare model is well developed and aims to provide every person with the support he or she requires, it sometimes appears to lack flexibility and the ability to meet individual wishes and needs.

The support from family and friends was greatly valued, as it gave the participants a sense of social belonging, of being cared for and the feeling of a good life. Having a good life also meant keeping oneself occupied and having meaningful everyday activities. The value of performing meaningful activities has also been described before [21,23–25] and is closely related to life satisfaction [26,27], highlighting the importance of minimizing barriers to participation. Adapting and achieving balance in everyday activities was part of their daily routine. This indicates that the participants were well adapted to their LEoP and no longer used their childhood coping behaviors, such as overachieving to blend in and not listening to the body [17].

Meaningfulness in everyday life was a source of energy for the participants and was found in nature, financial security and meaningful social relationships. Nature evoked joy and mindfulness, while financial security allowed them to live the life they wanted to live. Financial security makes things easier and as such, is a general resistance resource [6]. Enjoying meaningful social interactions gave a sense of belonging and being part of a context. Social contacts have previously been found important for SOC [16]. Having a social network can also be a general resistance resource, as it provides the person with the possibility of using the network as a resource for assistance [28]. In addition, being with loved ones was described as a source of meaningfulness in everyday life by our participants. As well as a sense of belonging, the closest relations seemed to give a feeling of being loved and accepted as one is. It is well established in the literature that regardless of the medical condition, social support and social belonging are essential aspects of life satisfaction, adaptation and experiencing health despite a disability [27,29–32]. Thus, we advocate that a strong focus on social belonging should be adopted among rehabilitation professionals and other healthcare professionals when managing people with a life-long disability.

4.3. Clinical Implications

The clinical implications of our findings are that the state of motion should be supported in order to increase comprehensibility, manageability and meaningfulness, and that barriers in the state of being should be reduced. To support the state of motion, rehabilitation professionals should be person-centered, listen to the person's narrative and lived experiences, and form a partnership where self-management support can be provided. By understanding the person's aspirations and meaning making, rehabilitation professionals could provide targeted and person-centered support. Persons' own initiatives, such as modifying the home environment, and meaningful activities such as voluntary work should also be encouraged and supported.

To prevent barriers in the sense of being, the instrumental support that persons require should be offered and unnecessary bureaucracy avoided. It is also important to determine whether the person is in acceptance of his or her condition, as this facilitates adaptation. If not, Acceptance and Commitment Therapy (ACT) could be a useful strategy, which has been previously used in persons with lifelong conditions [33]. It is also important to determine if the person is still relying on coping behaviors learned during childhood, due to the fact that some of these behaviors, e.g., overachieving, are no longer adaptive. In such cases, ways to adapt and achieve balance should be taught. Different group activities, such as forums for persons with LEoP, should be offered in order to increase social belonging for persons who lack a social network.

One way to support the sense of motion and prevent barriers in the sense of being is through an interdisciplinary person-centered, goal-oriented rehabilitation program for persons with LEoP [3]. In such a program, participants are active team members in their own rehabilitation process and take responsibility for their own rehabilitation plan. In this plan, they describe their difficulties, needs and what they want to be able to do now and in the future. The increased insight into their abilities, limitations and goals could be a booster to their inner drive, starting a process of positive change through self-management. As LEoP is a progressive condition, albeit slow, they need the certainty of having somewhere to turn if they require assistance or rehabilitation later in life. Thus, lifelong follow-ups in a specialized rehabilitation unit would be highly beneficial.

Knowledge from this study could also be applied in the management and rehabilitation of other life-long progressive disabilities. LEoP share many similarities with long-term post-infectious pandemics such as COVID-19. It has been suggested that knowledge of SOC can be used in the interventions aimed at reducing the pandemic's detrimental effects and promoting resilience [34]. In addition, we believe that knowledge of SOC could be applied in the management of frailty in old age [35].

4.4. Methodological Considerations, Strengths and Limitations

This study has several strengths. Men and women were equally represented and the age range of 65–84 years covers most persons with LEoP, at least in the western world. Their disability level also varied; some persons were quite ambulatory, whereas others used a wheelchair as their main mode of transportation. Both married/cohabiting and single persons were included, and those with different educational backgrounds, providing a rich source of experiences and thereby valuable insight into the meaning of SOC. The authors have different professional backgrounds (physicians specializing in rehabilitation medicine with extensive experience of persons with LEoP, a nurse, a physiotherapist and a neuropsychologist) and are members of rehabilitation teams with experience of different life-long conditions, studies of SOC and extensive experience of qualitative research. Thus, the authors' pre-understanding of persons with LEoP was considered a strength in the interpretation of the results. Finally, the person who conducted the interviews (MN) had no previous relationship with the participants.

There are also some limitations. The participants were chosen from a cohort that had, at some point, taken part in an interdisciplinary rehabilitation program. Consequently, they had been provided with support from rehabilitation professionals and might thereby be more adapted to their condition than persons who have not taken part in such a program. In addition, all participants were of Swedish origin and all had an educational level higher than primary school. Therefore, transferability to persons who have not taken part in rehabilitation, persons of other origins and with lower education levels, as well as younger persons with LEoP is limited. As SOC is also related to cultural, political, and economic factors, further research on SOC in other populations and different national contexts is needed.

5. Conclusions

SOC in persons with LEoP existed in two overarching themes that were closely intertwined: a state of motion and a state of being. A profound understanding of SOC as both a state of motion and a state of being is essential for rehabilitation professionals when providing self-management support to persons living with LEoP, in order to increase their sense of living a good life. This understanding can also be used in the rehabilitation of other life-long conditions.

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Institutional Review Board Statement: The principles of the Helsinki Declaration were followed. The study was approved by the Swedish Ethical Review Authority (Dnr 2021-01217).

Informed Consent Statement: All participants received written and oral information about the study and gave written informed consent to participate. They were informed that they had the possibility to withdraw at any time and that this would not affect their right to receive rehabilitation or healthcare at a later stage.

Data Availability Statement: All data were archived according to the Swedish Act concerning the Ethical Review of Research Involving Humans and are available upon reasonable request.

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References

1. Lexell, J. Postpoliomyelitis syndrome. In *Essentials of Physical Medicine and Rehabilitation*, 4th ed.; Frontera, W.R., Silver, J.K., Rizzo, T.D., Jr., Eds.; Elsevier: Amsterdam, The Netherlands, 2019; pp. 834–840.
2. Hammarlund, C.S.; Lexell, J.; Brogårdh, C. Self-reported impairments among people with late effects of polio: A mixed-methods study. *J. Rehabil. Med.* **2020**, *52*, jrm00084. [CrossRef] [PubMed]
3. Larsson Lund, M.; Lexell, J. A positive turning point in life—How persons with late effects of polio experience the influence of an interdisciplinary rehabilitation programme. *J. Rehabil. Med.* **2010**, *42*, 559–565. [CrossRef] [PubMed]
4. Larsson Lund, M.; Lexell, J. Life satisfaction in persons with late effects of polio. *Appl. Res. Qual. Life.* **2011**, *6*, 71–80. [CrossRef]
5. Lexell, J.; Brogårdh, C. Life satisfaction and self-reported impairments in persons with late effects of polio. *Ann. Phys. Rehabil. Med.* **2012**, *55*, 577–589. [CrossRef]
6. Antonovsky, A. *Unraveling the Mystery of Health: How People Manage Stress and Stay Well*, 1st ed.; Jossey-Bass: San Francisco, CA, USA, 1987.
7. Eriksson, M.; Lindström, B. Antonovsky's sense of coherence scale and the relation with health: A systematic review. *J. Epidemiol. Community Health* **2006**, *60*, 376–381. [CrossRef]
8. Larsson, G.; Kallenberg, K.O. Sense of coherence, socioeconomic conditions and health: Interrelationships in a nation-wide Swedish sample. *Eur. J. Public Health* **1996**, *6*, 175–180. [CrossRef]
9. Livneh, H.; Martz, E. Coping strategies and resources as predictors of psychosocial adaptation among people with spinal cord injury. *Rehabil. Psychol.* **2014**, *59*, 329–339. [CrossRef]
10. Nolvi, M.; Brogardh, C.; Jacobsson, L.; Lexell, J. Sense of Coherence in persons with late effects of polio. *NeuroRehabilitation* **2018**, *42*, 103–111. [CrossRef]
11. Nolvi, M.; Brogårdh, C.; Jacobsson, L.; Lexell, J. Sense of Coherence and the Association with Sociodemographics and Disability Related Factors in Persons with Late Effects of Polio. *PM & R* **2020**, *12*, 154–160.
12. Nolvi, M.; Brogårdh, C.; Jacobsson, L.; Lexell, J. Sense of coherence and coping behaviours in persons with late effects of polio. *Ann. Phys. Rehabil. Med.* **2022**, *65*, 101577. [CrossRef]
13. Hsieh, H.F.; Shannon, S.E. Three approaches to qualitative content analysis. *Qual. Health Res.* **2005**, *15*, 1277–1288. [CrossRef] [PubMed]
14. Sjödahl Hammarlund, C.; Lexell, J.; Brogårdh, C. Perceived consequences of ageing with late effects of polio and strategies for managing daily life: A qualitative study. *BMC Geriatr.* **2017**, *17*, 179. [CrossRef] [PubMed]
15. Lundälv, J. Förmåga till Välfärd. Trafikskadades Upplevelser och liv–ett Drama om Bemästring. Capabilities for Welfare. Traffic Victims' Experiences and Life—A Drama of Coping. Ph.D. Thesis, University of Helsinki, Department of Social Policy, Helsinki, Finlan, 1998. (In Swedish).
16. Söderhamn, U.; Dale, B.; Söderhamn, O. Narrated lived experiences of self-care and health among rural-living older persons with a strong sense of coherence. *Psychol. Res. Behav. Manag.* **2011**, *4*, 151–158. [CrossRef] [PubMed]
17. Sjödahl Hammarlund, C.; Lexell, J.; Brogårdh, C. Growing up with a disability following paralytic poliomyelitis: Experiences from persons with late effects of polio. *Disabil. Rehabil.* **2021**, *43*, 960–966. [CrossRef] [PubMed]
18. Yelnik, A.; Laffont, I. The psychological aspects of polio survivors through their life experience. *Ann. Phys. Rehabil. Med.* **2010**, *53*, 60–67. [CrossRef]
19. Forsberg, A. Liver transplant recipient's experienced meaning of health and quality of life one year after transplantation. *Theor. J. Nurs. Theory* **2002**, *11*, 4–14.
20. Winberg, C.; Carlsson, G.; Brogårdh, C.; Lexell, J. The Perception of Physical Activity in Ambulatory Persons with Late Effects of Polio: A Qualitative Study. *J. Aging. Phys. Act.* **2017**, *25*, 65–72. [CrossRef]
21. Aho, A.C.; Hultsjö, S.; Hjelm, K. Young adults' experiences of living with recessive limb-girdle muscular dystrophy from a salutogenic orientation: An interview study. *Disabil. Rehabil.* **2015**, *37*, 2083–2091. [CrossRef]
22. Rosengren, L.; Forsberg, A.; Brogårdh, C.; Lexell, J. Life Satisfaction and Adaptation in Persons with Parkinson's Disease-A Qualitative Study. *Int. J. Environ. Res. Public Health* **2021**, *18*, 3308. [CrossRef]
23. Seah, B.; Espnes, G.A.; Ang, E.N.K.; Lim, J.Y.; Kowitlawakul, Y.; Wang, W. Achieving healthy ageing through the perspective of sense of coherence among senior-only households: A qualitative study. *Aging. Ment. Health* **2021**, *25*, 936–945. [CrossRef]
24. Bryant, L.L.; Corbett, K.K.; Kutner, J.S. In their own words: A model of healthy aging. *Soc. Sci. Med.* **2001**, *53*, 927–941. [CrossRef]

25. Duncan, A.; Batliwalla, Z. Growing older with post-polio syndrome: Social and quality-of-life implications. *SAGE Open Med.* **2018**, *6*, 2050312118793563. [CrossRef] [PubMed]
26. Lund, M.L.; Lexell, J. Relationship between participation in life situations and life satisfaction in persons with late effects of polio. *Disabil. Rehabil.* **2009**, *31*, 1592–1597. [CrossRef]
27. Rosengren, L.; Forsberg, A.; Brogårdh, C.; Lexell, J. Social Belonging as the Main Concern for Achieving Life Satisfaction When Adapting to Parkinson's Disease. *Int. J. Environ. Res. Public Health* **2021**, *18*, 8653. [CrossRef] [PubMed]
28. Levasseur, M.; Naud, D. The Application of Salutogenesis for Social Support and Participation: Toward Fostering Active and Engaged Aging at Home. In *The Handbook of Salutogenesis*; Springer: Cham, Switzerland, 2022; pp. 249–258.
29. Finfgeld-Connett, D. Clarification of social support. *J. Nurs. Scholarsh.* **2005**, *37*, 4–9. [CrossRef]
30. Andersson, T.; Falk, K.; Bjerså, K.; Forsberg, A. Health is belonging: Lived experiences during recovery after pancreaticoduodenectomy. *Int. Sch. Res. Not.* **2012**, *2012*, 602323. [CrossRef] [PubMed]
31. Forsberg, A.; Cavallini, J.; Fridh, I.; Lennerling, A. The core of social function after solid organ transplantation. *Scand. J. Caring Sci.* **2016**, *30*, 458–465. [CrossRef]
32. Forsberg, A.; Karlsson, V.; Cavallini, J.; Lennerling, A. The meaning of social adaptation after solid organ transplantation. *Nord. J. Nurs. Res.* **2016**, *36*, 62–67. [CrossRef]
33. Kuba, K.; Weißflog, G. Acceptance and Commitment Therapy in the Treatment of Chronic Disease. *Psychother. Psychosom. Med. Psychol.* **2017**, *67*, 525–536.
34. Barni, D.; Danioni, F.; Canzi, E.; Ferrari, L.; Ranieri, S.; Lanz, M.; Iafrate, R.; Regalia, C.; Rosnati, R. Facing the COVID-19 Pandemic: The Role of Sense of Coherence. *Front. Psychol.* **2020**, *11*, 578440. [CrossRef]
35. Chen, H.; Fu, H.; Ye, B.; Wang, Y.; Yan, H.; Chen, Y.; Xu, J.; Nie, X.; Gao, J. Association Between Sense of Coherence and Frailty: A Cross-Sectional Study in China. *Front. Psychiatry* **2022**, *13*, 844439. [CrossRef] [PubMed]