



Long-Term Experiences of Men with Spinal Cord Injuries in Japan: A Qualitative Study

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Long-Term Experiences of Men with Spinal Cord Injuries in Japan: A Qualitative Study

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Key words: spinal cord injury; life course; narrative; Japan; KJ method; narrative analysis; interviews

Abstract: The goal of the current study was to examine how Japanese men with long-term spinal cord injuries constructed their post-injury life. To do this, I conducted semi-structured interviews with ten participants who had sustained spinal cord injuries. The interview data was transcribed and analyzed qualitatively using the KJ method, which is widely employed in Japan and has been developed by and named after the founder of the method, the anthropologist Jiro KAWAKITA (1967). The participants led lives similar to able-bodied individuals and tried to find specific positive aspects of their lives that they owed to their disabilities. They also developed collective identities as people with acquired disabilities through their relationships with others having disabilities. To alleviate their sense of loss, the participants also emphasized the unchanged aspects of their pre-injury lives. They understood that their lives were greatly influenced by a socially supportive environment that was regarded as being contingent. They recognized their inability to control the environment and valued the contingencies.

Table of Contents

- [1. Introduction](#)
 - [1.1 Disability in Japan](#)
 - [1.2 Meanings of disability](#)
- [2. Method](#)
 - [2.1 Participants and recruitment](#)
 - [2.2 Data collection](#)
 - [2.3 Data analysis](#)
- [3. Results](#)
 - [3.1 Main categories in chronological order](#)
 - [3.2 Case studies](#)
- [4. Discussion](#)
 - [4.1 Summary](#)
 - [4.2 Reconsideration of the meaning of disability](#)
 - [4.3 Collective identity as people with disabilities](#)
 - [4.4 Sense of coherence and contingency](#)
- [5. Conclusion](#)
- [Appendix: Interview Schedule](#)
- [References](#)
- [Author](#)
- [Citation](#)

1. Introduction

1.1 Disability in Japan

The current study investigated the long-term experiences of Japanese men with spinal cord injuries (SCIs) from a sociocultural viewpoint. According to a survey conducted by the Japanese Government Cabinet Office (COGJ, 2011), in 2006 an estimated 7,238,000 Japanese people had a disability (about 5.6% of Japan's population), approximately 3,663,000 of those being physical in nature. According to the [Japan Spinal Cord Foundation](#), current estimates indicate that more than 100,000 Japanese citizens have sustained SCIs, and the ratio of men to women with SCIs is 4:1 (SHINGU, 1995). [1]

An individual's ability to maintain independent bodily functions is often considered a prerequisite for participation in social activities (e.g., employment, education, and leisure), although opinion on this matter has been changing due to the influence of movements for independent living. After some disability movement leaders in Japan had learned about independent living in the United States, independent living has increasingly been accepted as a goal or alternative to institutional living, or living with family members, for people with mobility impairment. People with disabilities have recognized that using others (e.g., assistance for their own eating, changing clothes, bathing, or toileting) is important even if they struggle with these activities alone. In the 1980s, disability rights organizations began to negotiate with municipal governments to obtain attendant services. Individuals then began to live alone as a part of the community; however, one drawback was that they received limited personal care services. [2]

Currently, major welfare services have been provided in accordance with the Services and Support for Persons with Disabilities Act of 2006. This law aims to assimilate people with disabilities into community life through a nationwide, systematic establishment of services and improved employment support. However, there are a variety of issues; these can include expensive fees for services and limited attendant service providers in rural areas. 24 hour attendant services are often insufficient. [3]

According to Miyoko MIKE (2007), public assistance is lacking for people with high apartment rental fees, and real estate agencies are often concerned that people living alone with a severe disability is problematic. People with disabilities are thought to be more accident-prone (e.g., creating incidental fires), and they might be unable to escape from their apartment in case of an emergency. [4]

There is a strong cultural norm in Japan that parents of people with disabilities should take care of their children even as adults (STEVENS, 2007). As is often the case when caring for older adults (HASHIZUME, 2010), women or mothers are expected to provide care for persons with disabilities. There remains a cultural belief that using attendant services in the parental home should be

avoided, and asking for attendant care services is looked upon as a mother evading her duties. [5]

Adults with disabilities living with their families cannot receive many of the attendant services available to those who live alone. Therefore, current services are implemented to maintain the norm that parents are responsible for taking care of people with disabilities from childhood to adulthood. Some members of the disability rights movement have protested against their parents' care; they have insisted that parents often create "barriers" for living independently or participating in other social activities (HAYASHI & OKUHIRA, 2001). Miyoko MIKE (2007) indicated that a woman with cerebral palsy needed to go through long and tough negotiations with her mother and staff in a residential institution in order to live independently. People with disabilities often believe they have the "right to take risk." This means that they want to leave their parents' supervision and participate in various activities that might bring them harmful results. [6]

Employment is valued as an important aspect of social life and a means for economic independence. In Japan, the COGJ (2011) estimated that 43% of people with a physical disability aged 15 to 64 years (580,000 persons) had a job in 2006. For people in that same age range, the employment rate is lower than that for people without a disability by 20-30%. Employment can be found within the public sector (e.g., within central or municipal governments) and private companies. Japan has an employment quota system for individuals with disabilities based on the People with Disabilities Employment Promotion Law enacted in 1960. In 2011, the legal employment quota was 1.8% for private companies and 2.1% for statutory corporations, the central government, and local governments. The COGJ shows that the actual employment rate of people with disabilities in private companies accounts for 1.68% of the workforce, but this has steadily increased since 2009. However, this remains a low level as compared to the legal quota. [7]

Gender perspective is also an important aspect of life experience with a disability (MORRIS, 1993; ROBERTSON, 2004). Japan has historically been influenced by the philosophy of the coconscious and the *ie*-system¹; however, this has weakened over recent years. This philosophical tradition prescribes gender roles or social expectations regarding manhood. Employment is a key status symbol of manhood in Japan, as is often the case in other developed countries. In heterosexual romantic relationships, men are expected to be in a leadership position when dating. However, men with a disability often become nervous if they cannot fulfill this social expectation. Similar to research on individuals with SCIs in the United States and Great Britain (OSTRANDER, 2008; SPARKES & SMITH, 2002), men in Japan with SCIs struggled with changes to their sexuality or a loss of their masculinity or athletic ability (SENGOKU & YANAI, 2008). [8]

1 The coconscious and the *ie*-system means gendered house-hold roles within the Japanese family. The typical husband was expected to earn income for the family; on the other hand, wives were expected to take on the duties of cooking, cleaning, and raising the children.

1.2 Meanings of disability

Studies examining psychosocial issues of people with acquired physical disabilities have been influenced by theories developed in the United States, such as value change theory (WRIGHT, 1983) or stage theory (COHN, 1961). However, in Japan, the meaning of "acceptance" is not standardized in rehabilitation practices. This is partly due to the use of certain measurement scales (e.g., the "Acceptance of Disability Scale," LINKOWSKI, 1971) that were not developed in Japan. Tetsumi HONDA and Naoji NAGUMO (1992) categorized the various meanings of acceptance into three categories: a full understanding of incurability and loss of function, devotion to rehabilitate residual bodily function, and utilization of social welfare services. [9]

Researchers have suggested that the examination of psychosocial issues of people with disabilities who recovered from an acute, unstable medical condition should adopt a long-term perspective (GARSKE & TURPIN, 1998; KRAUSE, 1998) because adjustment to an acquired disability is an ongoing process. Even when people with disabilities have "accepted" their disabilities, they may still encounter new problems in everyday life. These problems include bodily functions, aging, and mild depression (NAGUMO, 2000), along with the reconstruction of family life and reemployment (WEITZENKAMP et al., 2000). As such, people who have sustained SCIs should continue to be evaluated long-term in regards to the severity of impairment on bodily functions and its impact on social activities (VILLE, RAVAUD & TETRAFIGAP GROUP, 2001). [10]

In addition to addressing these everyday problems, it is important to remember that people with disabilities—like able-bodied people—seek meaning from their lives across the life span (KING, 2004). The meaning of life is not an inner state but is instead created through narratives (BRUNER, 1990). According to Arthur FRANK (1995), the narrative of people with illnesses or disabilities can be classified into three categories: restitution, chaos, and quest. The essence of the restitution narrative is that a patient will recover owing to medical technology or medicine. This story connotes that medicine can cure the illness. The chaos narrative is a story that a patient cannot tell because of the severity of the illness. The quest narrative is defined by the person's belief that something is to be gained from the illness experience (SMITH & SPARKES, 2002). Arthur FRANK (1995) considers that all three types of narrative are equally important; however, some have suggested that the quest narrative is similar to meaning seeking (BRUNER, 1990; KING, 2004). [11]

People with acquired disabilities are in a marginal position between people who were born with disabilities and able-bodied individuals (TAGAKI, 2004). People with acquired disabilities often swing back and forth like pendulums between the non-disabled and the disabled aspects of themselves (YOSHIDA, 1993). Masahiro NOCHI (2000) finds that some people with traumatic brain injuries considered their disabilities temporary, even when they recognized them as not being easily cured. Similarly, people with SCIs indicated that their post-injury lives contain both "good days and bad ones" (SMITH & SPARKES, 2004, p.623). [12]

One limitation of prior research is that it fails to account for the consideration of the meaning of life in the context of experiencing a disability over the long-term. Stuart KRAUSE (1998) indicated that self-rated adjustment outcomes declined over time for those successfully employed after sustaining SCIs. This suggests that people with acquired disabilities actively reconsider the meaning of their disabilities and learn to accept them over the long term. [13]

To further investigate such changes over the life span, I will present a qualitative analysis of the life stories of people with disabilities. Elizabeth KENDALL and Nicholas BUYS (1998) insisted that qualitative analysis of interview data recounted the experiences of people with disabilities, and is a suitable analytic process to understand ongoing adjustments to disabilities. The concrete context of one's life must be examined to study the meaning of disabilities. Although we cannot deny the physical reality of disabilities, the meanings of that reality are nonetheless shaped through socio-cultural narratives (SMITH & SPARKES, 2008). Many methods can be used to analyze narratives or stories (MURRAY, 2000; SMITH & SPARKES, 2008); I will focus here on what research participants tell in a holistic fashion. My approach is consistent with qualitative analyses of long-term adjustment to chronic illness and disability (KELLY, LAWRENCE & DODDS, 2005). [14]

Generally, a qualitative study of life stories often focuses on relationships of interviewees with their significant others or important events, by restructuring data from the interviews (LEVINSON, 1978; PLATH, 1980). David PLATH (1980) examined the change in the social networks of significant others that takes place through the course of individuals' lives. His examination is a suitable approach to understand persons with disabilities in long-term perspective. It is anticipated that persons with acquired disabilities might make social comparisons with their acquaintances who have disabilities as well as with those who do not have disabilities, to evaluate their situation after their disability. Daniel LEVINSON (1978) concentrated on an analysis of the change in life patterns such as occupation or family life in the life histories of middle-aged men. Life patterns constitute a concept of daily activity that is similar to that included in the social welfare service system in Japan. The term "daily activity" refers to what people with disabilities do in the daytime, such as jobs, school, rehabilitation, or recreation at welfare institutions. Nevertheless, in the study of life stories, the process of change in subjects pertaining to not only events or daily activities but also their meanings are worthy of serious consideration. For example, Nancy CREWE (2000) found that employment was a turning point in the experience of self-efficacy for people with SCIs from a long-term perspective. Additionally, persons with an acquired disability can be considered a former able-bodied person. Therefore, they might tell stories about their pre-injury life experiences as an able-bodied person without discussing their life post-injury (PARKES, 1970). [15]

The aim of my study was to explore how Japanese men with long-term acquired physical disabilities construct their post-injury daily activity. This involves an understanding of meanings generated from these patterns by considering the

adjustment to changes in bodily function, social activities, and social attitudes toward disability issues in Japanese society. [16]

In the following method section, I will describe semi-structured interviews with ten men with spinal cord injuries and the KJ method of qualitative analysis for the narrative data. In the results section, each participant's meanings of daily activities and some case studies are presented. Finally, I consider their understanding of disabilities in the discussion section. [17]

2. Method

2.1 Participants and recruitment

A purposive sampling method (TEDDLIE & YU, 2007) was used to recruit participants from local SCI support groups located in the western region of Japan. I explained the purpose of the study to the leaders of those groups and asked for their assistance in finding appropriate participants for semi-structured interviews. [18]

The criteria for participant recruitment included the following: 1. The participant's age at the time of injury had to be approximately 20 years (because epidemiological data indicated that the majority of incidences of SCI began in the late teens and continued into the twenties); and 2. the time since the injury occurred had to equal more than ten years. 3. The participants included men only; as previously mentioned, the ratio of men to women with SCIs is 4:1 (SHINGU, 1995). I employed these criteria also in an earlier study on life stories of people with SCIs (TAGAKI, 2004). I provided thorough information to the group leaders related to the privacy protection methods that were to be used. The ethics committee of the host university also approved the study protocol. [19]

After the group leaders forwarded information related to participant candidates, I followed up by making an initial phone call or by sending an e-mail to each candidate. They were given information about the aforementioned research interests and the study's privacy policy. Their background information is presented in Table 1. I sought to establish rapport by attending their support group events because there were no personal relationships between the participants and me prior to the study. The first interview was scheduled after participants provided clear verbal consents. Participants' average age was 26.5 years, and the average time elapsed since injury was approximately 18.4 years.

Name ²	Age Group	Severity ³	Injury Cause	Injury Duration (years)	Employment	Marital Status
L1	40–49	Quadriplegia	Traffic accident	16	Employed	Married
L2	40–49	Quadriplegia	Traffic accident	19	Unemployed	Unmarried
L3	40–49	Paraplegia	Traffic accident	19	Employed	Married
L4	40–49	Paraplegia	Traffic accident	21	Employed	Married
L5	50–59	Quadriplegia	Sports accident	23	Unemployed	Unmarried
L6	30–39	Quadriplegia	Sports accident	16	Unemployed	Unmarried
L7	30–39	Quadriplegia	Traffic accident	16	Employed	Married
L8	40–49	Quadriplegia	Traffic accident	19	Unemployed	Married
L9	30–39	Quadriplegia	Sports accident	18	Unemployed	Unmarried
L10	30–39	Quadriplegia	Traffic accident	17	Employed	Unmarried

Table 1: Background of the participants [20]

2.2 Data collection

Since the current research examined participants' meaning of living with disabilities within their context, especially from a long-term perspective, the interview method was suitable to tap their concrete life experiences. I conducted two semi-structured interviews with each participant at either the participants' homes, in the support group conference rooms, or at the local welfare center. The interview method was based on the life story interview (ATKINSON, 2001; YAMADA, 2007) in that I asked the participants to speak about their disability experience from a life-span perspective. According to Yoko YAMADA (2007), the life story interview is a version of a narrative interview; however, in the narrative interview, interviewer is expected to be only a listener, while in the life story interview, the interviewer ask questions to elaborate the interviewee's narratives

2 Participants' names were changed to protect their privacy.

3 Quadriplegia means all four limbs are paralyzed, and paraplegia indicates that only the lower limbs are paralyzed.

and prevent tangential diversions. Therefore, I used a detailed interview schedule. The interview schedule is presented in the [Appendix](#). [21]

At the first interview, participants were requested to describe the passage of their post-injury lives, including hospitalization, post-discharge, and current life activities. They also were asked to consider the life trajectories they might have experienced if they had not sustained an SCI. Background, demographic information (family members, primary sources of income, education, employment, and welfare service, if applicable) and the trajectories of daily activities, such as school, symptom stability and medical rehabilitation, vocational training, or employment were also collected at the beginning of the first interview using a questionnaire. The questionnaire was administered to allow me to understand the passage of their post-injury life in chronological order. "Daily activity" was used in the same manner as in the Japanese social welfare service system.⁴ Daily activities for each participant and age are described in Table 2.

Table 2: Daily activities of each participant. Click [here](#) to download the PDF file. [22]

Following the completion of the first interview with all ten participants, I conducted a second interview some months later, in which I asked the participants to elaborate on the issues they discussed at the first interview as well as incorporating some new questions. During both interviews, participants' stories did not progress chronologically because sequences were disrupted by voluntary utterances. All interviews were recorded. Each interview lasted approximately 90 minutes. I judged that all the participants answered the questions fully, thus, I did not do a third interview. [23]

Before the first interview, the aim of the research and the study's privacy protection policy were explained to all participants. I emphasized that respondents were not required to discuss any topic that was inconvenient or in any way uncomfortable, and they could stop the interviews at any time. Furthermore, participants were assured that the interviews would be published as academic articles only after careful consideration was made of their privacy. At the end of the second interview, they were asked to comment on the interview experience, and to place particular focus on whether any part of the process made them feel uncomfortable. [24]

The first interview for each participant was conducted between September and December 2002; the second interview took place between May and June 2003.⁵ An experienced transcriptionist drafted verbatim transcriptions. Then, I reviewed the drafts to ensure accuracy. A total of 20 interviews were completed. Following transcription, each interview ranged between 25 and 46 pages in length. Because

4 In Japan, municipal governments provide welfare services, as well as disability services, based on the nature of daily activities the participants would like to do, and other conditions such as their bodily functions and family situation. For example, a person with mobility impairment could do light duty work at a welfare institution on weekdays, and pursue leisure activities with an attendant service during weekends. However, there are people with disabilities who pursue a full-time employment or attend school without any disability service.

5 The current interview was part of my doctoral dissertation completed in 2005.

of the highly personal nature of the interviews, all transcripts were stored in a locked cabinet. [25]

2.3 Data analysis

I decided on five steps for obtaining the participants' meaning of daily activities. The first four steps were related to understanding each participant's experience. The final step was to identify the relationships between categories across the participants. [26]

Following the completion of the interviews, I employed the KJ⁶ method, a qualitative analysis method developed by a Japanese ethnologist, Jiro KAWAKITA (1967). He adapted this method from Charles S. PEIRCE's notion of abduction and it relies on intuitive, non-logical thinking processes (SCUPIN, 1997). According to Masahiro NOCHI (2013), there are similarities between the KJ method and grounded theory methodology (GLASER & STRAUSS, 1967): Both develop connections between categories consisting of codes generated from segmented text data. At the same time, there are some distinctions: The aim of grounded theory methodology is to develop a logical integration of categories into a theory; in contrast, the aim of the KJ method is to create new connections between new ideas or concepts that might be contradictory or non-logical categories. NOCHI suggested that the distinctiveness of the KJ method is suitable for analysis of people's self-narratives, because they express many contradictions or inconsistencies. The method was originally developed to interpret ethnographic data in Nepal; it became a popular qualitative analytic method in many fields, including developmental psychology (SATO, HIDAKA & FUKUDA, 2009) and gerontology (FUKUI, OKADA, NISHIMOTO & NELSON-BECKER, 2011). [27]

I took the standard procedure of the KJ method. First, I carefully reviewed the transcripts to gain an overall sense of each participant's life story. Second, sentences within each transcript were compiled into basic semantic units (in general, three or four sentences) that resulted in approximately 200 units for each participant. Third, I provisionally grouped and organized the units for each particular participant and made gradual comparisons. For instance, similar expressions within units were grouped and provided with abstract labels that characterized the grouped units (e.g., new units). If a unit was not semantically similar to other units, the unit was left untouched. Fourth, I further grouped and organized original and new units. I conducted grouping and labeling procedures approximately four times to obtain sufficiently aggregated categories. [28]

An average of 20 categories was obtained for each participant. Categories revolved around rehabilitation efforts to ensure, overcome, or maintain independent living. They included job difficulties, relationships with friends with disabilities, interests in issues pertinent to people with disabilities, hardships experienced with caregivers, mobility/wheelchair issues, and an evaluation of

6 The "KJ method" is named after the founder of the method, KAWAKITA, Jiro.

their lives as a whole. While obtaining too many categories can be problematic, a moderate level of categories is necessary to concretely depict a participant's life trajectory (SATO et al., 2009). [29]

Fifth, I illustrated the categories, drawing lines between them to represent their semantic relationships, and developed a brief life story about each participant based on these results. Following a complete analysis of a particular participant's data, I began the analysis of the next participant's data. [30]

The two case studies L4 and L6 in the results section were based on this analysis. The reason I selected the two participants was that they were typical examples for a reconsideration of the meaning of disability. I focused on the difference that L4 had continued his full-time employment; L6 had not been employed, and was deeply involved in welfare activity or sports for people with disabilities. Tables 3 and 4 indicate relationships between the daily activities and categories of L4 and L6, respectively. [31]

Finally, I analyzed relationships that existed among the entire participant group and mixed up the categories, which I present as "main categories" in Table 3 and Table 4. Two supervisors who were experienced in qualitative research examined the analytical process to ensure that it was both logical and appropriate for the data.

Table 3: L4's relationship between daily activities and categories. Click [here](#) to download the PDF file.

Table 4: L6's relationship between daily activities and categories Click [here](#) to download the PDF file. [32]

3. Results

The results of the main categories from all the participants are presented in chronological order (Section 3.1). Additionally, I present L4 and L6's brief life stories as important, illustrative case studies (Section 3.2). [33]

3.1 Main categories in chronological order

3.1.1 Ordinary lives pre-injury

Most participants recounted having ordinary pre-injury lives and not experiencing any particular problems, although Participant L1 mentioned that he had been faced with "a wall" in his job⁷. For example, Participant L2 said that he was leading a very full life as a distinguished university student. He had a part-time job at a repair factory, worked as a cram-school teacher,⁸ was a member of the

⁷ He begun to feel "little problems" in his job, but he did not explained concretely.

⁸ Cram schools or Juku in Japanese are specialized schools for students to pass the entrance examinations of high schools or universities. University students are often employed as part-time teachers to earn money for their school tuition or leisure.

motocross team and the astronomy club, and was a home tutor. Participant L2 added that he had not imagined what it was like to be disabled. Participant L3 also enjoyed an active life as a university student; he enjoyed studying science and had a successful part-time job delivering newspapers. [34]

3.1.2 Injury

Each participant was injured in either a car accident or a sports accident. Most participants did not remember the situation surrounding their injury well, either because they fainted or simply could not understand what had happened at the time of injury. However, L2, who was injured while riding his motorcycle, was still conscious after the accident. He asked the attendant at the gas station to call an ambulance. [35]

3.1.3 Feelings of powerlessness and incurability during hospitalization

The participants worked hard and continuously during rehabilitation in the hope of a full recovery. Some individuals were torn between a hope for recovery and the desperation borne out of potential incurability. [36]

The participants recalled feeling deeply shocked and powerless when discovering that their disabilities could not be cured, as indicated by explanations from their doctors and the situations of other patients. Participants L2, L8, and L10 even considered suicide; they could not imagine what living with a disability would be like and could not cope with the prospect of life in a wheelchair. L8 said, "I felt pathetic and wanted to die."⁹ Before the injury, Participant L10 was a sports science student working to become a sports educator. He mentioned that physical strength and full mobility was the most important aspect of his identity; thus, he did not want his friends to see his damaged body. [37]

Participants L1 and L4 regarded their family lives as "ordinary" ones and felt a keen responsibility to maintain their family roles as the primary earners. L1 recounted that his biggest concern was whether he could maintain his marriage and domestic life with his wife and children, and he was afraid that there might be a divorce. [38]

3.1.4 Broadened recognition of disability issues

3.1.4.1 Recovery from feelings of powerlessness with encouragement from people with similar disabilities

All participants said they began to recover from their disappointment and sense of powerlessness, in part because others with similar disabilities informed them about the recovery process and ways to manage the activities of daily living (ADL). They mentioned the establishment of medical rehabilitation goals and in some cases sought to improve their ADL beyond those levels of other patients with similar

⁹ All quotations had been translated from Japanese to English.

disabilities. Participant L1, for example, extracted useful lessons from others for his ADL improvement. Patients who had been hospitalized again because of bedsores told him about the situations he could face in the future, because they had already experienced a return to society. L8 regarded disability as normal in his hospital, specifically noting, "It was 'normal' for people with the same kinds of disabilities to be in wheelchairs and this made me forget that I was in a wheelchair." [39]

As is often the case with hospitalization, many of the participants obtained lessons or encouragement from people with similar disabilities. They considered their advice more useful than the advice from medical doctors because it was based on direct, real-life experiences in a wheelchair. L2, L6, L8, and L10 said that after they left the hospital, they felt isolated because they had no friends with similar disabilities with whom they could share their difficult hospitalization experiences. Consider the following from L8 living in a rural area:

"I worried that my neighbors laughed at me for being in a wheelchair because I was playing and got in a traffic accident ... After about two years, I no longer worried about people looking at me. It is then that I started going out in my car and finding out that people with disabilities more severe than my own were going out in their cars." [40]

Overall, isolation seemed to be relieved through relationships with people with similar disabilities. This could be accomplished by participating in wheelchair basketball leagues or when participants were readmitted to the hospital for further rehabilitation. Participants L8 and L10 reported that they also received encouragement from people with similar, but more severe disabilities. Participant L7, whose function of all their limbs were severely impaired, or quadriplegic, said that he could not learn from people with paraplegia. They could freely use their hands in spite of their SCIs. He considered that since people with paraplegia can perform daily tasks, they are "the elite among people with disabilities." [41]

3.1.4.2 Recognition of diversity within disability and spreading awareness

The participants became aware of the diversity that exists among people with disabilities. L1, L5, L6, L7, L9, and L10 stated they utilized their experience as people with disabilities socially. They began to recognize that they should reveal their disabilities to society and thus attract public attention to disability issues. Moreover, people with more severe disabilities such as cerebral palsy¹⁰ made strong impressions on L1, L5, L7, and L9, thus helping them understand that disabilities go well beyond those from SCI. [42]

10 According to MAGILL-EVANS and DARRAH (2011), cerebral palsy is a group of conditions that occur in about two to three infants per 1000 births. The primary disorder affects the development of movement and posture due to an insult to the developing fetal or infant brain. Most cases of cerebral palsy are prenatal in origin. The physical disorders of cerebral palsy can be accompanied by disturbances of sensation, perception, cognition, communication, and behavior, and by medical problems such as epilepsy and swallowing difficulties.

L1 joined an educational tour to promote awareness of disability issues in the United States. The tour encouraged him to develop interests in other issues related to disabilities, such as intellectual or internal disabilities. He said:

"Thanks to my injury, I learned about the world of disability. I made friends with people with various disabilities—intellectual disability, cerebral palsy, and internal disability, as well as spinal cord injury. My experience in the US helped me recognize that problems experienced by people with disabilities did not solely lie with them. Societies do not consider them full-fledged members." [43]

L1 actively participated in his sons' school events to spread awareness about people with disabilities. He also became involved in his community as a member of the local residents' association for his apartment complex. [44]

L5 was particularly surprised to see people with cerebral palsy moving their wheelchairs with their chins. In reaction, he began to enlighten people about problems regarding people with disabilities: "I got a job at a social welfare office. While working, I wanted the townspeople to see that people in wheelchairs could work." [45]

3.1.5 Confidence and distinctiveness

With the passage of time since the injury, participants often found that there were an increasing number of activities that they could perform with some assistance. For instance, L2, L6, L7, and L9 obtained confidence through successful social activities like certification examinations, job performance, sports, or academic achievement. L9, who graduated from high school after injury, said, "I became confident because I was able to study just as well as able-bodied persons." [46]

Participants like L1, L4, L5, L6, L7, and L10 seek their distinctiveness through living with disabilities. L5 appreciated the importance of his hard work, setting an example for his child and broadening his interpersonal relationships. L5 said:

"I was able to show my child I was working hard. My child said, 'You are working hard, so I will work hard as well.' This is the most important thing to me ... Since becoming a person with a disability, I have become acquainted with doctors, university professors, and individuals in various fields. I would never have met these people had I not become disabled." [47]

L7 said that he was leading a life filled with steady progress in comparison to other people in his age group who had no goals. These participants saw evidence of their personal psychological growth that included increased sympathy for others, better judgment, and a greater understanding of the diversity of disabilities. For example, L10 stated, "My way of looking at things was one-sided before I became disabled. But, after becoming disabled, I became more calm and neutral." [48]

3.1.6 The impact of disability on daily life due to insufficient consideration or support

Many participants said that they experienced mobility problems such as difficulty parking the car, challenges when preparing to go out, and bicycles parked in their path. In Japan, able-bodied people often park their cars at parking spots designated for people in a wheelchair. There is no legislation to prevent such parking. Additionally, SCI often impairs many key bodily functions, including body-temperature regulation, urination, or bowel evacuation. L10 said, "[a]bout once a day, when I see people on the street, I think that I want to be an able-bodied person. This is because I would be able to solve my difficulties." [49]

L2, L3, L5, L6, and L7 expressed that there was a shortage of daily attendants, as well as little assistance from others on the street. Clearly, the former is more serious. Even though participants L2 and L6 used attendant services provided by local governments, the services were insufficient. Thus, they have had trouble receiving proper help and care from their older adult parents. They were worried about the burden placed upon their parents and alternative care in case of their death. Participant L5, who lived alone, said that he must put his cellular phone at his bedside at night because he would have to call for an ambulance in case of an emergency. [50]

3.1.7 Job difficulties

All the participants except for L10 had difficulty obtaining or maintaining employment. Even when employed, they faced various additional problems: low salary, physical difficulty, and reluctance to ask for support. L7 reported that he was not able to become a full-time employee until he expressed an interest in doing so himself. Participant L2 lost his job despite his hard work and diploma from a distinguished university. He was fired after his absence from work because of his disability.

"I did not want my co-workers to think I could not work because of my disability, so I finished my work faster than them and did not think about recreation at all. I became a full-time employee before my probation period ended and thought my superiors would acknowledge me if I did what I was supposed to do. However, my company used my absence from work because of my accident as an excuse to force me to quit." [51]

Participants L1 and L8 thought that their poor salary and/or unemployment were because of their disabilities, respectively. L1 said:

"My salary is half of that of my associates. It is too low. I work eight hours a day telecommuting. I would not request a full salary, but the current amount is extremely low. However, I am able to participate in my children's development at a deeper level." [52]

Participant L8 married an able-bodied woman after his injury. He said, "[u]nemployment made a bad impression on my parents-in-law who do not like me because of my disability. However, there is no appropriate position, because many applicant age ranges are below my age." [53]

Additionally, consideration for one's disability at the work place is required. L3, for example, said, "[p]eople with disabilities are not given consideration at my place of work. There are social gatherings at places that are not accessible by wheelchair." Participants also mentioned needing small assistance from others on the street as they often go out alone. [54]

3.1.8 Owing their achievement to their inner states

All participants, except L1, spoke about either the stability of their values or how their personality had remained unchanged despite the disability. In addition, the participants attributed improvements in their ADL or successful social activities to their unchanged personality traits. L5 indicated that he had fought against people using their authority as a shield against requests from people with disabilities even prior to his injury. Participants L2, L6, and L10 strengthened their enthusiasm as a way to cope with difficulties in spite of their disabilities. They attributed their improvement in bodily function and social activities (e.g., job and sports activities) to their strong will. Participant L10 said, "I have been willing to try every difficult activity, and thus, I can get successful results." Participant L2 said that progress (in various activities) is dependent on his own motivation. [55]

Nevertheless, L3 and L4 now more fully appreciate the increased kindness exhibited towards people with disabilities in recent years. L3 specifically noted,

"[s]ocial understanding of people with disabilities has improved, although it is not sufficient. Fifteen years ago, if I asked others to help me in a wheelchair on a busy street, they got nervous and ran away. It was like a junction of streams for them. But currently, people voluntarily get closer to me and ask me if I need help." [56]

3.2 Case studies

The results of post-injury life have so far been described in a segmented manner across a variety of the participants. Categorized data, however, is somewhat away from the individual and the context within which these insights emerged (HASHIZUME, 2010). To address this limit, this section focuses on two cases selected for a more detailed, contextualized analysis. [57]

3.2.1 L4

L4 was 49 years old and had been living with SCI for 21 years. He lived with his wife and child. He worked in a "distinguished" company, having worked in a small factory prior to his SCI. [58]

Before his injury, he was "active 24 hours a day, 365 days a year," continuously engaged in hobbies and social activities. He was 28 years old when he sustained his SCI in a traffic accident. He thought he could be treated with an operation. However, when he was told that his injury was untreatable, he thought that, "everything was denied." He could not accept that he could no longer walk. Despite this setback, he did not feel alone as compared to those who did not have family members available to help. He considered that having a family was "a minimal life." However, he would not be dependent on their assistance, because he felt he had a responsibility to his family as the primary earner of income. As the primary earner of the family, it was important for him to be economically independent. [59]

He learned how to urinate and prevent bedsores from people with the same kinds of disabilities.

"I noticed that there are people who had jobs in spite of SCI. I began to recognize what I should do, although I am neither economically nor socially independent. I am glad to see the possibility of employment, if I do my best in rehabilitation." [60]

After being discharged from the hospital, he joined a wheelchair basketball team. L4 said, "[o]ur teammates with similar disabilities are equal to each other. We are not concerned about disabilities; we are gathering, and have solidarity as intimates with similar disabilities." At the age of 29, he went back to work for the factory where he worked prior to his injury, although there were some tasks he could not do. For instance, he could not lift heavy objects like trunks nor could he drill holes. He felt awkward asking for help and considered changing jobs. Within several years after his accident; however, he accepted his situation. He said that it took two or three years for him to "see" himself, observing that, "there is not a single specific factor, but various overlapping ones. I gradually noticed the fact that I am a person with a disability." [61]

When he was 32 years old, he "took a once in a lifetime chance" and entered a rehabilitation center. He came across an article in the newspaper and applied even though the hiring period was already over. With an introduction by the rehabilitation center, he acquired a job doing office work at a company. Before he was 40 years old, he wholly devoted himself to the job to feed himself and his family; he simply could no longer afford to do volunteer activity. [62]

From this point on, he grew accustomed to work and became involved with social activities and sports for people with disabilities. L4 said that he "overcame" his difficulties once he established stable employment and secured his family's situation. Furthermore, although he only asked for help when desperate in the years immediately following his injury, eventually he was comfortable and confident enough to ask for help even when it was not that urgent.

"When I got a position in the current company, I asked for others' support on the basis of priority that I made by myself. If I need to climb many stairs or change trains many times, I quit going out. However, after age 40, I came to ask for support,

regardless of the priority. For example, I get thirsty, and want canned coffee; I will ask someone (to buy it at vending machine, which is impossible for people in wheelchairs)." [63]

He was deeply satisfied with his current job. He reported that his disability and experience at a vocational rehabilitation center enabled him to work for a world famous company at a position specifically for people with disabilities. He said, "[w]ithout disability and as only a high school graduate, I would have continued at the small factory." [64]

Even though he was satisfied with his current job, he had difficulties related to excretion and diarrhea, and often became irritated with other limitations in bodily function. He said, "[t]his issue never goes away ... However, even able-bodied people become irritated." He had to rest the day after he had gone out to participate in one of his hobbies. He said, "[i]t was because of my disability and age." [65]

Regarding his entire post-injury life, he said that he solved problems one at a time. For him, an "environment" including people with the same kinds of disabilities, and family is important. The equipment needed for accessibility in public facilities has also improved during his lifetime, thus reducing inconveniences associated with being in a wheelchair. Having valued social activities prior to his injury, he continues his volunteer activities that contribute to society. [66]

3.2.2 L6

L6 was 32 years old and had been living with SCI for 16 years. He lived with his parents. He worked in a welfare institution for people with disabilities. He had been a high school student prior to his SCI. He was injured playing sports at the age of 16. He was frustrated with his coach for "not being able to prevent the accident." During hospitalization, he thought he could be treated but was shocked when his doctor told him that he "would never move his body again." He was angry that he alone had to go through such an experience and was frustrated that he could not go to school. He also felt lonely because he thought he was being left behind by his schoolmates who would soon get jobs or pursue additional educational opportunities. He thought rehabilitation was meaningless because he believed he would simply move around in a wheelchair and that his functions would not improve. After he saw people with the same kinds of disabilities being positive, however, he thought, "I too must try." [67]

Despite this enthusiasm, he was nevertheless lonely after he was discharged from the hospital because he had only his family to talk to. For the first two years, he strongly resisted the idea of being in a wheelchair because of people looking at him and wanted to carry a sign that read, "I am not a person with a disability." However, one day he came across a man dressed as a woman and was "shocked as if he had been punched" because he was walking outside without caring about people looking at him. Realizing that he was staring at this man, he then thought

that, "being stared at for being in a wheelchair was the same as being stared at because of loud or strange fashion, like dressing as a woman." [68]

Although he accepted being in a wheelchair, he subsequently used his disability to become passive toward everything. However, when he was 22, his older sister invited him to go diving and he improved more quickly than he had expected. After starting diving, he became "psychologically stable." Diving provided him with an opportunity to go out and try new things of his own volition. He got an attendant and got in the custom of going out for normal daily activities or enjoyment. He switched to an electric wheelchair and no longer loses his balance. Furthermore, he reconfirmed the importance of his own will at the welfare institution where he worked as a representative. [69]

Unfortunately, in the last two to three years, he has begun to again think that he is actually passive, his activity being a misconception:

"There would be energy pulling me forward or something pushing me from behind and this may have allowed me to go forward one step at a time. I may still be passive and in this sense, I may not have changed at all." [70]

He began to appreciate the support from his older sister and other people who were close to him.

"There are many things that I can do with support. They are done with their support as well as my own will. Without my older sister's help, I could not go diving and did not accept my disability. With energy that encouraged me to go out or manage the [welfare] institution, I made my progress step by step. Without them, I might be in the same position." [71]

As a representative of a welfare institution, he has an opportunity to turn his own ideas regarding welfare service into a business depending on the new welfare system for people with disabilities. However, at this point, the direction of the business is not yet decided. He said, "I go to our office two or three days a week, so there is little that I can do by myself. Representative is only a title." [72]

He was also satisfied with the fulfillment of his social status within the welfare institution:

"Becoming the chairman of the people with disabilities group and the representative of the workshop are things people in my age group may not have been able to do. Such a position was suitable for me because I have lived as a person with a disability. Along with former classmates who do fulfilling work, I am also living my own life." [73]

Despite this view, he was nonetheless quite worried about his care once his parents pass away. His activity sphere was restricted, because he could not get rid of phlegm in his throat without an attendant. He also often got frustrated because he could not do little things (e.g., scratching an itch). He also felt brief pangs of regret in various situations. For example, he was envious of people

exercising and sweating. In short, after becoming disabled, he did not become acquainted with the people he would have otherwise met. [74]

4. Discussion

In this section, I will show the summary of the result of the entire participants' narratives because the findings might be complicated. Furthermore, I will discuss the findings with regard to the reconsideration of meanings of disabilities, narrated collective identities, and sense of coherence. [75]

4.1 Summary

After injury, the participants tried to have an ordinary life and searched for a meaning, different from that of able-bodied people, while simultaneously working to constrain and control the problems arising from their disabilities. In short, they wanted to enjoy elements of ordinary life such as jobs, family life, leisure time, sports or hobbies, and interpersonal relationships, as people without disabilities do. [76]

Some participants overcame the burdens of everyday life and associated stigmas with the confidence they obtained through successful social activities like certification examinations, job performance, sports, and academic achievement. According to Gillian KING (2004), people with disabilities generally seem to perceive the significance of their lives in terms of the activities to which they devote themselves continuously and in terms of affiliation with groups. They respected themselves for having succeeded in what able-bodied people usually did. [77]

In particular, successful employment was one of their core experiences that symbolized their ability to operate as full-grown men alongside able-bodied people. Participants L1 and L4, who attempted to go back to their original jobs, felt a responsibility to maintain their family roles as the primary earners. However, some participants faced difficulties with their jobs. For example, Participant L2 did not want his co-workers to think he could not work because of his disability; thus, he tried to finish his work faster than his colleagues to garner their respect. With the cultural custom of lifetime employment and the academic meritocracy in Japan, Participant L2 could have been successful in his career. However, he lost his job despite his hard work and diploma from a distinguished university. [78]

Bengt NIRJE (1970) suggests that a principle of normalization for people with disabilities involves performing "normal" developmental tasks at each stage of life. NIRJE's theory is likely based on the notion that each life stage has a set of developmental tasks that is common across human experience. However, we should not implicitly presume a universal "normal" life course. From a "normal" developmental perspective, people obtain education and become independent as young adults. They find full time employment with a desirable salary. They also find partners and perhaps start a family. However, it is important to critically examine the commonly held assumptions about progression through life and the

social institutions that regulate this progress (PRIESTLEY, 2003, pp.26-28). As is evident from the stories reported here, the participants redefined these assumptions about progress. [79]

The importance of gender roles could also be a burden for those who cannot find a stable job. Participant L8 stated that unemployment created a bad impression with his parents-in-law who did not like him because of his disability. In Japanese society, married couples have close relationships with each parental in-law, even though they live away from the parents, and thus they have to be concerned about the parents' suggestions for their marriage life. Conversely, participants L3 and L7, who married able-bodied women after their injuries, did not mention a similar concern. This might be attributed to their stable employment. [80]

Participants also tried to find significance in their lives where able-bodied people may have been unable to do so. For example, Participant L4 attributed his current employment to his disability. Moreover, participants valued activities that did not necessarily lead to economic independence, such as sports and institutions specifically catering to people with disabilities. Participant L6 assessed his position as a representative of an institution that serviced people with disabilities as age-appropriate and compared his success favorably to that of his former classmates. [81]

4.2 Reconsideration of the meaning of disability

The participants also reevaluated aspects of their post-injury life that they had initially regarded as positive. For example, even though L4 returned to work for the factory he worked at prior to his injury, there were some tasks he could not fulfill. He thus considered to change the job. L6 also later denied that he showed initiative in taking up diving and participating in society, believing instead that he was still passive and that his successes in diving came as the result of advice from his older sister. [82]

L6's episode about diving is a typical example of the reconsideration of the meaning of disability. Further revising his view of the significance of diving led him to rethink the significance of other events, such as those related to his family and the welfare institution. He even said that his position as "institution representative" was just a title and that he did not do any practical work. [83]

People with mobility impairments attach great importance to working, living an independent life apart from their parents through the use of available services, becoming actively involved in sports for people with disabilities, and supporting other people with disabilities (e.g., managing an independent living center), even though few people with disabilities manage to achieve all this. L6 deeply valued his participation in sports for people with disabilities (diving) and managing his institution. It is likely that taking part in sports and managing the institution were critical issue to L6; despite his disabilities, he could help others and was not simply a recipient of support from his parents and attendant. [84]

It is wrong to attribute his participation in various activities on the advice of others to a lack of independence. Indeed, what he describes as passivity could also be seen as a realization of the importance of the support of friends and family, in particular, his elder sister. As the support of friends and family is essential for people with disabilities, L6 acknowledges that he overestimates his own power. [85]

Masahiro NOCHI (2003) found that the meaning of aphasia constructed by a man had become multi-layered. He regarded his aphasia as either a negative aspect of himself or a temporary condition in the early period following his injury. However, he added new meaning to his disability, such as seeing it as a challenging, a shared attribute with people with similar disabilities, or social themes, in addition to the early meanings. Similarly, one might consider that L6 also obtained new meaning when he reconsidered his initiative. People with disabilities, who are often asked to try social activities, can ultimately accept others' support. Nonetheless, they are also concerned about the degree to which they should seek such support. L6 began to accept this social discourse and notice his passivity. Welfare policies for people with disabilities often require self-determination. However, such demands can also force them to accept the result that comes from such efforts. L6's passivity might relieve such burdensome feelings. [86]

4.3 Collective identity as people with disabilities

The participants also respected their new and deeper understandings of the position of other people with disabilities, their increased appreciation of family or others' kindness, and their serious engagement in medical and/or vocational rehabilitation. Janet Z. GIELE and Glen H. ELDER (1998) suggested that significant others are one of the main anchor points within life-long human development. People with similar disabilities are also important for those who have sustained SCIs (HAMMELL, 2007). The participants said they owed their recoveries from the powerlessness and shock of incurability to practical advice and encouragement from people with similar disabilities. Because this input was based on real-life experiences of wheelchair life, it was more useful than the advice from their medical doctors. L4 said that his teammates were "gathering, and had solidarity as intimates with similar disabilities." Consistent with current disability movements, it was also suggested that the participants share common needs with each other and develop a collective disabled consciousness or social identity (MANNIS & CHAD, 2001; YOSHIDA, 1993). [87]

The collective identity as people with disabilities might contribute to relief of social devaluation by able-bodied people. For example, Participant L8 (who lived in a rural area) worried that his neighbors laughed at him for being in a wheelchair because he was playing and got in a traffic accident. Participant L8's comments reflect the value of Japanese neighboring communities in rural areas. Participant L3 mentioned that he strongly refused help from others on a busy street; this might reflect a social stigma attributed to people with disabilities. Given participant L8's experience, stigma might be more complicated in rural areas. This might be the result of strong social ties where residents understand their

collective living conditions. Thus, there is a strong desire to maintain homogeneity in the community and to exclude social minorities. However, participant L8's concern was relieved after he joined a wheelchair basketball team. The similarity of the disability is not always relevant for them, of course. The participants grew to recognize the heterogeneity of people with disabilities; they actively judged for themselves what aspect of people with similar disabilities was relevant for them. L1 considered others' conditions to extract useful lessons for his own ADL improvement. The advice provided by patients who had been hospitalized again was also useful. [88]

Although the participants might draw distinctions between people with SCI and people with congenital disabilities, this does not mean that they felt superior to those with congenital disabilities. Richard SCHULZ and Susan DECKER (1985) suggested that those who sustained long-term SCI did not always make downward social comparisons. Furthermore, social comparisons are not always a judgment of their own situation; it can be a lesson for broadening their awareness. Participants such as L1 or L5 thought that relationships with people with different disabilities provided great experiences that broadened their view about disability issues. [89]

4.4 Sense of coherence and contingency

The participants' beliefs that their personalities had remained unchanged despite their injuries are worth further consideration. We should not judge whether their personalities really did remain unchanged, instead, we should consider this as a sense of coherence. According to Aaron ANTONOVSKY (1979), sense of coherence is defined as

"a global orientation that expresses the extent to which one has a pervasive, enduring, though dynamic feeling of confidence that one's internal and external environments are predictable, and that there is a high probability that things will work out as well as can reasonably be expected" (p.123). [90]

ANTONOVSKY (1993) called this confidence "comprehensibility." The development of a sense of coherence promotes adjustments to an acquired disability (LUSTIG, ROSENTHAL, STRAUSSER & HAYES, 2000). For example, people with acquired brain injuries wanted to find continuity between pre-injury self and post-injury self (GELECH & DESJARDINS, 2011). The development of a sense of coherence might be the result of an effort to create a biographical narrative. L6's reassessment of his diving represents a reversion to his character before his injury. He attaches significance to it to preserve self-consistency and self-continuity after re-evaluating his post-injury experiences—not because he is suddenly harkening back to his pre-injury days. His views in this regard were greatly influenced by the social discourse that it is wrong to sink into passivity after becoming disabled. The present findings suggest a connection between the participants' pre- and post-injury lives. They also diminish the gravity of the actual dramatic changes in bodily functions and social activities, highlighting instead the importance of human relationships and employment. [91]

The participants recognized that their lives were greatly influenced by a socially supportive environment including disability services, the social awareness of disability, and the contribution of luck or chance to the course of one's life. The participants assumed that such contingencies are distant from them, and they could not control them. This understanding connotes that achievement of improvements in bodily functions or social activities are not solely the result of their efforts. L3, who has often received assistance on the street, thought that the social acceptance of people with disabilities had improved, although it was not sufficient for him. L4 regarded his entrance into the rehabilitation center as a stroke of good luck and appreciated that he was living in a period in which disability services were substantially developed. [92]

These remarks are in line with the view of Janine PIERRET (2003), who insisted that studies on experiences of illness should examine narratives concerning their social backgrounds as well as their personal lives. It was also suggested that events of contingency, for example, assistance by people on the street, equipment for accessibility to public facilities, and welfare services, serve as mediators between a person and society. The participants did not take them for granted, although some of them were legally recommended. The importance of contingency leads to the relief of burdensome feelings that could come from self-determination, as previously seen in L6's passivity. [93]

Moreover, we could argue that "contingency" is not a fact, but a story reflecting the Japanese "humility" norm. This norm suggests that people should not strongly emphasize their own efforts, but they should express their gratitude toward others' support. [94]

5. Conclusion

The participants lived their life courses similar to those of able-bodied individuals, and they tried to find specific, meaningful aspects of their lives that resulted from their disability. They had a sense of coherence between pre- and post-injury, which relieved their experience of loss due to the injury. They recognized their inability to control everything, and valued these contingencies as a relief from burdensome feelings. [95]

The meanings of disability are constantly changing. The participants overcame continual problems one by one, and sometimes reassessed the meaning of their disability through social activities, such as paid work, a welfare job, sports, or intimate relationships with people with SCIs. L4's work, or L6's diving, are typical examples. [96]

Additionally, even though the participants shaped their social identities as people with SCI and considered itself as meaning aspects of living with disabilities, they also recognized the differences among themselves and readily acknowledged the dichotomy of people with disabilities and able-bodied people. [97]

There are certain limitations in this study. The interview data is out of date, and more than ten years have passed since I conducted the interviews. Many new disability policies have been implemented. Therefore, I will conduct further interviews with the participants to examine their change of meaning of disabilities. [98]

Appendix: Interview Schedule

Hope for full recovery and shock of incurability

Relationship with people with similar disabilities during or after hospitalization

Injury's influence on family life

Problems with bodily functions and arrangement of attendant services

Social disadvantage relating to disability: employment, education, leisure, or social activities

Recognition of disability issues

New values or accomplishments in life after injury

What is not changed despite sustaining injury?

Assumed life trajectory without disabilities

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