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Short Title: Tōjisha research and narrative medicine

Author: Maxence Gaillard

Affiliation: Interfaculty Faculty Initiative in Information Studies, The University of Tokyo, Japan

Contact: Maxence Gaillard, Rikkyo University, Graduate School of Arts, 3-34-1 Nishi-Ikebukuro, Toshima, Tokyo 171-8501, Japan (maxe.gaillard@gmail.com)

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Tōjisha research and narrative medicine:

Contribution of a Japanese experiment in the investigation of patients' personal experience

Abstract: *Tōjisha* research is a methodology intended to help psychiatric patients through dialogue. It was introduced in the context of community care in Bethel House (Hokkaido, Japan) in the early 2000s and later spread to other parts of Japan as well as abroad because of its originality and apparent therapeutic success. It offers patients a framework to investigate their own problems, symptoms, and delusions and to build a discourse around them. In this paper, I present a short account of *tōjisha* research and I put it in the context of current debates over the benefits and drawbacks of narrative medicine. I argue that there is an original conception of the self and of empowerment of patients in *tōjisha* research compared to other models of narrative medicine. Finally, I mobilize these original aspects to address some rebuttals of narrative medicine.

Keywords: narrative medicine, psychiatry, self, subjective experience

1. Introduction

Tōjisha research is a methodology for psychiatric patients initially introduced in the 2000s in Japan.¹ It has recently witnessed a boom in publicity, including in media coverage, official

¹ The activity has originally been developed at Bethel House, a non-profit organization dedicated to community mental care in Urakawa, Hokkaido, until it received attention at the national level.

credit from the government,² and academic activities.³ The idea behind tōjisha research is to build a kind of narrative of illness from the point of view of the patients themselves. In this methodology, psychiatric patients present and discuss their own problems, delusions, and hopes. Tōjisha means literally a *person concerned*; the purpose of Tōjisha research is to give the floor to patients' subjective experience. By doing individual and collective research on their experience, patients become experts in their own subjectivity. The focus on first-person experience has a long tradition in psychology (introspection), in psychiatry (especially psychiatric phenomenology), and in medicine. In this paper, I will argue that, tōjisha research, despite many commonalities with narrative medicine, has the advantage of not privileging a linear narrative which allows patients to tell their stories in the manner that makes most sense to them.

I consider here narrative medicine as a general approach emphasizing storytelling to make sense of one's life. Narrative medicine puts the patient at the center of medical practice to highlight medicine's humanity. It is sometimes a move against the following: mechanization and biological reductionism in current medical practice, the inflated role of technology, and the strict focus on symptoms, disease, and treatments instead of persons, care, and support. The philosophy of Bethel House is very close to this trend. Narrative medicine and tōjisha research rely on a similar methodology of dialogue and of formulating one's own illness story.

² The proponents of tōjisha research at Bethel House have been the recipients of several official prizes. For instance, the community has been selected as "best practice" for its support of the independence of people with mental disabilities by the Ministry of Health, Labour, and Welfare (Survey project on the welfare of handicap).

³ Academic developments include academic publications about tōjisha research where philosophers and sociologists discuss tōjisha research (Ishihara 2013), and the institutionalization of tōjisha research in the academia, such as the Tojisha-Kenkyu laboratory (Kumagaya lab) at the University of Tokyo, Research Center for Advanced Science and Technology (<http://touken.org/>).

They represent two varieties of empowerment of the patient—empowerment by speech, by writing, and by showing consideration and respect for others. However, tōjisha research diverges from other models of narrative medicine with regard to the kind of storytelling involved.

Here, I take the case of tōjisha research to argue in favor of narrative medicine in general. Narrative medicine has faced criticisms from philosophy of medicine. Narratives are generally considered as having a potential for life-trajectory repair (Frank 1995), as they restore coherence and unity in a life devastated by illness. In doing that, narrative medicine relies on strong assumptions regarding the continuity of one's life—it is often assumed that lives themselves have or should have a narrative unity (MacIntyre 1981), or that the narrative is constitutive of personal identity (Schechtman 1996). As a consequence, narrative medicine has been accused of imposing a normative model of the good life, which raises ethical and epistemological issues: the narrative might be forced, inauthentic, misleading, and a source of misconception about one's past (Strawson 2010). I concede that these criticisms might hold for the versions of narrative medicine that they target, and I claim that tōjisha research presents an original alternative to mainstream models of narrative medicine. In particular, many discourses supporting narrative medicine have been developed in the context of family medicine (Charon 2006). Psychiatric patients can be seen as a challenge for narrative medicine, as they might not even master the cognitive tools required to build a narrative and notions such as continuity or coherency of life might appear problematic. Tōjisha research offers an original structure of the narrative, which is quite different from the default linear structure criticized by skeptics about illness narratives. I argue that the context of the construction of the narrative in tōjisha research allows for a better understanding of the collective, public dynamics of storytelling. These differences are related to the conceptions of the self and of

empowerment underlying the development of narrative medicine on the one side and of tōjisha research on the other.

While the innovative features of tōjisha research might help reconsider some aspects of narrative medicine which are, according to its opponents, putative weaknesses, the features highlighted by tōjisha research are not exclusive to it and can be present at a degree or another in every enterprise in narrative medicine. As a consequence, a broad understanding of narrative medicine, drawing lessons from tōjisha research, should protect it from some of its drawbacks.

I will first describe what tōjisha research is, giving a general presentation of its context of development and elaborating a little bit further on its methodology. Then I will give a brief account of some aspects of narrative medicine, underlining some of its pros and cons. In the last part, I will highlight the divergence between tōjisha research and other models of narrative medicine and draw the lessons for narrative medicine.

2. What is Tōjisha research? The context

Tōjisha research is the umbrella term for one of the support activities designed in Bethel House, a nonprofit organization active since the 1980s in Urakawa, a small town of Hokkaido.⁴ Hokkaido is an island at the margins of Japan. With a harsh climate, its main resources are agriculture and tourism. Local areas such as Urakawa suffer from isolation and

⁴ The book by Karen Nakamura, *A Disability of the Soul. An ethnography of schizophrenia and mental illness in contemporary Japan* (2013) offers an ethnography of Bethel House in all its aspects. The interested reader is encouraged to consult her comprehensive fieldwork for an overview of Bethel House's activities and its context of development.

unemployment.⁵ For decades, the mental health care system in Japan faced a difficult situation (Taplin & Lawman 2012), with limited resources dedicated to public facilities and the proliferation of small private psychiatric facilities with a low standard of care. Long-term hospitalization and extensive use of psychiatric drugs were the norm.⁶

Bethel House, established in 1984, clearly presented an innovative practice in this background. The “house” refers to an unused Christian church that was turned into a place where psychiatric patients (who might also be jobless or homeless persons) could stay. Today, the organization runs many shared apartments and houses across the city and hosts around 150 members, that is, patients. Bethel House is a community of shared living, including supervision for healthcare, collective activities such as cleaning and cooking, a café, and a business of seaweed packaging. One can think of Bethel House as an ongoing experiment in deinstitutionalization, moving from a model of confinement to a model of community care.⁷

Bethel is a community and as a result every member is engaged in its daily functioning. However, several key persons have played a major role in the historical development of the

⁵ Nakamura holds this point to be an essential factor accounting for the development of Bethel House: “Because Bethel is in the middle of nowhere, the members really have nothing to do but to focus on their own issues and support each other.” (Nakamura 2013, 186).

⁶ High dosing of psychiatric drug consumption is a common practice in Japan (Sim et al. 2004).

⁷ All these features might for a good part explain the overall success of the enterprise, but I want to focus here on one aspect of the therapeutic practice occurring at Bethel. This is the difference between existing publications about Bethel House (especially Nakamura’s) and this paper. I focus here on the methodology of Tōjisha research, while others focus on aspects such as healthcare, general conditions of life, the social context of Bethel House (friendship among members, comradeship, religion), and support activities (especially, supervised professional activities such as seaweed packaging). This approach is evident in Nakamura’s book. As she is conducting an anthropological study in Urakawa, she wants a comprehensive picture and insists particularly on understanding social connections and people’s communal life. She is in a way trying to grasp the “spirit of the community.” I do not want to exclude the contribution of all these factors to the well-being of patients since, clearly, camaraderie and humor are important. However, I am here on the side of methodology of medicine and science, especially the problem of access to first-person experience and the methodology to report first-person experience.

organization. The first of them is Ikuyoshi Mukaiyachi, a social worker (now a university professor of social work in a clinical context) who is the “heart and mind” of Bethel (Nakamura 2013). The second one is Toshiaki Kawamura, a psychiatrist at the Urakawa Red Cross Hospital who served as referring physician for most Bethel House members. As far as the exploration of patients’ subjective experience is concerned, Kawamura’s philosophy is important (Urakawa Bethel House 2005). As a psychiatrist, he is committed to reducing the amount of drugs that patients consume every day. If medicine contributes to tempering symptoms, it can also alter patients’ consciousness and experience, even to the point that it is sometimes difficult for them to speak, interact, or make plans. Psychiatrists are generally interested in symptoms as tools to categorize the disease and find the appropriate treatment.⁸ They are satisfied when the symptoms have disappeared, and most of the time, there is no particular interest in the discourse and experience of patients. For the better and for the worst, drugs are silencing patients. By contrast, Kawamura wants to reduce the intake of medicines, make the patients aware of their experiences, and get them back on their feet for a social and inner life.⁹ While social life (having friends, hold a job...) is a factor of well-being, inner life (e.g., attention to one’s own mental states) is a preliminary condition for the development of tōjisha research as an exploration of patients’ subjective experience. The doctor should step back if patients are to regain autonomy in their lives.

As part of the activities at Bethel House, there are daily group meetings in which members discuss with their peers the problems they are currently facing. In this context, tōjisha research was developed in the 2000s. Here is a tentative vocabulary explanation: I

⁸ This is Kawamura’s account of Japanese psychiatry. Similar perspectives have been defended in the US (Luhmann 2000).

⁹ See for instance Kawamura’s interview from 35’20 in Karen Nakamura’s documentary: *Bethel: Community and Schizophrenia in Northern Japan* (2007).

choose to translate the expression *tōjisha kenkyū* as per *tōjisha* research, as there is no proper corresponding word for *tōjisha* in English, and the meaning of the term in Japanese is important for understanding the significance of the activities conducted under this label. The word is composed of three characters: *tō*, which means this one, proper, appropriate; *ji*, which means matter, something; *sha* is the suffix added to refer to a person (such as *-er* in “researcher”). Literally, *tōjisha* is a legal term referring to a stakeholder, a person concerned, somebody related to something—for instance, the interested parties in a legal issue (by contrast with “third parties”). But it also implies “victim,” the person harmed in a situation, or someone who is discriminated against. Since the 1970s, the term *tōjisha* has been extensively used to refer to individuals facing discrimination and advocating their rights to self-determination. First mobilized in the women’s liberation movement, the concept then spread as a keyword in the minority rights discourse in general. Persons with disabilities or sexual minorities have identified themselves as *tōjishas* (e.g., gay *tōjishas*). The concept was a tool for organizing social movements (*tōjisha* activism): identification of individuals and groups as *tōjishas*, sharing *tōjishas*’ experiences, and formulating *tōjishas*’ needs. It also helped found a common ground among discriminated minorities. For instance, Shoji Nakanishi and Chizuko Ueno, respectively a disability activist and a feminist, offered in *The Sovereignty of the Tōjisha* (2003) a plea for a connection between all kinds of *tōjishas*. However, there is another side of the concept which has sometimes fueled controversy. *Tōjisha* is also an exclusive notion: It is often highlighted that non-*tōjishas* do not have access to the shared experience of discrimination that constitutes *tōjisha* subjectivity and thus are not legitimate to represent and speak for the *real* *tōjishas*. Two important issues are subsequently raised: Who can identify themselves as *tōjishas*? How should non-*tōjishas* (e.g., researchers studying minorities) relate to *tōjishas*? Some advocates of minority rights movements oppose what

they denounce as a “tōjisha nationalism” (for a review of the use of the notion in the context of the gay tōjisha movement, see McLelland 2009).

The concept of tōjisha came in the field of medicine through the disability movement (e.g., cerebral palsy). Transposed to medicine, one can keep the idea of engagement and involvement. Patients are, of course, persons concerned with the illness and deeply involved in it. In that sense, they certainly are tōjishas. Furthermore, patients may be victims of discrimination, especially when they are psychiatric patients. And they may also see a benefit of constituting tōjishas’ communities to defend their rights as discriminated persons.

If tōjisha is not a word used every day, *kenkyū* is a common term signifying research, as in a research laboratory, a research project, and so on. It can refer to any situation of *study* but is generally related to the professional activity of *scientific research*.¹⁰ When recalling the very beginning of tōjisha research, Mukaiyachi insists on the effect of the “research” label (Urakawa Bethel House 2005, 3). A Bethel’s member with schizophrenia, including episodes of violent outbursts, was in the psychiatric ward. After one of these violent episodes where he destroyed the public phone, Mukaiyachi came to him and proposed: “how about doing some research with me on these ‘explosions’ that happen to you and how to live with them?” Mukaiyachi claims that the idea of doing “research” is well received by patients and that it raised a “spirit of adventure” among them. As tōjisha *kenkyū* is a “research” procedure, it implies a methodology for creating distance between the subject and the object and ensuring a certain kind of objectivity. Overall, “tōjisha research” emphasizes the idea that a person is

¹⁰ Most of the expressions composed with *kenkyū* relate to research in the professional sense. For instance, *kenkyūshitsu*, literally “a place for *kenkyū*,” refers to the scientific laboratory. The more general term for study (e.g., the study engaged in by a pupil or a student with textbooks and lessons) is *benkyō*. It is not by chance that the term used to refer to the activities conducted under tōjisha research connotes a scientific investigation rather than just study in a broad sense.

simultaneously the object and the subject of research.¹¹ Ishihara (2015) suggests that there is a major difference between *tōjisha* activism in general and *tōjisha research* as defined by Mukayachi and colleagues. *Tōjisha* activism is in line with the minority rights motto according to which minorities should define their needs themselves, echoing the famous “nothing about us without us.” By contrast, the insistence on *research* unveils a fundamental uncertainty about the construction of *tōjishas’* claims. *Tōjishas* themselves might not perfectly know who they are and what they need and want. While the first goal of *tōjisha* research is to explore and reinforce self-knowledge, contributing to a better definition of one’s needs and desires, it may also be a tool to build a stronger political discourse for the *tōjisha* community as a whole, as I will discuss below.

To sum up, *tōjisha* research is a kind of self-investigation conducted by the persons concerned. As most *tōjisha* researchers at Bethel House are psychiatric patients with schizophrenia, a large part of the research is focused on the personal experience of patients, their expectations, feelings, and their mental life, including hallucinations and delusions.

3. What is *Tōjisha* research? A methodology

¹¹ Nakamura translates *tōjisha kenkyū* as “self-directed research,” after saying that a literal translation should be “research on yourself-as-part-of-an-affected-class” (Nakamura 2013, 173). She also claims that if one sticks to grammar, *tōjisha kenkyū* should be translated as “research by interested party” and not “research on interested parties.” This remark seems to contradict the translation “research on yourself-as-...” Obviously, the research is at the same time *on* and *by* interested parties, because the so-called researchers are precisely interested in their own mental life. One of the major proponents of *tōjisha* research in academic research settings defines it as “studying oneself through communication with others who share similar experiences” (Kumagaya, 2015) and gives sometimes the term “first-person study,” although he keeps also the Japanese term (see the ‘*Tōjisha-Kenkyū* laboratory’ at the University of Tokyo, mentioned in note 2). I stick here to the original term “*tōjisha*” because existing translations miss part of the meaning.

How is this research conducted? At the beginning of the process, the investigation is conducted with a pen and whiteboard during discussions mainly involving peers. The research process also involves time to think about problems on your own, writing notes and drawing charts to describe the complexity of the experience. Notes and drawings make the research on personal experience more objective and they can be used as a support of communication in peer meetings. Communication and discussion occur at several levels, the peer meetings being only the first step. Some meetings are open to the public, such as local residents and visitors. Open meetings are intended to communicate about Bethel's activities and reduce the stigma associated with mental illness. They convey the message that the institution is transparent, in contrast with the image of opacity and mystery still often associated with psychiatric care facilities. At the next level, public presentations are made before a large audience. Every year in Urakawa¹² there is a contest for the Delusion and Hallucination Grand Prix, attracting thousands of participants to the show by tōjisha researchers. The public includes patients—tōjishas—from different local communities, family members, doctors, or people coming out of curiosity. This event is the big annual conference of tōjisha research—a serious scientific society should have its big conference regularly. Notes and drawings become PowerPoint presentations, and some tōjisha researchers are quite skilled at PowerPoint presentations. In fact, the course of tōjisha research is analogous to academic research: from the more or less prepared presentation at the weekly lab meeting to the PowerPoint presentation at the big annual conference. Similarly, some of the research is published: a dozen books have been published by Bethel's community. These books are generally collective volumes, featuring the community or Mukaiyachi as editors, and including individual

¹² As tōjisha research expands, the congress has been hosted by various cities in recent years.

contributions of tōjisha researchers. Participation at big conferences and publication is also part of the therapy.

Tōjisha research reports include research on the following topics: “research on my syndrome of allergy to human beings,” “research on why I can’t stop crying all the time,” “research on my feelings of guilt,” and “research on how to take the ambulance.” Several hundreds psychiatric patients have followed this methodology till date. All the examples mentioned below (unless otherwise specified) are extracted from (Mukaiyachi and Bethel House Urakawa 2006). Presentations generally follow a common pattern.

First, an *Introduction*. Speakers do not jump into a chronological life narrative, but rather focus on a specific target, i.e., one problem that they want to solve at that time and which is generally the main source of their suffering. For instance, if a person with schizophrenia is hearing voices, he or she will introduce his or her auditory voices. The voice can be labeled Dear Auditory voice (*Genchō-san*) and presented as a real person with whom they are facing trouble at that time. Then the speakers provide a self-diagnosis, generally not in official terms but those chosen by patients to illustrate their conditions. Diagnosis includes, for example, “I suffer from schizophrenia that runs out of money at the end of the month” (Nakamura 2013, 174), “syndrome of permanent slack in the lacrimal canal including self-harm,” and “schizophrenia that takes the ambulance many times because of the explosion of anxiety attacks of the aggressive type.” This individual labeling helps tōjishas claim the subjective experience of illness as a determinant of their personal identity (see section 5).

Second, the tōjisha defines a *Research purpose*. The main goal of the research is generally to understand the mechanisms underlying the problems and share the insights on these mechanisms with the community. Tōjisha researchers want to describe, circumscribe, and understand the main obstacles in their life, which are generally delusions, hallucinations,

paranoia, the inability to communicate with other people, and so on. For instance, a person suffering from paranoia will state as a goal “to understand the mechanism leading to constant misunderstandings with other persons.” In such a case, the ultimate goal of the research is not only to describe and understand the phenomenon of misunderstanding but to share this description with others for better communication. Other examples of research purposes include “to understand why I take the ambulance” and “to explain to others why I cry, that is, to make them understand the meaning of my tears.”

Third, the *tōjisha* defines a *Research methodology*. Methodological procedures include noting every instance of delusion, talking to others in support groups, and drawing charts. Notes and recordings are stabilizing the subjective experience before doing research on it. Charts are particularly important for retracing the sequence of the ups and downs of a chronic problem, and then to understand the causality behind it or the possible actions for change. There are no limits to methodological innovation. For instance, a *tōjisha* researcher with hallucinatory voices adapts his mental life for the stage. Each hallucinatory voice is a character, resulting in a complex theater play involving different characters such as the prime minister and other politicians, policemen, and yakuza, interpreted by the *tōjisha* and/or peers. The subsequent video recordings of the plays are analyzed and the reactions of the characters discussed by the group. Methodologies generally aim at turning the mental content of subjective experience into something objective, so that it can be discussed with peers or presented in public.

Fourth, the *Profile of the trouble* gives a full account of the mental content of the *tōjisha*. It describes in detail delusions, hallucinations, and also problems faced in everyday life. It can be considered as the field notes of *tōjisha* researchers, or observation reports on their subjective experience. However, this part is also the most similar to a classical life

narrative as it often describes chronologically the sequence of events in life and family leading to the diagnosis of psychiatric disorder and the medical record. Patients describe how they came to tōjisha research by giving elements of context, but this context is not intended as an explanation or as a set of causal mechanisms resulting in the trouble. Furthermore, this life narrative is always embedded in the research procedure and it is not the main object of research.

Fifth, *Results of research* section primarily describes the gain in comprehension of the problem stated in the introduction. A model of the subjective experience is proposed with recurrent associations and behavioral outcomes. For instance, the sequence of events and ideas resulting in “a call to the ambulance” or a “flow of tears” is analyzed and illustrated by a chart. In such cases, the result of research is an understanding of some mechanisms of the mental life of the subject, described as a cycle of ideas and actions. Another result is whether improvement can be seen in addressing the aforementioned problem. If a specific modulation of behavior or variation of some parameters in life has been already suggested in the methodology or profile section, the effects of these variations are reported here. For instance, a change at a specific stage of the cycle may block the action “crying” or “calling the ambulance.” In this last case, the call to the ambulance is successfully replaced by a call to a friend, as well as by the participation in tōjisha research.

Sixth, the *Conclusion* discusses the future path for the patient as well as the future objectives of the research. If some cycle of events or mechanisms has been clearly identified, the next step is to find the appropriate reaction to avoid the life-destructing consequences.

One of the lessons is that considering the mental life of the person as an object of investigation adds value to it. It conveys the message that the listener is not only interested in the mental life of the speaker as a tool for diagnosis and for determining the most

appropriate therapy, but also as a human experience which is intrinsically worth listening. The patients are not looked down upon by psychiatrists who will include the personal experience of patients in a diagnosis grid or in a category table. Patients can be aware of their own experience and do not have to be ashamed of it. There are also accorded a status: Patients become researchers with their own experience. There is, of course, a lot of irony in labeling this kind of storytelling “research.” Chronic psychiatric patients have generally gone through several treatments and therapies, which are presented to them as the output of biomedical research. In our societies, “research” is associated with technology, intelligence, power, and cost. As suggested by narrative medicine advocates (underlying that this should not be the only answer to the suffering of the patient), “modern medicine” or “scientific medicine” often take the form of new drugs or sophisticated technological devices. If tōjisha is a kind of research, it is low-tech research, far from the lab and the company, putting the focus on the subjective experience of patients. For most tōjisha researchers, that is, marginalized patients, being called a “researcher” implies an elevation of social status, and even an ironic inversion of position: now they are the researchers.

4. Narrative medicine and its discontents

In this section, I give a brief account of narrative medicine as an academic and health care enterprise and I present some of the difficulties it has faced from the perspective of philosophy of medicine. Narrative medicine has emerged as a response to the limitations of current mainstream medical practice in which “health care professionals may be knowledgeable about disease but are often ignorant of the abyss at which patients routinely stand” (Charon 2006, 19). The problem with current medicine is that scientific expertise, technology, and economic pressure are widening the gap between the patient and the health

care professional. Narrative medicine is aimed at tackling the questions that expert and technologically sophisticated medicine leaves unanswered: questions of meaning of illness, identity, personal experience.¹³ This enterprise is built on a rich tradition of illness narratives, or storytelling focusing on the subjective experience of illness. In this view, narratives can help bridge the divides hindering the encounter between health professionals and patients, through communication of experience and shared meaning.

Turning the attention to illness narratives is required for both healthcare professionals and patients. At the clinical end, physicians and caregivers can be trained to listen to narratives or to build narratives themselves. This is intended to shift the focus of the physician from the disease to the person—or from a mechanistic view of the body to the perception of an embodied patient. For doing so, one needs to change perspectives. “Centrality of storytelling” is the keyword. Listening to a narrative is a way to enhance empathy and embrace the patient’s viewpoint.

For patients, the narrative is a tool to make sense of one’s situation. When asked to speak about their lives, rather than being asked to describe succinctly their current symptoms, patients do not focus on the narrow and negative aspects of their illness. Developing a narrative about one’s illness is a step toward acceptance and resilience. There can even be a positive experience of illness, an additional richness of experience, as if suffering offered an understanding or lucidity about the meaning of life that one could not have had without the illness (Murphy 1987; Carel 2008). There is now a very large corpus of patients’ narratives, and some of these narratives are major literary achievements, transfiguring the experience of

¹³ Narrative medicine is a supplement to medicine; thus, other ‘forms of medicine’ are not expected to be substituted by narrative medicine. Narratives are not supposed to replace drugs. In a similar way, Dr. Kawamura does not advocate the suppression of treatment, he only wants to avoid overprescription.

illness. Even if one cannot expect this degree of achievement to become a standard in everyday clinical situations, these landmarks do provide a model accessible to everyone. Regarding the practice of medicine, the main claim of proponents of narrative medicine is that patients should be offered the opportunity to express their experience—and this narrative should not be left unheard.

If patients are given a chance to express their narratives, and if the doctor is carefully listening to them, many issues that would otherwise have not come to light are revealed during the clinical encounter. Through dialogue, the patient and the caregiver build a converging narrative. At the end, agreeing on a narrative is a way to make better informed decisions, as many medical decisions involve both the physician and the patient.

Behind narrative medicine, there is also a more fundamental assumption that life itself is a narrative: a story with a beginning and an end told by a narrator and focused on a protagonist—the person, myself. Life might be composed of parts, but the parts are interconnected. Connections can be logical consequences or involve unexpected breaks. The sudden emergence of an illness in a peaceful life is in a way a break in a life story. In another way, the expected decay resulting from a degenerative disease is similar to a story progressing step by step. According to Behrendt (2017), advocates of narrativity rely generally on two assumptions. First, a “whole life unity assumption”: life is a story beginning with birth and ending with death. A benefit associated with illness narratives connected to this assumption is the “life-trajectory repair” potential, as narrative brings back a feeling of coherency or unity of one’s life against medical events seen as chaotic and pointless biological hazards. Second, a narrative identity assumption: the self is constituted in the narrative, or the identity of my person is built in my story. In this case, the associated benefit is identity restoration, as the

narrative restores a sense of the self when personal identity is threatened by the illness (due to changes in the body, in capacities, in social status...).

Narrative medicine is not immune to criticisms. The point of Behrendt is precisely that the two benefits listed above might not be beneficial after all and that the two assumptions about whole life unity and narrative identity are questionable. The main risk for narrative medicine is to adopt a simplified version of a certain kind of linear life story focused on the individual from birth to the current situation. This can be taken as an epistemological or methodological gap in narrative medicine, but there is also a practical or clinical concern. In narrative medicine, doctors in one way or another encourage patients to build narratives. What kind of narrative is expected? If the prevailing view is an oversimplified version of what a narrative is, then there is the risk that the narrative does not do justice to the experience of the patient, especially the part of patient's experience which is informative for diagnosis. As patients are pushed to build a narrative of their illness, they can choose more or less arbitrarily a guiding line for the narrative, and then distort or even invent symptoms in order to fit them into the main structure of their narrative, which might pave the way for wrong diagnosis (Solomon 2008). Suspicion over the authenticity and reliability of first-person narratives has grown with the expansion of the narratives themselves (Shapiro 2011).

Part of the simplified conception of a narrative is the idea of unity and continuity of life, and that there is one narrator at the center of this story. If we think that our lives are narratives in this sense, the reflection on one's life should automatically be shaped as one integrated story. However, critics such as Galen Strawson (2004) have pointed out that we do not know if our lives are narratives in this sense. After all, we often say that a person has several lives (one can have a private and a public life, or a family life and an affair). We can also note that a person has changed his or her life at a certain point (e.g., after changing jobs

or partner). Persons with several lives diachronically or synchronically juxtaposed might not be expected to formulate their experience in a continuous story from the beginning to the end. Strawson considers that some persons are bound to be diachronic, regarding themselves as one continuing person, while others might be “episodic” (2004) or “non-diachronic” (Strawson 2010). Whether one is more inclined to be diachronic or episodic is a matter of individual character and is a question in descriptive psychology. In contrast with diachronic persons, episodic persons do not tend to see their life in the frame of a narrative. If there are non-diachronic persons, they should not reasonably be asked to grasp their lives in a narrative—to expect a narrative is simply misplaced. As a consequence, asking any patient for an integrated narrative of his or her life is normative in a wrong way; it carries a request on what his or her life should be, and it can even be inquisitive.

This would especially be the case with patients affected by personality disorders or those with a difficult family history. And what should we do with multiple personality disorder patients? Narrative medicine has primarily been developed as a component of family medicine or general medicine, as can be seen in the works of Charon. Most of the cases mentioned by Charon are clinical encounters in the context of family medicine. Patients and physicians are confronting very tragic medical situations such as cancer or genetic disease, and the patients have some difficult history, are in pain, or are not able to plan for the future due to their illness. However, they are able to build a narrative of their experience and suffering, making way for empathy and resilience. A typical example given by Charon relates to living with a genetic disease in the family: Retracing the collective history of the illness, and sharing the story with the physician, helps face the illness and transform anguish into a certain sense of responsibility (Charon 2001). These patients, though, are not psychiatric patients. Psychiatry poses a specific challenge for narrative medicine. In most situations, the narrative

is impossible, as the discourse appears fragmented, exploded. Patients are unable to build a coherent story or even talk to somebody else. For instance, schizophrenia may involve delusions or hallucinations which are precisely hindering the ability to build a coherent narrative promoting an attractive image of the self. Strawson's objection to narrative medicine claims that "episodic" personalities are not its right customers, and patients suffering from schizophrenia are likely to be among them.

As an answer, narrative medicine can insist that the field focuses on the development of a "narrative competence" rather than the production of narratives *per se* (Charon 2006, but see also Charon et al. 2017). Engaging in a narrative is entering a process, it does not mean that the storyteller has to write a coherent and complete story of one's life. The goal is to "think with stories" (Frank 1995), not to possess stories as a "descriptive postscript" (Spencer 2017) to illness and life. I argue that the abstract guide presented in tōjisha research as a "research methodology" contributes to descriptions of subjective experience which are minimally loaded in implicit conceptions of the self and which do not imply that life is a story from birth to death with a single author-narrator. The tools developed by tōjisha researchers are particularly interesting in a psychiatry context, formalizing the idea expressed by Glover (2014) that delusive experience can be integrated in a life narrative. For Glover, visions are part of William Blake's identity not only as an artist but as a person. Visions make a somehow positive contribution to his sense of the self, his confidence, and his control over life. In this perspective, tōjisha research offers a unique framework to integrate all kind of experiences in a useful narrative.

5. The self as a moving target

The operational framework of tōjisha research does not suggest a linear narrative. When tōjisha researchers present their research in the aforementioned template, it provides a grid for the description of subjective experience. They are responsible for the choice of their research “methodology,” but not for the medium, as they follow a predefined framework. This represents an adhesion to a certain “objective” and “natural” style of storytelling. Tōjisha researchers do not have to overemphasize the linearity of a life story and to exaggerate the coherence of the description. They are not writing their autobiography. Moreover, in tōjisha research there might be less temptation to build a narrative of oneself and to stick to it than in other narratives. One does not have to find harmony through storytelling, precisely because the task is to describe an evolving situation. The question is often how to live with all the problems (including delusions), not how to get rid of them. With this purpose, tōjisha researchers present the results of their ongoing research, that is, they explain what they are carrying out, by themselves, with their friends, or with their auditory voices, to overcome problems.

Opponents of narrative medicine have criticized the model of biography or autobiography in literature—integrating all the aspects of an existence in a linear chronology—suggesting that the underlying conception of the self is oversimplified. In *tōjisha* research, there are problems, delusions, there is Dear Auditory Voice or the Prime Minister calling by telepathy in the middle of the night, or there are aliens asking to climb into their UFO. Of course, all these mental events happen to a person, the author and object of the research, but this person is a member of a network of researchers, connected by the fact that they have the same kind of psychiatric disorders and the same will to communicate through a shared methodology. Tōjisha research is a kind of *action research*; its goal is not only to describe and understand but also to improve the life of the patient. Keeping that in mind, it

appears that tōjisha research does not favor a fixed conception of the self: It relies on a dynamic conception of the self. Not in the sense that personality evolves through time—this last point can be perfectly captured within the framework of a narrative and is a classical model of storytelling: I was this kind of person and then I changed into this kind of person—but in the sense that the self is an evolving material of research. The self presented during the last lab meeting is not the self that I will present and study today: What are the results of your ongoing research? How are the delusions doing? Changing narratives, changing stories is precisely the sign that research is advancing and that something is happening at the therapeutic level. It does not necessarily mean that the delusions are gone and that the research object disappears; it means that the relationship that the patient has with Dear Auditory Voice or with the Prime Minister is evolving, hopefully for the better.

In the very notion of tōjisha, there is the idea that the persons concerned are speaking for themselves. This can be seen in the process of naming the illness as close as possible to one's personal experience. Many of the tōjishas declare that they do not want to heal, or to be cured. On the contrary they want to live as normally as possible staying as they are, with their disabilities, their bizarre subjective experience, and their hallucinatory voices. Characteristics associated with mental illness such as odd behavior and deviant inner life have become part of their identity and they claim it. This can be seen as a pragmatic strategy: if you cannot get rid of your trouble, embrace it. However, even if their mental health were to improve dramatically, discriminated persons will still likely bear the stigma of mental illness. Putting illness into narratives is not aimed at overcoming bad experience by rejecting it in the darkness of the past. On the contrary, the narrative gives a public status to the experience—it makes it real. In a sense, tōjishas can claim a certain originality and creativity that their society may lack. But the ethical implications are deeper. Originality and creativity can be seen

as marginal virtues associated with eccentricity. Here, the notion of “research” plays a major role in increasing tōjishas’ self-esteem. Subjective experience is considered as a given: it does not depend on individual fantasy. As subjective experience is given to particular individuals, it happens that only tōjishas have access to a certain kind of experience. Hence, these particular persons are in a privileged position to research the features of this kind of experience. “Research” refers here to the exploration of existing things. A tōjisha ‘researcher’ is not a person *suffering from* or *subject to* delusions; he or she is a person observing some natural phenomenon that occurs uniquely to himself or herself. For instance, only the tōjisha can name his or her illness in an appropriate way. What was seen as a weakness is turned into a strength.

6. Empowerment as a collective enterprise

Narrative medicine generally conceives storytelling as a dialogue between two parties: a teller and a listener, or a writer and a reader.¹⁴ The narrative can be the narrative of patients themselves, or the life story of the patient built by the doctor. However, there are many ways to be engaged with a story. The main paths suggested by narrative medicine to understand the story of the patient are through listening to the narrative, through the reconstruction in imagination of the narrative, or through dialogue in the clinical encounter. All these situations involve only two persons. This can be seen as a consequence of the focus on the individual on both sides of the narration: the individual who tells the story he or she authored and the individual who listens to the story and identifies with the author.

¹⁴ “Narratives are stories that have a teller, a listener, a time course, a plot, and a point” (Charon 2006, 9). This aspect is even reinforced in conceptions of narrative medicine relying on hermeneutics and comparing the clinical encounter with reading (Svenaesus 2000; Abettan 2017).

In narrative medicine, patients are persons confronted with the difficulty of illness. If we push a little further the idea that building a personal life narrative is per se a step toward resilience, then patients are overcoming existential difficulties due to their narratives, and not due to careful doctors, supporting families, and understanding friends. The key is in the stories that one tells to oneself, incorporating suffering and distress “into a heroic storyline” (Shapiro 2011). Ideal patients are individual heroes, writing a legend of themselves. This conception is deeply individualistic and seems to suggest that individuals are the only masters of their destiny, which is obviously not the case.

By contrast, *tōjisha* research offers a true polyphony. It puts the emphasis on the exchange between peers and research as a collective enterprise. There is simultaneously a primacy of the author, as the *tōjisha* is doing research on himself or herself and is the first to be concerned and aware of his or her own experience—no one else can have authority on personal experience—and a mutualized field of experiments favored by the “research” format. After all, science is produced by and for an assembly of peers. In *tōjisha* research as well, the research on personal experience is presented before groups of peers. In a way, *tōjisha* research is collective research, adding the contributions of other researchers to a personal investigation. As in research, there are lab meetings, discussion groups with members of Bethel House, and conference presentations. Publication of *tōjisha* research is one of the explicit goals of the research. Through publication, research on personal experience reaches a certain kind of universality and objectivity that a private discussion during consultation does not reach. Things that one might be ashamed of, that are usually not told, become part of one’s identity because they are publicly presented and written, or integrated into PowerPoint presentations.

As a consequence, tōjisha research relies on an original conception of empowerment. In tōjisha research, empowerment is a group action—this can be found in the meaning of tōjisha as victim, or someone discriminated against. Psychiatric patients are often suffering from discrimination (Thornicroft 2006). Each case of discrimination is singular, as is the individual pathology and its familial context, but there are some common patterns of exclusion and rejection that psychiatric patients share as a group. The defense of tōjishas does not rely on collective storytelling, each tōjisha being affected in its own way. However, building individual narratives as part of a collective enterprise such as tōjisha research suggest that members belong to a discriminated minority. By presenting their personal experience, by affirming the existence of their very peculiar mental life, tōjishas are defending their rights. They make the subjective experience public, they attribute a certain value to it (this experience is worth *researching*), and proceed to an individual and collective inquiry into the nature of this experience. Arguably, starting from a shared standpoint as a common ground for collective action may also be a source of tension. By definition, there are no two tōjishas sharing the same experience. The problem has been highlighted in the context of sexual minorities movements, as LGBT tōjishas could not agree on a common framework to identify themselves as a tōjisha community (McLelland 2015). Tōjisha research might not be sufficient in itself for community building, but it might be a tool to publicize the discourse of usually voiceless persons and to achieve the political goal of defending the minority's rights.

7. Conclusion

I have suggested that the conceptions of narrative and of empowerment differ in certain ways in classical models of narrative medicine and in the model proposed by Tōjisha research. What exactly is a narrative? In tōjisha research, the narrative is not linear, the self is no permanent

entity. Storytelling is problem-oriented. Most of the time, the self is not the main protagonist of Tōjishas' stories, there is no single voice, but a network of hallucinatory voices and imaginary friends or monsters taking part in the narrative. Critics of narrative medicine focus on a narrow version of narrative and point out the drawbacks of narrative building. Especially, they insist that a narrative is too poor an account of the complexity of human life. The narrative is felt as normative, as an oversimplified framework imposed on subjective experience and distorting it. The quest for coherency through storytelling ends up in an artificial construct which is beneficial neither for the person concerned nor for the listener, especially in a clinical context.

Narratives build by tōjisha research resist this line of criticisms. The self is always evolving, as it is precisely a matter of research. The consideration of tōjisha research suggests that, if one adopts a broader definition of narrative, critics of narrative medicine will likely fail to make their point. Tōjisha research, a kind of discourse on subjective experience that does not fit into the narrow definition of narrative, is nonetheless an attempt to communicate the experience of illness. It provides tools that enable psychiatric patients to talk about their subjective experience to cope with it, by making sense of their difference and by sharing their stories.

I do not want to claim that tōjisha research is totally different from other models of narrative medicine. It provides an example of a good practice related to narrative medicine's concerns, grounding on a broad conception of a narrative. But features extracted from tōjisha research and presented above could be found in some versions of narrative medicine as well. For instance, empowerment through the externalization of mental content, publicity given to subjective experience, and narratives as written publications, are of course important aspects of narrative medicine in general. Personal memoirs, illness narratives written in the form of

books are precisely aimed at this kind of universality and objectivity. My conclusion is that the consideration of a methodology such as tōjisha research as an alternative to mainstream narrative medicine should incline us to see the drawbacks of narrative medicine as methodological limits that are to be overcome in the future. Tōjisha researchers remind narrative medicine of the strong connection between the constitution of the self through narrativity and the role of narrative in community building. Their research, considered as a collective enterprise, is at the same time a very personal exploration of subjectivity and a common demand for dignity against discrimination.

References

- Abettan, Camille. 2017. From Method to Hermeneutics: Which Epistemological Framework for Narrative Medicine? *Theoretical Medicine and Bioethics* 38: 179–93.
- Behrendt, Kathy. 2017. Narrative Aversion: Challenges for the Illness Narrative Advocate. *The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine* 42 (1): 50–69. <https://doi.org/10.1093/jmp/jhw031>.
- Bethel House Urakawa. 2005. *Bethel no ie no tōjisha kenkyū (Tōjisha Research from Bethel)*. Tokyo: Igaku-Shoin.
- Carel, Havi. 2008. *Illness: The Cry of the Flesh*. Stocksfield: Acumen.
- Charon, Rita. 2001. Narrative Medicine, a Model for Empathy, Reflection, Profession, and Trust. *Journal of the American Medical Association* 286 (15): 1897–1902.
- Charon, Rita. 2006. *Narrative Medicine. Honoring the Stories of Illness*. New York: Oxford University Press.
- Charon, Rita, DasGupta, Sayantani, Hermann, Nellie, Irvine, Craig, Marcus, Eric, Rivera Colon, Edgar, Spencer, Danielle, and Maura Spiegel. 2017. *The Principles and Practice of Narrative Medicine*. New York: Oxford University Press.
- Frank, Arthur, 1995. *The Wounded Storyteller*. Chicago: The University of Chicago Press.
- Glover, Jonathan. 2014. *Alien Landscapes? Interpreting Disordered Minds*. Cambridge: The Belknap Press of Harvard University Press.
- Ishihara, Kohji, ed. 2013. *Tōjisha Kenkyū No Kenkyū (Research on Tōjisha Research)*. Tokyo: Igaku Shoin.
- Ishihara, Kohji. 2015. Learning from *Tojisha Kenkyu*. In *Disability Research Today* (pp.27-42), Tom Shakespeare (ed.). London: Routledge.
- Kumagaya, Shinichiro. 2015. Tojisha-Kenkyu of autism spectrum disorders. *Advanced Robotics* 29(1):25-34. <https://doi.org/10.1080/01691864.2014.967723>.
- Luhmann, Tanya. 2000. *Of Two Minds: The Growing Disorder in American Psychiatry*. New York: Knopf.
- MacIntyre, Alistair. 1981. *After Virtue*. Notre Dame: University of Notre Dame Press.

- McLelland, Mark. 2009. The Role of the 'tōjisha' in Current Debates about Sexual Minority Rights in Japan. *Japanese Studies* 29(2): 193-207. <https://doi.org/10.1080/10371390903026933>.
- Mukaiyachi, Ikuyoshi, and Bethel House Urakawa, eds. 2006. *Anshin Shite Zetsubō Dekiru Jinsei (A Life of Peace and Despair)*. Tokyo: NHK Shuppan.
- Murphy, Robert. 1987. *The Body Silent*. 1st ed. New York: Henry Holt & Co.
- Nakamura, Karen. 2013. *A Disability of the Soul*. Ithaca and London: Cornell University Press.
- Nakanishi, Shoji, and Chizuko Ueno. 2003. *Tōjisha Shuken (The Sovereignty of the Tōjisha)*. Tokyo: Iwanami.
- Sartorius Norman, Schulze Hugh. 2005. *Reducing the stigma of mental illness*. Cambridge: Cambridge University Press.
- Schechtman, Marya. 1996. *The Constitution of Selves*. Ithaca, NY: Cornell University Press.
- Shapiro, Johanna. 2011. Illness Narratives: Reliability, Authenticity and the Empathic Witness. *Medical Humanities* 37 (2): 68–72. <https://doi.org/10.1136/jmh.2011.007328>.
- Sim, K., A. Su, J. Y. Leong, K. Yip, M. Y. Chong, S. Fujii, S. Yang, et al. 2004. High Dose Antipsychotic Use in Schizophrenia: Findings of the REAP (Research on East Asia Psychotropic Prescriptions) Study. *Pharmacopsychiatry* 37 (4): 175–79. <https://doi.org/10.1055/s-2004-827174>.
- Solomon, Miriam. 2008. Epistemological Reflections on the Art of Medicine and Narrative Medicine. *Perspectives in Biology and Medicine* 51 (3): 406–17. <https://doi.org/10.1353/pbm.0.0038>.
- Spencer, Danielle. 2017. Narrative medicine. In *The Routledge Companion to Philosophy of Medicine* (pp.372-382), Miriam Solomon, Jeremy R. Simon, and Harold Kincaid (ed.). New York and London: Routledge.
- Strawson, Galen. 2004. Against Narrativity. *Ratio* 17 (4): 428–52. <https://doi.org/10.1111/j.1467-9329.2004.00264.x>.
- Strawson, Galen. 2010. Narrativity and Non-Narrativity. *WIREs Cognitive Science* 1 (6): 775–80. <https://doi.org/10.1002/wcs.92>.
- Svenaesus, Fredrik. 2000. Hermeneutics of Clinical Practice: The Question of Textuality. *Theoretical Medicine and Bioethics*, no. 21: 171–89.
- Taplin, Ruth, and Sandra Lawman. 2015. *Mental Health Care in Japan*. Oxon: Routledge.
- Thornicroft, Graham. 2006. *Shunned. Discrimination against people with mental illness*. Oxford: Oxford University Press.