Narratives of Ambivalent Meanings of Acquired Physical Disability in Japan

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Narratives of Ambivalent Meanings of Acquired Physical Disability in Japan

Masakuni Tagaki[1]

Abstract

Experiences of people with disabilities cannot be simply examined from positive aspects or negative ones; both aspects are required. This study examines the ambivalent meanings of acquired disability through a qualitative analysis of the life stories of Japanese men with spinal cord injuries. Semi-structured interviews were conducted with 10 men who had sustained the injury over 10 years ago, at around the age of 20. The participants valued job and welfare or social activities, by managing their impairments. They regarded their personal disability issues as social ones and actively promoted social awareness. However, some of them recounted ambivalent experiences; they maintained the vision that they would become able-bodied people again, or were reluctant to participate in social activities, because they felt inferior to more socially active peers. Examination of ambivalent meanings of acquired disability is necessary for an understanding of the actual situation of people with disabilities.

Keywords

acquired disability, spinal cord injury, life story, ambivalent meaning

Inroduction

Disability in Japan

The current study investigated the long-term experiences of Japanese men with spinal cord injuries (SCIs) from a socio-cultural viewpoint, in comparison with an earlier investigation, which was conducted through interviews. Longitudinal study on the same participants was required to examine changes in meanings of disabilities (Saldaña, 2003).

According to the Japan Spinal Cord Foundation (2014), 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).

Currently, major welfare services are 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 is a variety of issues, including limited attendant services in rural areas. Moreover, 24-hr attendant services that are provided are often insufficient.

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 since the 1970s. Japan has a strong cultural norm 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.

Employment is valued as an important aspect of social life and a means for economic independence. In Japan, the Cabinet Office, Government of Japan (COGJ; 2014) estimated that 12% of people with a physical disability who are aged above 18 years (approximately 3,830,000 persons) had a job in 2014. 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 2015, the legal employment quota was 2.0% for private companies and 2.3% 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 1.76% of the workforce, but this

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has steadily increased year on year. However, this remains at low level as compared with the legal quota.

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 system; however, this has weakened over recent years. The coconscious and the ie system refers to gendered household roles within Japanese families. For example, typical husbands or fathers are expected to earn an income for the family, while wives or mothers are expected to take on household duties like cooking, cleaning, and raising the children. This philosophical tradition prescribes gender roles or social expectations regarding manhood and family norms, which are important in disability issues in East Asia including Japan (Yan, Accordino, Boutin, & Wilson, 2014). Employment is a key status symbol of manhood in Japan, as is often the case in other developed countries.

Meanings of Disability From a Long-Term and Sociocultural Perspective

Researchers have suggested that the examination of psychosocial issues of people with disabilities who have recovered from an acute, unstable medical condition should adopt a long-term perspective (Krause & Bozard, 2012; Pershouse et al., 2012; Rose, 2012), 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, including secondary worsening of difficulties (Kumakura et al., 2002), aging (Rose, 2012), and psychological issues (Rose, 2012) such as mild depression (Nagumo, 2000), along with family life (Weitzenkamp et al., 2000), and social participation such as re-employment, social life (Krause & Bozard, 2012). As such, people who have sustained SCIs should continue to be evaluated long term in regard to the severity of the impairment of their bodily functions and its impact on social activities (Simpson, Eng, Hsieh, Wolfe, & Spinal Cord Injury Rehabilitation Evidence Research Team, 2012).

In addition to addressing these everyday problems, it is important to remember that people with disabilities—like able-bodied people—seek meaning from across the span of their lives (King, 2004). The meaning of life is not an inner state but is instead created through narratives (Bruner, 1990). For example, Crewe (2000) found that the life stories of people with SCIs could be categorized into three narrative types: comedy, romance, or tragedy, and indicated that each participant tried to describe their self-continuity from their pre-injury to their post-injury life.

Yamada and Kato (2006) suggested that researchers should consider the ambivalent meaning of loss experience from a long-term perspective. This is different from a model that attempts to compensate for the damage or loss caused by the disability through other positive aspects. They emphasize that the experience of loss has both positive and negative aspects. This perspective is analogous to the current study on acquired disability. People with acquired disabilities often swing back and forth like pendulums between the non-disabled and the disabled aspects of themselves (Yoshida, 1993). Nochi (2000) found 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). Krause (1998) indicated that self-rated adjustment outcomes declined over time for those successfully employed after sustaining SCIs. Rose (2012) and Hammell (2007) showed that lives of people with SCIs were multi-faceted, and they experienced both the loss of pre-injury bodily function or social activities and the development of new values or psychological growth. These pieces of research suggest that people with acquired disabilities can actively reconsider the meaning of their disabilities and learn to accept them over the long term.

Although it had a long-term perspective, prior research has often been limited by not accounting sufficiently for considering the meaning of life from a sociocultural viewpoint. The International Classification of Functioning, Disability, and Health or ICF (World Health Organization, 2001) and the current Basic Act for Persons with Disabilities that was established in 1970, and amended in 2011 in Japan have indicated that disability has a strong relationship with social norms or customs, it is important to investigate social beliefs or policy systems within a wider sociocultural perspective (Olkin & Pledger, 2003).

The current study focuses on the social discourse of people with disabilities experiencing conflicting social demands in school, the workplace, or other social activities. There is a social expectation from mass media, medical or social welfare professionals, and people without disabilities, that they should attain physical or economic independence (Tagaki, 2006). There are many difficulties in attaining this goal. If people with disabilities try too hard to achieve this goal, they may be criticized for not understanding the reality of disabilities. However, if they only make a moderate effort, bearing in mind their disabilities, other people might consider that they do not work hard.

To further investigate such changes over a person's life span, I will present a qualitative analysis of the life stories of people with disabilities. Kendall and Buys (1998) have insisted that qualitative analysis of interview data recounts the experiences of people with disabilities, and is a suitable analytic process to understand ongoing adjustments to disabilities. Although we cannot deny the physical reality of disabilities, the meanings of that reality are nonetheless shaped through sociocultural 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 related in a holistic

Table 1. Background of the Participants.

Name	Age	Severity	Injury cause	Injury duration	Employment status	Marital status	Disability classification	Means of transport
L1	53	Quadriplegia	Traffic accident	24	Non-regular	Married	4	Car
L2	50	Quadriplegia	Traffic accident	28	Unemployed	Unmarried	5	Car
L3	50	Paraplegia	Traffic accident	28	Regular	Married	—	Car
L4	58	Paraplegia	Traffic accident	30	Regular	Married	—	Car
L5	61	Quadriplegia	Sports accident	32	Unemployed	Unmarried	5	Train
L6	41	Quadriplegia	Sports accident	25	Unemployed (welfare)	Unmarried	6	Train
L7	44	Quadriplegia	Traffic accident	25	Regular	Married	—	Car
L8	50	Quadriplegia	Traffic accident	28	Unemployed (welfare)	Married	—	Car
L9	43	Quadriplegia	Sports accident	26	Non-regular	Unmarried	—	Train
L10	44	Quadriplegia	Traffic accident	26	Non-regular	Unmarried	6	Car

Note. "Disability classification" is graded from 1 to 6, a higher classification represents a greater need for welfare services. In the employment status column, "welfare" refers to work in a welfare institution as part of the social welfare system for the disabled. Participants L6 and L8 were conducting light duties at their local welfare institution. It should be noted that since the participants in the present study were the same as those in previous work (Tagaki, 2015), the designations"L1," so on, refer to the same participants.

fashion. My approach is consistent with qualitative analyses of long-term adjustment to chronic illness and disability (Kelly, Lawrence, & Dodds, 2005).

The aim of my study was to explore how Japanese men with long-term acquired physical disabilities construct an ambivalent meaning for their disabilities from a Japanese sociocultural perspective.

Method

Participants and Recruitment

The participants were those who joined semi-structured interviews that were conducted during 2002 and 2003 (Tagaki, 2015). To examine fluctuations in the meaning of disability, it is necessary to build a detailed life story, and on this basis, I decided that rather than interviewing new participants, it would be more appropriate to re-interview participants who I already know and inquire into their experiences in more detail.

I used the criteria for participant recruitment, including the following in the work: (a) 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 to the twenties); (b) the time since the injury occurred had to be equal to or more than 10 years; and (c) the participants included only men; as previously mentioned, the ratio of men to women with SCIs is 4:1 (Shingu, 1995).

A purposive sampling method (Teddlie & Yu, 2007) was used to recruit participants from local SCI support groups located in the western region of Japan. With regard to the method used for the previous interviews, I explained the purpose of the study with the leaders of the SCI support groups, and those leaders forwarded information related to members or acquaintances who could act as participants in the study. I

sought to establish rapport by attending their support group events because I did not have any personal relationships with the participants prior to the previous interview. As I had not maintained personal contact with the participants since the previous interviews, I contacted each of them by phone or by e-mail, explained the purpose of the study, and obtained their consent to participate in the study. The ethics committee of the university to which I was affiliated approved the study protocol. Their background information is presented in Table 1. The participants were aged between 41 and 61 years old (*M* = 49.4), the time elapsed since injury ranged from 24 to 32 years (*M* = 27.2). The causes of injury were traffic accidents and sports accidents. Each participant was issued with disability identification cards from the Japanese government that indicated the severest degree of impairment. Two of the participants had paraplegia, indicating that only the lower limbs are paralyzed, and eight had quadriplegia, meaning that all four limbs are paralyzed. With regard to the disability classification determined by the municipal governments when a person receives welfare services, L1 was classified as 4, participants L2 and L5 were classified as 5, participants L6 and L10 were classified as 6, and the rest of the participants had not received an evaluation.[1]

Data Collection

As the current research examined the meaning that participants attached to life with disabilities within their context, especially from a long-term perspective, the interview method was suitable for tapping their concrete life experiences. The interviews were conducted with each participant at their homes, in cafes, or at the local welfare facility. The interview method was based on the life story interview technique (Atkinson, 2001; Yamada, 2007). According to Yamada (2007), the life story interview is a version of a narrative interview; however, in the narrative interview, the interviewer

Table 2. Episodes on Reconsideration of Meanings or Ambivalence in the Previous Interviews.

L1	His wages were around half that of his colleagues because he worked at home. On the other hand, he was able to get involved in his children's future life course.
L6	He felt that ever since he tried his hand at diving, he had become more positive toward a range of activities, including the running of his local welfare institution. He felt that, as a person with disabilities, he was uniquely suited to his job running the welfare center, which he said could not be done by his able-bodied peers. On the other hand, as time went by, he was becoming more passive toward his work. He said he was only doing it because his sister and friends recommended it to him, and he had started to feel that he was incapable of meaningful activities compared to his peers.
L8	He succeeded in getting married after meeting a woman at a disabled sports group. However, his relationship with his parents-in-law was strained. This was because he was unable to find work owing to his disability.
L9	While he was hopeful about finding meaningful work at a disability welfare institution, he had difficulty being positive about marriage and romance.
L10	He wanted to conduct life activities without having to worry about assistance. He thought about wanting to live like an able-bodied person once a day.

Note. Reconsideration of meanings or ambivalence could not be detected among the comments of the other participants in the previous interview.

is expected to be only a listener, while in the life story interview, the interviewer asks questions to elaborate the interviewee's narratives and prevent tangential diversions.

The participants' current demographic information (family members, primary sources of income, employment, and welfare service, if applicable) and the trajectories of daily activities, such as medical rehabilitation, vocational training, or employment, were also collected at the beginning of the interview using a questionnaire. The questionnaire was administered to allow me to understand the passage of their post-injury life since the previous interview. "Daily activity" was used in the same way as in the Japanese social welfare service system.[2]

Before the present interview, I reviewed the records and analysis results of the previous interviews focusing on episodes of changes in meaning or ambivalence on disability. Table 2 shows examples of these episodes such as experiences concerning work (L1), passivity and comparison with peers (L6), family and work (L8), marriage and romance (L9), and desire for recovery of function (L10).

I conducted the present interviews in the following order. First, I inquired into basic details about the participants' situation, including the present state of their disability, their utilization of medical and welfare services, and their means of transportation. I inquired with careful attention about their utilization of services, as the welfare system had changed dramatically since the time of the previous interviews. I then asked them about changes that had taken place over the last 10 years, including changes in physical function, the lives they had led, and whether any major events had occurred. For the next step, I asked the participants to think of any experiences they had that they considered obvious examples of a change in meaning or ambivalence. I also asked the participants to consider the life trajectories they might have experienced if they had not sustained a SCI, the changes they experienced around the time they sustained their SCI, how they felt about the prolongation of the time since injury, and their outlook for the future.

As interviews involve an interaction between the interviewer and interviewee, it is important to consider the relationship that exists between the two in an interview situation (Holstein & Gubrium, 1995). The fact that I am an adult male and a professor at a university specializing in social welfare may have encouraged the participants to provide detailed accounts on the importance of their marriages and work as well as the significance of their activities in welfare facilities (Tagaki, 2007). The participants knew from the previous interviews that I have mobility impairment. They did not refer to my impairment during the present interviews, but this knowledge may have facilitated their statements about the importance of functional recovery.

Each interview lasted from 60 to 90 min. The average time was 75 min. The interviews were recorded with the permission of the participants. The period of the survey was from February to October 2011.

Data Analysis

To fulfill the current research aim, I had to understand the "subjective" meaning of the participants' life-changing process, as well as the sequence of their daily activities, over the past 10 years. I used the KJ method, a qualitative analysis method, and is named after the founder of the method, KAWAKITA, Jiro (1967). I decided on five steps for ascertaining the meaning that the participants attached to their daily activities. The first four steps were related to understanding each participant's experience. The final step was to identify the relationship between these categories among different participants.

Kawakita (1967) adapted this method from Charles S. Peirce's notion of abduction, relying on intuitive, non-logical thinking processes (Scupin, 1997). According to Nochi (2013), there are similarities between the KJ method and grounded theory methodology (Glaser & Strauss, 1967): both develop connections between categories that consist 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 ideas or concepts that might be contradictory or non-logical categories. Nochi (2013) suggested that the distinctiveness of the KJ method is suitable for the analysis of people's self-narratives, because they express many contradictions or inconsistencies. This method was originally developed to interpret ethnographic data in Nepal; it has become a popular qualitative analytic method in many fields, including developmental psychology (Sato, Hidaka, & Fukuda, 2009) and gerontology (Fukui, Okada, Nishimoto, & Nelson-Becker, 2011).

I took the standard procedure of the KJ method. First, I carefully reviewed the transcripts and memo that I took during the interview to gain an overall sense of each participant's life story. Each interview was transcribed into 21,000 letters in Japanese.

Second, sentences within each transcript were compiled into basic semantic units (in general, three or four sentences) that resulted in approximately 130 units for each participant using ATLAS.ti (Version 6.0). 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 4 times to obtain sufficiently aggregated categories. I used Idea Tree Version 7.0 (Dicre) from the second to the fourth step.

An average of 11 categories was obtained for each participant. Example of categories included priorities of children (L1, L7, L8); job, social activities, passivity, and hesitation (L6); and desire for recovery (L8, L10). Although 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).

As for the fifth step, I compared the past and the present, focusing in particular on reconsideration of meaning or ambivalence since sustaining the injury. I did this because I did not repeat the entire interview regarding the participants' experiences from their injuries until present, but rather inquired into reconsiderations of meaning or ambivalence, as well as their overall conditions over the last 10 years. Following a complete analysis of one participant's data, I began the analysis of the next participant's data.

Finally, I analyzed the relationships that existed among the entire participant group and combined the categories, which I present as four main categories in the results.

For the analysis, I used two qualitative research software programs, while taking into consideration their advantages and issues (Flick, 2007). It may not be possible to conduct a complete analysis using one software program alone. Therefore, different software has to be adopted for different types of analyses. ATLAS.ti was useful for giving sentences a single code, but Idea Tree was convenient for comparing one code with another to generate a category.

Table 3. Daily Activities Over Last 10 Years.

L1	He sustained various diseases, left the job he was doing before, and does part-time work at home when his physical condition permits.
L2	He is conducting life activities at home as before and has been looking for work, but he is unable to find any on account of illness.
L3	He is continuing work at the same job as before.
L4	Left the work he was doing before, now engaged in legislative activities.
L5	He is conducting life activities at home as before and participating in disability support group activities.
L6	He is conducting life activities at home as before, participating in disability support group activities and the running of a welfare institution.
L7	As before, he works on weekdays and practices disabled sports on days off.
L8	He found work, but left after 6 weeks as the long commute proved a burden. He has given up on going to work since the birth of his child and is currently engaged in light duty work at a welfare institution.
L9	He changed jobs but is working in the same type of job as before.
L10	He left the disability support job that he was doing previously for financial reasons and has started training as a lecturer on disability welfare.

Note. "Before" refers to the time of the previous interviews.

Results

The daily activities for each participant are described in Table 3. Although there was significant change in daily activities, such as changing jobs, resignation, or hospitalization, since the previous interview in L1, L4, L8, and L9, there was no change in L2, L3, L5, L6, and L7.

I developed the following four main categories: Coping With Physical Challenges, Engagement in Absorbing Activities, Using Disability to Exert Influence on Society, and Changes in Meaning or Ambivalence. In addition, I present brief life stories of L1 and L6 as important, illustrative case studies.

Results of KJ Analysis of Present Interviews[3]

Coping with physical challenges. SCI causes major impairment to the lower limbs and sometimes, depending on the area of the injury, the upper limbs, impairment of excretory function, and risk of bedsores. Accordingly, the participants had to cope with considerable restrictions on their physical movement. For example, the participants do things like reform their home, use wheelchair-friendly rail routes, and investigate the places they are going to beforehand. They spoke of how they manage to tailor the services to match their own life rhythm by looking at the difference in hours of operation between helper-dispatching businesses and the helpers' capabilities.

In addition, a number of participants expressed anxiety about placing the burden of care on their families. L9 said, "My parents look after me, so if they get sick there'll be a problem. I suppose if they do get sick, I'll use a helper or something."

Engagement in absorbing activities. The participants have found great meaning in their lives by engaging in absorbing activities, including work, social activities, welfare activities, involvement in child rearing, and leisure activities. The participants spoke especially of the importance that work has in their lives. L9 said,

> I'm treated much better in my current workplace [than previous one]. It is very fulfilling, because I can now learn new skills. Marriage and romance seem like too much of a bother. I want to continue working as long as my body will allow it.

L8 mentioned that he had given up on finding work and spoke about his proactive participation in events held by a kindergarten class and in leisure activities with his friends. L8 said, "Well, I attended my child's [the child was born several years ago] sports day." "I attend end-of-year parties with my old classmates [friends that date back to pre-injury]."

Using disability to exert influence on society. The participants place great importance on using their disability to send a message to society about the realities of disability. At the same time, they try to identify how social attitudes toward people with disabilities are being affected by this message. For the participants, "society" refers to other people with disabilities, members of the general public they encounter while out, and disability policies. These efforts to change societal attitudes are derived from "coping with physical challenges" and "engagement in absorbing activities," and the aim behind these efforts is less about resolving their own difficulties and much more about deepening society's understanding toward people with disabilities at large. L5 complained about the financial burden shouldered by people with disabilities, although it did not apply to him personally. He said, "It may be none of my business, but I don't think it's a good idea to charge disabled people themselves for welfare services. Many of those who are disabled are short of money." Participants proactively attempt to communicate about their disease and disability to others. L4 said that he tried to educate people about how to assist the disabled on the train to present the message to public that people in wheelchairs cannot manage all things by themselves.

Changes in meaning or ambivalence. 4 Changes in meaning of disability or ambivalence about disability are understood in the context of the above three categories and based on comparison of episodes in the present interview with the previous ones shown in Table 2. L1, L6, L8, and L10 mentioned similar experiences, respectively.

Participants L8 and L10 both expressed their desire for the recovery of physical function. L8 did not speak this time about his poor relationship with his parents-in-law, who dislike him because of his unemployment. He did mention, however, the desire he has had for the recovery of physical function since the birth of his child. L10 mentioned that he still maintains a desire for a recovery of function.

> L8: The other day, my child asked me to teach him cartwheels. Nowadays, the child understands more and more about disability and it makes me really wish that I'll be cured. If I were cured, I'd teach him cartwheels as much he wants.

> L10: [Because my job is lecturing on disability issues], I may look as if I don't have any hang-ups about my own disability. However, not a day passes when I don't wish I were able-bodied . . . I wish I could be liberated from the stress of having to ask people for help . . . It's a rather complex thing.

In the previous interviews, L9 discussed his worries about romance and marriage. However, as mentioned on above category "Engagement in Absorbing Activities," he said that he is now placing much more importance on his work life in the present interviews.

Case Studies

The results have so far been described in a segmented manner across a variety of the participants. Categorized data, however, is somewhat separate from the individual and the context within which these insights emerged (Hashizume, 2010). To address this limitation, this section focuses on two cases selected for a more detailed, contextualized analysis.

L1

Summary of the previous interview. L1 was 53 years old and had been living with SCI for 24 years. He lived with his wife and children. He had worked in a company prior to his SCI. He was injured in a traffic accident at the age of 29. During hospitalization, he realized the criticality of his condition as a SCI. He was thankful to other patients with similar disabilities who had given him tips about using a wheelchair.

After discharge, he returned to his job at the same company by telecommuting with his workplace, because he genuinely wanted to live with his family. He even tried to join communities to spread awareness about disabled people. He tried to develop an interest in issues about intellectual disability and internal disability, and realized that the problem of disability did not solely lie with disabled people but with society. Although he enjoyed his family life and activities for people with disabilities, he grew dissatisfied with his salary after his injury, which was half that of his colleagues'.

Summary of the current interview. Even though L1 prioritized his job, he remarked on some problems relating to his employment,

such as no pay raise. He quit his job, partly because he had to cope with his organ disease and bedsores that did not improve, and his company demanded his resignation. He added that pay was less at his current company, but he need not be worried about his children's education fees, so it balanced out.

L1 sometimes had to manage his attendant service due to "an ability gap" among the attendants from the agency. He sometimes negotiated with the agencies to meet his needs in an emergency. He felt that he was "responsible" for educating people about disability issues and communicating his experience to people with SCIs. L1 said, "There are not many people with SCIs as well as X disease, so I think it would be good to issue spinal injury news articles to remind people of such things."

Despite his disability, he emphasized that he spent lots of time with the children, and that giving them advice about his chosen path in life [science] would encourage them to choose that path themselves. He recounted that living with a disability had contradicting positive and negative aspects. L1 said,

> I had to start using a wheelchair because of the unexpected accident, but I remember saying that it is not all negative; there are some positive aspects, too./If I never sustained the injury, I probably would have developed the company worker mindset and had little time to spare for my children.

L6

Summary of the previous interview. L6 was 41 years old and had been living with SCI for 25 years. He was injured playing sports at the age of 16. During hospitalization, he was told his incurability by his doctor, and thought that he was being left behind by his schoolmates. After he saw people with the same kinds of disabilities being positive, he thought, "I too must try." After discharge from hospital, he subsequently used his disability to become passive toward everything, although he accepted being in a wheelchair.

When he was 22, his older sister invited him to go diving and he improved more quickly than he had expected. Diving provided him with an opportunity to try new things of his own volition. He became a leader of a welfare institution or disability support organization. He said that holding this position was something that other people in his age group might not have been able to do.

Nevertheless, he had begun to think again that he was actually passive. He did not turn his own ideas into a real enterprise in the welfare institution. In addition, he had begun to appreciate the support from his older sister and other people who were close to him.

Summary of the current interview. L6 continued to be proactively involved in the management of welfare activities through which the members could earn more money through light work. He often asked the municipal office to increase the number of hours for services that his friends with similar disabilities received. L6 expressed his support for the social model of disability and he said, "My legs are no good, so I use a wheelchair . . . If blind folks can't take an exam, they should be provided with Braille print."

Although he did not attribute disability issues to personal factors, he had an ambivalent view about his bodily function or his way of life. Over the past 10 years, he had often had to stay at home due to the malfunction of his wheelchair or his health condition. He mentioned these times as "blank period and loss." He said, "If I hadn't become disabled, I wouldn't have experienced this blank period, provided that I didn't become ill and get hospitalized."

He emphasized his passivity and hesitation throughout his life from the perspective of his interest in diving. L6 said,

> [After success of diving] I needed to change my passive attitude . . . I adopted a positive, forward-looking attitude./[However]I could only do diving thanks to the preparations made by my sister and the ship's owner . . . [From the time before the accident until now] I am probably still too passive./But since I first went diving, I am full of gratitude and I want to express it.

He added another example of his passivity and hesitation when he was going out. He said that he could not ask people to assist him with eating, because such assistance required significant time.

Because of his passivity, he felt that he was behind his socially active peers or able-bodied friends. L6 said,

> When I'm in the presence of someone with a real job title . . . I get a feeling of being left behind. One of my old classmates is running a boutique . . . It's much more remarkable than living with a disability . . . /I sometimes wonder whether I'm really doing work or activities that warrant the job title of "representative of an organization for the disabled . . ."

Discussion

In the following section, the results are elaborated and the participants' changes to meanings and their ambivalent meanings are discussed in their sociocultural contexts. Overall, the participants coped with their disabilities while tailoring the medical and social services, and transportation facilities to meet their needs. They found meaning in their lives through activities, such as work, socializing, and welfare. As the duration of disability became longer, the requirement of community acceptance may have played a broader role. The participants shared the ways that they perceived themselves as connected to society through their disabilities by conceptualizing society as its physical barriers, its engagement in community activities.

The participants believed that the ways in which they presented their physical disabilities influenced the ways that disabled people are generally perceived and that resolving their personal physical problems would contribute to resolving the problems of other disabled people or deepen public

awareness of people with disabilities. They might feel solidarity with other disabled people and consider disability-related issues as social tasks, rather than personal ones. They believed the significance of the social model reflected a social discourse in which it is argued that problems faced by disabled people are not solvable through their personal efforts alone and that societal acceptance is essential. These social messages have strengthened from the mid-2000s, when the legislation of the anti-discrimination act began to be discussed in our central government.

Ambivalence in the Meaning of Disability

The effectiveness of an ambivalent viewpoint was confirmed in "Changes in Meaning or Ambivalence." The positive and negative aspects of disabilities were perceived as indivisible in this category.

It is worth noting the subjunctivizing reality (Bruner, 1986) of "Changes in Meaning or Ambivalence" with respect to their narratives regarding the avoidance of their injuries. Subjunctivizing reality has been criticized by value change theory in rehabilitation psychology as the veneration of medically difficult functional recoveries (Wright, 1983). However, recent research on brain damage and other disabilities, as well as spinal injuries, has pointed to the significance of subjunctivizing reality (Gelech & Desjardins, 2011). The conclusion of a narrative in subjunctive reality is invariably uncertain and, consequently, participants are able to speak freely about their images of their current situations as an objective or to give a richer interpretation of their present conditions.

"Changes in Meaning or Ambivalence" indicated that the difficulties related to their respective disabilities were juxtaposed with their intimate involvement in child rearing (L1) and support of disabled people (L6 and L10). The particular experiences were considered to be possible only because of their disabilities. Although L8 presented a narrative in subjunctive reality related to his recurring desire for functional recovery for child rearing, he did not state that child rearing was a consequence of his disability. With regard to L1, we might argue that he tried to find a new family role in opposition to the traditional one in which the mother should be actively involved in child rearing, while he held the role as breadwinner.

L6's narrative, "[From the time before the accident until now] I am probably still too passive," modifies his experiences prior to becoming disabled through his reconsideration of the significance of his post-accident diving experience, which may be interpreted as his preservation of the consistency of his sense of self. The episode to which he referred can be considered not so much as an example of his passivity as his realization of the value of the support he received from others and his dilemma between that support and personal assertiveness. I could argue that this episode is reflecting the Japanese "humility" norm. This norm suggests that people should not strongly emphasize their own efforts or activity, but they should express their gratitude toward others' support.

In addition, society expects people with disabilities to try their best to cope with their daily lives and, if their efforts are insufficient to meet their needs, they are expected to accept assistance (Phillips, 1985). Nonetheless, they are also concerned about the degree to which they should seek such support. They are therefore caught in a dilemma in which they must achieve a balance between their personal efforts and accepting others' assistance (Tagaki, 2006). There is another cultural norm, which dictates that people with disabilities should "not be a burden on others" (Iwakuma, 2014). An example of such a burden is the request for support for public or worsening disabilities resulting from excessive effort. L6's ambivalence on passivity signifies this dilemma.

We might argue that "Changes in Meaning or Ambivalence" suggests that people with acquired disabilities are compelled to respect the behavioral norms of the disability support groups that they attend. People with acquired disabilities were originally able-bodied, and their physical functioning and social lives before their disabilities form important parts of their identities; thus, it might be natural to mention recovery. However, L10's narrative suggests that the disability support group is a context in which it is easy to talk in depth about disability, but the expression of desires to return to an able-bodied physical state is taboo. Value change theory argues that contact with other people with disabilities is an essential activity for learning how to live as a disabled person in (Wright, 1983). However, the extent to which the norms of disability support groups may relate to changes in meaning has not been considered.

Ambivalent Meaning and Life Course

Discussion on ambivalent meanings provides implications for the life course of people with disabilities. Nirje (1970) suggested that a principle of normalization for people with disabilities involves performing "normal" developmental tasks at each stage of life. For example, adult men are expected to earn money for their family through employment. This norm was dominant in East Asian countries, and became a pressure against adult men with acquired disabilities (Tagaki, 2016).

However, we should not implicitly presume a universal "normal" life course. It is important to critically examine the commonly held assumptions about progression through life and the social institutions that regulate this progress (Priestley, 2003). As it is evidenced in the participants' stories, they tried to find diverse purpose in welfare and disability sports activities. Although these activities do not necessarily lead to economic independence, they can be readily taught as excellent ways to live by people who have been disabled for a long time or those with a more recently acquired disability, at hospitals, welfare institutions, and disability organizations.

The participants might redefine these assumptions about life course progress. Based on their stories, we might argue that normalization suggests that the meaning of life includes things that are characteristic of people with disabilities, as well as things that people with disabilities have in common with able-bodied members of society (Hori, 1994).

Participants L6 and L10 scored the highest on the disability identification card for people with physical disabilities and they obtained the highest classifications of need for welfare services. Their scores may explain why they found great meaning in experiences that allowed them to view their disabilities in positive terms.

Conclusion

All of the participants were disabled for a considerable period, which gave them diverse experiences that could not be classified into a dichotomy of positive and negative events. This showed the actual experiences of people with acquired disabilities, and focusing on only one experience might lead to a stereotypical image of them. The ambivalent meanings of disability were strongly related to family issues, disability-related experiences, and age/generation normative experiences (Fritz, Lysack, Luborsky, & Messinger, 2015), where sociocultural norms regarding family, gender, and disability in Japan took an important role. The current participants did not passively accept these norms but actively challenged them. They spoke of the significance that they attached to their experiences in terms of the changes in meaning and the dilemmas they faced. They often referred to the disability support group; it could be a context where people with acquired disabilities promote solidarity with one another, but they felt that it was taboo to mention functional recovery.

People have narrative modes of thought about their lives that is aimed to constitute meaning-making. They are not static, but dynamic and open-ended (Bruner, 2002). Life stories, which are based on narrative modes, are neither true nor false (Brockmeier, 2012). This is regarded as advantageous for people with disabilities who try to create new meanings for their experiences (Smith, Papathomas, Ginis, & Latimer-Cheung, 2013). The changes in meaning may be opportunities for people with acquired disabilities to reorganize significant aspects of their lives. For example, L6's sense of passivity and hesitation might lead him to consider the significance of things in his life such as welfare activities. The participants will create new meaning through new experiences, and thus a follow-up study is required.

Author's Note

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Notes

1. Both the identification card marking the severity of the degree of disability and the disability classification were authorized by the Japanese government, and have a positive co-relationship. However, the former is a measure of impairment, while the latter mainly indicates the degree of requirements of welfare services that a person with disabilities receives.
2. 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.
3. In quotations from the participants' narratives, " . . . " indicates an omission of repetitive content. "/" shows that I have minimally altered the narrative for readability.
4. To avoid repetition, L1 and L6's narratives will be quoted in the following case section.

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