Narrating Disability in Contemporary Japan: [One Liter of Tears] and [A Therapeutic Sexy Trip]

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DOI: 10.4000/books.cdf.12490
Publisher: Collège de France
Place of publication: Paris
Year of publication: 2022
Published on OpenEdition Books: 7 February 2022
Series: Institut des civilisations
Electronic EAN: 9782722605817

http://books.openedition.org

Electronic reference

This text was automatically generated on 9 February 2022.
In Japan, like in many other countries, “disability” has long been a topic of writing, in the sense that “different” bodies and minds have fascinated society, intellectuals and writers for centuries. As in Western countries, the category of “disability,” as a unified framework encompassing a broad set of situations, came to the fore only in the second half of the 20th century; the first law dealing with “disabled people” in general, and not just people with a specific type of impairment, was enacted in 1993. On the other hand, writings featuring disabled characters or dealing with disabilities, be they considered as belonging to a common framework or not, have existed since the dawn of Japanese literature. However, with few exceptions they have traditionally been authored by people who were not disabled themselves: most of them were able-bodied doctors or “experts” tackling this issue from a supposedly objective point of view. In the 1970s the Disability Rights Movement, led by associations of people with disabilities, sought to denounce the confiscation of discourses on disability by able-bodied professionals and to defend disabled persons’ rights to self-expression, thus promoting people with disabilities as experts on their own situations. This movement fostered the burgeoning of disabled people’s self-narratives as a literary genre, a development that can be seen through both the number of published authors and texts and the commercial success met by some of these works.

This paper aims at questioning the diversity of narrative strategies implemented by disabled authors in order to express, analyze, highlight and share with the reader their subjective experiences of disability. It is based on a comparison between two works: [One Liter of Tears. A Young Girl’s Fight for Life (Aya’s Diary)] / 一リットルの涙 and [A Therapeutic Sexy Trip], published by Kitō Aya 木藤亜也 in 1986, and [A
Therapeutic Sexy Trip] / 療しのセクシー・トリップ\(^3\) (hereafter [A Therapeutic Sexy Trip]), written by Asaka Yūho 安積遊歩 in 1993. Both works were written around the same period, by authors living with a physical impairment. Moreover, they are both women's self-narratives: the experiences of living with a disabled body which they relate are thus experiences of female bodies. Yet in several respects they are also significantly different. [One Liter of Tears] is a diary that the author wrote from age 14 to 21; it narrates events as they happen, as an immediate experience (although one can assume that some editing work has been carried out at the time of publication, as we will see later). By contrast, [A Therapeutic Sexy Trip] is an autobiography by a 37-year-old author; therefore it is the work of an adult woman revisiting her past and somehow retrospectively recreating the events that punctuated her individual construction, through the lens of her experience. Moreover, while the author of [One Liter of Tears] wrote primarily for herself, for her own personal pleasure and with no goal of publishing (at least initially), the author of [A Therapeutic Sexy Trip] explicitly pursued an activist purpose. Indeed, Asaka Yūho played an active role in the Disability Rights Movement, and writing her autobiography was part of her experience as an activist: she wrote to be read, not only by disabled women who would identify with her experience, but also by a broader audience, aiming to deliver a message about what disability is (and what society should be). Finally, even though both authors belong to the category of "physically disabled people," their situations are clearly different. Kitō Aya suffered from spinocerebellar ataxia, a neurodegenerative disease diagnosed when she was 14, which gradually made her lose her motricity, then her speech capacities, leading her to an early death at age 25. Asaka Yūho, on the other hand, lives with congenital imperfect osteogenesis, diagnosed a few months after birth, a condition that does not significantly evolve over time. However, this difference should not be overestimated: [One Liter of Tears] is indeed a “disability narrative” and not an “end-of-life narrative,” to the extent that, until an advanced stage of her disease, Kitō Aya is not aware that it is incurable and deadly. Quite to the contrary, her narrative is that of a quest to tame disability and to learn, at every stage of the disease, how to live in the new condition that is hers. The issue of death appears only at the end of the work and is by no means one of the central themes. Moreover, it is indeed as a “disability narrative” that [One Liter of Tears] is presented to and know by Japanese readers. In fact it stands out as one of the biggest commercial hits in the field of disabled people's self-narratives in Japan, its success leading even to adaptations as a manga and as a television drama. To understand the distinct perspectives on the experience of “disability” that are presented in these two works, we must return to the definition of the concept itself. Michael Oliver\(^4\) contrasts what he calls the “medical model of disability” — that is, the traditional definition of disability as an individual, medically identifiable affliction, whose cause lies inside the disabled person — with the “social model of disability,” a perspective in which disability does not originate in disabled people but in a disabling environment. In the social model, disability is first and foremost defined by the barriers that a given society sets against individuals. This conceptual opposition has turned out to be very fruitful, both in the social and human sciences and in the activist field, even though the “medical model” does not exist as such and represents rather a repellent model, theorized for the sole purpose of criticism. Yet the “social model” has in turn been severely criticized, especially for its tendency to define disability primarily as a form of oppression, thus ignoring some of
its specific dimensions, such as the non-social aspects of disabled people’s experiences, like bodily sensations.3
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The social model had been theorized a few years before the two works presented here were written. While it had no influence on Kitō Aya’s writing, as she had no contact whatsoever with activists, it had a very clear impact on Asaka Yūho’s: indeed, in addition to her active participation in the Japanese Disability Rights Movement, she stayed for six months in California and established strong relationships with the American Independent Living Movement. Even though neither of them explicitly refers to these terms, it can be said that Kitō Aya’s perspective belongs to the medical model, and Asaka’s to the social model of disability.

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How is this difference in perspective reflected in the narrative choices made by the two authors? A comparison of their two strategies will allow us to highlight the elements that are stressed and emphasized, or on the contrary are set aside or concealed, in each of them.

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Let us mention that working on autobiographical materials requires a few methodological precautions. Autobiographical writing is founded upon what Philippe Lejeune6 calls the “autobiographical pact”: the author of a self-narrative commits, in his/her text, to deliver what he/she believes to be the truth. This does not necessarily imply that the narrative is true, but it presents itself as such. Therefore, in the texts studied here, we will not find “the truth” about the life of disabled people in Japan, in the sense of an objective analysis, but rather “truths” based on individual experiences that are reconstructed through writing.

Impairment: a bodily experience

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First, let us consider the storytelling of what the medical model defines as the core element of disability: impairment, an organic or cognitive dysfunction identified in medical terms. What do the two authors present of their individual bodily experience of spinocerebellar ataxia and imperfect osteogenesis, respectively?

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[One Liter of Tears] is written as the narrative of a decline, in the sense that the author depicts, step by step, the progression of her disease and her increasing physical difficulties. The body is therefore at the core of her narrative, first of all as a source of pain, a theme which pervades the whole work. Depictions of pain are aimed at providing the reader with a clear perception of the evolution of the disease, by giving a detailed account of each step, in a style that often verges on pathos.

My right leg, my knee throbs. Finally?... When I take a bath, I caress it and whisper: “My back that hit the floor when I fell, my shoulder, my poor body that hurts everywhere.”

8
The goal of Kitō Aya’s text is not only to evoke the reader’s sense of pity. It also constructs a heroic image of a young girl struggling against her own body. Indeed, the narration is based on the body/mind dichotomy, the physical decline shown at each step being used to demonstrate the author’s desire to be brave, as bravery appears necessary when facing a disability presented as an individual tragedy. Writing seems to have therapeutic properties for the author, or at least to act as a self-fulfilling
prophecy: she writes to give herself courage, in an inward-looking quest to find in herself the resources needed to overcome her difficulties. This is why the narrative is also sprinkled with scenes where the author marvels at minor details of daily life or writes poems which exalt the trivial things that nourish her desire to live and to resist pain. However, in the last chapters, when it becomes clear that the progression of her disease cannot be stopped, bodily sensations become progressively associated with the idea of death, even though the author carries on her quest for hope:

Is it right that you live? Even if you disappear, there will be nothing left of you. [...] Mum, is it right for ugly creatures like me to live in this world? I think that, maybe, Mum can find something that shines inside me. 生きていていいのか？お前がいなくなっても何一つ残りはしない… お母さん、私のような醜い者が、この世に生きていてもよいのでしょうか。私の中の、キラッと光るものをお母さんなら、きっと見つけてくれると思います。

In striking contrast to this storytelling of the disabled body as a painful and mortal body, the author of [A Therapeutic Sexy Trip] makes no mention of impairment, in the sense that she never writes about her living with a body that suffers from a medical affliction. Her perspective on pain is therefore very different from Kitō Aya’s, to the extent that she never mentions any pain directly linked with her imperfect osteogenesis. For example, even though she mentions several times the fact that her fragile bones sometimes get broken, she never says a word about the pain or the physical experience related to those broken bones. Pain directly resulting from her disease and, more generally, the bodily sensations associated with her disease are entirely concealed. On the other hand, she makes a strong connection between pain and the medical treatments intended to cure her.

The doctor probably intended to cure me sincerely. Nevertheless, I felt at that time – and I still feel this way – that I was used as a guinea pig. As it was said that male hormones would be good for me, I had repeated injections, every two days, from age 0 to 2. [...] An adult at least understands what is going on and why. But a baby does not understand anything. The only thing that this little me understood was that, for some unknown reason, it was always made to suffer.

Asaka Yuho’s goal is thus to contest the vision of disability as impairment and of doctors as omnipotent. She specifically denounces the fact that the medical treatment she received turned out more harmful than the “problem” it was supposed to solve. In this example, she clearly speaks out as an activist: her narrative of disability is indeed rooted in the social model, as opposed to the medical model. It rejects the vision of disability as individual impairment and, by so doing, omits the bodily dimension of disability, a tendency that has often been noted in the social model and its champions’ writings. Regarding the depiction of disability as impairment, the two texts are thus strongly opposed. For Kitō Aya, the idea of a deficient, vulnerable, painful body is at the core of the narrative. It structures the narration, based on the stages of her disease’s progression. It also plays a key role in the construction of the figure of the narrator as heroic, the extraordinary hardships faced by her body revealing the exceptional
strength of her mind. Asaka Yūho, on the contrary, rejects the narrative framework of disability as tragedy and the heroization of the disabled person. She thus takes the opposite view by clearing from her text any depiction of physical sensations unrelated to social situations of oppression, thereby asserting her militant commitment at the risk of concealing a part of her personal experience.

**Disability as a limitation of activity**

11 Beyond its purely bodily dimension, the experience of disability implies a limitation of the person’s capacity to perform some actions. The two texts diverge in their ways of narrating the experience of life with an incapacity.

12 In [One Liter of Tears], the author gives a progressive narrative of her loss of capacities. The reader is a spectator to the gradual loss of her mobility, experienced as a decline. In each chapter, she draws up a list of actions that she is no longer able to perform, of activities that become inaccessible.

It has become difficult for me to pronounce the consonants “m”, “w”, “b” and “n”. I was asked a question during science class, and even though I knew the answer was “minus”, I couldn’t say “mi”. I can make the form with my mouth, but I have no voice, only air comes out.

マ行、ワ行、バ行、ンが言いにくくなってきた。化学の時間にあてられて、答えはマイナスとわかっていたのに、マが言えなかった。口の形はできるんだけど、声にならず空気だけぬけていく。10

13 This loss of capacities results in guilt and the shame of feeling herself becoming increasingly dependent on other people’s help. While this feeling is frequently attested in the narratives of people acquiring a disability in the course of their lives, it is even more acute in Japan where one of the central elements of social life is the injunction to avoid embarrassing others (an injunction particularly criticized by the Disability Rights Movement). Dependence is thus associated not only with a feeling of helplessness, but also with the impression of being a heavy burden for one’s family and friends.

14 The limitation of activity suffered by Kitō Aya is thus lived with a feeling of guilt, that of being no longer able to perform actions considered as “normal” for a person of her age. This guilt is all the stronger since in Japan, following the Buddhist logic of karmic retribution, disability is seen as originating in evil deeds from a previous life.11 “Becoming disabled” thus means confronting strongly negative representations and progressively acquiring an identity marked by guilt and discredit. In this sense, the narrative is a record of Kitō Aya’s “career” (in Howard Becker’s sense)12 as a disabled person, that is, her shift from an “ordinary girl’s” identity to a “disabled person’s” identity, self- and socially recognized as such.

15 Writing plays a key role in this change of identity. It is indeed through the writing of her diary that Kitō Aya manages to distance herself from her experience and to draw, at each step, an assessment of her lost and remaining capacities and her feelings associated with both. The persona she constructs in her diary, with the above-mentioned tendency to heroization, stresses her willingness to maintain hope, to take a view which opposes her mostly negative feelings concerning disability by pointing out her remaining capacities and highlighting her ways of carrying on the fight of her mind against her body. This tendency is especially visible at the end of the text when, having
lost most of her mobility, the author wonders about her capacity to pay back the efforts made for her by her loved ones:

In the warmth of my home, I feel loved. But I can't express my love for them all. Because I can't talk, because I can't do any action that could express it...I can only do my best to answer their love with a smile! I try to get up early in the morning, brush my teeth early too, so that I won't be late for breakfast either, and to do my exercises properly every day. And I strive to respond to their love.

This extract reveals the ambiguity of Kitō Aya’s feelings toward her loss of capacities. On the one hand, it shows the guilt she feels concerning the help she receives from her family in daily life and her feeling of imposing additional work, lost time, and permanent concern on her loved ones. On the other hand, it highlights the young girl’s willingness to overcome her physical limitations to place herself in a reciprocal relationship in which she not only “receives” from others, but is also able to “give”, insofar as possible. By stressing the emotional aspect of the exchange (“love for love”), she tries to conceal her uneasiness regarding its concrete unfairness (“daily help versus smile”) and to recreate equality by pointing out the amount of physical effort required for her to smile, using a style that participates in the process of heroization. Kitō Aya therefore tries, through writing, to give value to her remaining capacities, but this valorization remains deeply rooted in a heavily negative representation of disability and the disabled person, defined first and foremost as a useless burden, a representation she can escape only through heroization. The author of [A Therapeutic Sexy Trip], much to the contrary, refuses all forms of individual heroization of the disabled person. For Asaka Yūho, disability cannot be defined at a solely individual level, in a perspective that leaves the person with the entire responsibility for her limitation of activities (and the resulting dependence). This is why she champions the perspective that lies at the core of the social model: a person is disabled only to the extent that she lives in a disabling environment.

(When I took part in the Movement) of course I used a wheelchair. This “of course” is meaningful. I was really astonished when my friends in the movement told me it was OK to use one. As I mentioned earlier, in the special school where the ultimate goal was to resemble non-disabled people, I had always been told that I should not use a wheelchair. It didn’t matter that I could not walk, I was told to keep on striving to use crutches. [...] When my friends in the movement told me, “Wouldn’t it be nice for you to use a wheelchair and go wherever you want?”, I felt like the entire world was opening up before me.

This excerpt reveals very explicitly Asaka’s perspective: in her opinion, her ability to move is not limited by the specificities of her motor capacities, but by social norms imposing bipedal walking on everyone and considering the use of a wheelchair as an abnormality. Asaka’s narrative is thus an invitation to rethink the traditional image of 

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the disabled person as an isolated individual struggling against him/herself, to break with individual guilt and to focus on the role of society in the limitation of activities suffered by disabled people.

18 Following the same approach, the text hardly mentions the issue of dependence, and never in terms of guilt. On the contrary, Asaka aims to portray interdependence as part of ordinary human relationships, with or without disabilities. This intention is especially visible in passages describing her relationships with people whose motor impairments are heavier than hers, especially with one of the Movement leaders who becomes her partner. Indeed, she depicts this relationship from the angle of balance and harmony between partners, highlighting the fact that each of them brings a different contribution to the relationship, depending on their particularities (and not on their capacities because, to her, disability is first and foremost a specific feature, one among many individual features, and not merely a limitation).

19 However, the reality of incapacity, and of painful lived experiences associating incapacities with individual devaluation, sometimes shows up behind the militant discourse. This is especially noticeable when Asaka deals with more intimate subjects like sexuality. She mentions that intercourse is not possible with her partner from the Movement, due to his physical impairment. Yet because of social norms pervading Japanese society, intercourse is the only form of sexuality imaginable for both of them. This incapacity leaves him with the feeling of being an incomplete man, and her with that of not being a “real woman” with a partner like him (for example, she cannot consider him as a potential spouse since marriage, at that time, means for her a union with an able-bodied man). This is why, with her partner’s consent, she lives a sexual life dissociated from her romantic relationship, with able-bodied men; yet this agreement results in frustrations and tensions for both partners. Although Asaka Yūho narrates this episode in her autobiography with the clear intention of showing the force of social norms weighing on disabled people’s sexuality, it nonetheless reveals the reality of painful subjective experiences associated with the situation of incapacity and the difficulty of escaping the process of individual shaming, even for people actively involved in the militant world.

20 These texts therefore show two aspects of the same social situation: the reasoning linking disability, limitation of activity and individual guilt. Kitō has fully internalized this framework and uses writing as a means of expressing her ambivalent feelings within it, through pathos and the construction of a heroic figure. Asaka Yūho tries, on the contrary, to escape it and to overcome the individual representation of limitations on activity, in order to reveal the key role played by society in constructing barriers that hinder disabled people’s lives. But behind the militant discourse, her narrative also gives a glimpse of individuals’ difficulties in breaking away from guilt, and of distressing experiences of limitations on activity in intimate, romantic and sexual life.

Disability as a social experience

21 The issue of the relational dimensions of activity limitation raises that of the social experience of disability: what does it mean, for the two authors, to live as a “disabled person” and to be recognized as such in Japanese society? Both attest to the fact that in Japan, disability is first and foremost defined as something that should be “cured”. Yet their attitudes towards this representation are clearly opposed.
In [One Liter of Tears], Kitō Aya plays the part of the “ideal patient.” She narrates her fight against the disease through descriptions of the discipline and exercises prescribed by rehabilitation professionals: her entire daily routine is structured by her doctors’ recommendations. She thus fits into the “sick role” that functionalist sociologists have defined, to the extent that she takes to heart her “duty to recover.” Therefore, she never makes a single comment on the treatments she receives, on the possible side effects of drugs, on pain felt during exercises or on the attitudes of the professionals she meets. She completely relies on the doctors’ competence and displays absolute docility. Her total submission to medical experts can of course be partially explained by the fact that Kitō Aya’s disability results from a disease, but it is nevertheless striking to notice that the majority of the text depicts her attitude as that of an ideal patient, even during periods when she lives in a barely-medicalized environment.

On the opposing side, following the ideas championed by the Disability Rights Movement, and especially the Green Grass Association / 青い芝の会 / Aoi shiba no kai, Asaka Yūho’s discourse is extremely critical towards doctors. [A Therapeutic Sexy Trip] thus condemns medical treatments as a form of oppression. To Asaka, the medicalization of disability results from discriminatory thinking towards disabled people, which tends to consider them as people who “should not exist” and should be made invisible. Her vision has been strongly influenced by the ideas of Yokozuka Kōichi, one of the leaders of the Green Grass Association, who condemns the “internalized eugenics” lying at the core of disabled people’s social treatment in Japan. She prominently depicts scenes in which she feels treated as a guinea pig, enduring treatments with no purpose of improving her condition.

Therefore, even if the tendency toward the medicalization of disability in Japanese society is visible in both works, the two authors deal with it with radically different attitudes. Kitō Aya perfectly fits into the norm of the disabled person as a patient receiving with docility and discipline a treatment aimed at curing her, while Asaka Yūho, on the contrary, rises up against this norm and endeavors, through her narrative, to contest the power of doctors.

An analysis of the two authors’ reactions towards the normative behavior expected from a disabled person would not be complete without a mention of gender: indeed, in addition to being “disabled”, both writers are women. The issue of gender is thus key to understanding their attitudes, be they conforming to or opposing social expectations. Docility and submission are not only attitudes required from disabled people, they are also qualities expected from women. Indeed, the social image of femininity in Japan has been marked by the official injunction, declared by the state in the Meiji era, to become “good wives, wise mothers.” Even though this injunction has been discussed, criticized and negotiated since the dawn of its appearance, social norms of femininity throughout
the 20th century have revolved around this idea of women as wives and mothers and, more implicitly, as providers of love and care. Indeed, as numerous researchers in the field of gender studies have shown, the social definition of femininity is based on the idea that the social mission of women is to ensure harmony in their families and, more widely, in their surroundings. Therefore, while women are held responsible for the way they manage their households, they are at the same time expected not to stand out as individuals — that is, they are not supposed to express themselves freely, but rather to maintain harmony in their families/groups/teams while complying with guidance given by a male leader. Disabled women are thus in a position of double submission (to medical authority and to male authority, both intertwined in the numerous male doctor figures appearing in the two texts). They are expected to comply with instructions provided by their male doctors, which means that as disabled persons they must be willing to “recover” following instructions from medical experts, and as women they are responsible for ensuring peace and harmony around them, be it in their families or at the hospital (and therefore they are not expected to express any form of anger or criticism). In this respect, Aya Kitō’s attitude fits perfectly into the “passive and obedient disabled girl” stereotype, while criticizing doctors’ attitudes, as Asaka Yūho does, turns out to be highly subversive.

Yet Japanese society, however gender-structured it may be, paradoxically tends to erase disabled people’s sex and to categorize them as gender-neutral “people” with disabilities. Indeed, since disabled people are viewed as unable to fulfill social expectations regarding their gender (that is, for men to work hard and provide for their families, and for women to bear children and carry out housework), from early childhood on they are treated as neither boys nor girls. The two texts are thus permeated to various extents by the idea that disabled women do not fit into norms of femininity and, therefore, are not socially recognized as women. [One Liter of Tears] explicitly expresses the idea that a disabled woman is ugly, and thus unworthy of love:

My disease is worse than cancer. It has stolen the beauty of my youth. If it wasn’t for this weird disease, I could even find love.

私の病気は、ガンよりひどい！私の青春の美しさを奪った。こんなへんな病気でなかったら、恋だってできるでしょう。

Noteworthy is the fact that the narrative, written by a teenager, does not mention any form of romantic feeling whatsoever, even though the afterword, written by one of Aya’s doctors, depicts her as passionately in love with a young male intern working in the service where she was hospitalized. This “omission” can inspire two interpretations. On the one hand, one can imagine that Kitō Aya herself chose not to write on this subject in her diary, performing some form of self-censorship when writing. On the other hand, equally plausible is the hypothesis that the passages she may have written have been deleted by her family or her editor at the time of publication. This raises the complex question of the literary status of the text of [One Liter of Tears]. Indeed, as Philippe Lejeune remarks, almost no diary is published as it was written. At the time of publication, authors frequently give in to the temptation of editing a text written several years earlier. But the editing work is also sometimes performed by families, as in the case of posthumous publication, especially of children’s diaries (such as Anne Frank’s diary). Might the family not wish to emphasize the heroic character of the late child and to erase any signs of discrepancy between the author and the figure of the model child expected by readers? Even though it is impossible to validate this assumption without access to the original manuscript, it seems fairly
likely that [One Liter of Tears] has gone through a similar editing process, which would explain the stereotyped aspect of the work, the tendency toward the author’s heroization, and her perfect fit with the expected figure of the model disabled girl: docile, obedient and sexless. Therefore, although it is not possible to assess to what extent Kitō Aya’s manuscript has been edited, the striking absence of the issue of romantic feelings in the work can be seen as a symptom of the widespread idea that it is not appropriate for a person with a disabled body to express love or desire for another person.

28 Asaka Yūho’s work is also influenced by the existence of this norm, but with the opposite perspective: indeed, as clearly stated by its title, [A Therapeutic Sexy Trip] is a narrative focused on the issue of love and sexuality. The author’s goal, through writing, is to assert herself as a sexual being, a subject and an object of desire, to account for her struggle to be recognized as such and to deliver to her (female) disabled readers a message of empowerment. She openly condemns several barriers that have hindered her personal fulfillment and deals especially with some taboos like sexual violence (which she received from a doctor as a teenager), or the dominant sexual script making intercourse the only legitimate sexual practice — an impossible one when she shares her life with a physically disabled partner, to the frustration of both lovers:

There was no model, no message around me saying “sex is not only intercourse”. [...] If at that time we had both thought that we didn’t have to force ourselves into impossible intercourse, I think we would have lived without suffering so much.

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She also depicts her different romantic relationships, the balances found with her partners, the joys and anxieties nourished by each encounter:

He who didn’t have a disability, did he feel something sexual for this small, abnormal body of mine, did he accept it? Was I attractive? I wanted to be embraced softly, I wanted to be kissed. I wanted him to tell me “you’re pretty”. [...] When I understood that he accepted my body, that I too could become a sexual object for a man, instead of wondering whether we loved each other spiritually [...] I wanted, through him, to receive the proof that “I was all right with this body.”

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Thus on the level of the social experience of disability, the two texts present a similar reality: a social environment in which disability is mainly considered as a situation that should be fixed, in a highly medicalized perspective. Moreover, they both reveal that norms of docility and passivity are applied even more severely to disabled women, for whom the possibility to live and express themselves as sexual, desiring and desirable beings is especially prohibited. However, the texts adopt opposite perspectives towards this reality. [A Therapeutic Sexy Trip] is deeply rooted in a militant perspective based on social criticism, while [One Liter of Tears] reveals, through the stereotypes it relies on, the norms weighing on a disabled young girl, even when publishing an autobiographical work.
Conclusion

These two narratives clearly embody the opposition between the social and medical models of disability and the imperfections of both models. [One Liter of Tears] reveals the idealized figure of a disabled girl who combines docility and heroism in an individual fight against disability experienced as an inner enemy. On the opposite side, [A Therapeutic Sexy Trip] is based on a definition of disability as oppression, narrating the author’s struggle not against herself, but against her social environment. In this respect, the three-dimensional analysis grid of disability (biological dysfunction, limitation of activity, social disadvantage) serves as a tool to account for the conjunction of social and individual factors constituting the lived experience of disability, even though it induces, in the analysis of self-narratives, somewhat artificial distinctions between elements of the narrative.

In both works, we notice the presence of some of the stereotypes and limits specific to each model. In [One Liter of Tears], we see an extreme individualization of disability and a reinforcement of the representation of the disabled person as a “singular individual” who risks isolation. In [A Therapeutic Sexy Trip], there is the omission of individual bodily sensations related to disability, and of pain in particular. These differences can of course be partially explained by the authors’ different situations, as presented in our introduction, but they also reveal clear narrative choices made by the two writers, through their selection of elements of their experience which are emphasized or neglected, or even concealed. It is essential to point out, in both cases, the role of writing as an instrument in the quest for self: writing is aimed at making sense of the experience of a disabled body. It is part of the author’s search for her own identity, one that must deal with the existence of a disability, be it rejected or fully embraced. The meaning of this experience is found individually and is expressed subjectively through literary creation, which in this respect contrasts with the “objectivity” intended by medical discourses. The literary status of [One Liter of Tears] is subject to debate, and the subjectivity that emerges therein might be less the author’s own than that of her parents, her editor, or that expected by readers. Yet precisely because of the stereotypes it is based on, this narrative reveals the normative figure of the ideal “disabled young girl” as she exists in the Japanese imagination, thus making explicit the model that weighs heavily upon real disabled girls. The special status of this work, as the embodiment of a normative imagination, makes it an essential point of comparison to understand both the originality and the limits of a narrative like Asaka Yūho’s.

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NOTES

2. In this text, we use the Japanese way of writing personal names, with family name first, followed by given name.
8. Ibid., p. 184.
14. Asaka, [A Therapeutic Sexy Trip], op. cit., p. 82-83.
15. Asaka has been a member of this association, which pioneered the Disability Rights Movement, since the late 1970s.
17. Asaka, [A Therapeutic Sexy Trip], op. cit., p. 33.
20. Kitō, [One Liter of Tears], op. cit., p. 47.
22. Let us mention that the text was published in her lifetime, two years before her death.
23. Asaka, [A Therapeutic Sexy Trip], op. cit., p. 117.
24. Ibid., p. 92-93.

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