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Japanese Association for
Philosophical and Ethical Researches in Medicine

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This volume of the Journal of Philosophy and Ethics in Health Care and Medicine contains one invited paper and three papers accepted through peer-review.

The opening paper is an invited paper authored by two members of the National Bioethics Committee of the Republic of San Marino, Luisa Borgia and Giampiero Griffo. In past years, the committee created a few documents concerning bioethics and disability, including one entitled *Bioethical Approach to Persons with Disability*, published in 2013. These documents provide detailed discussions as to what it means to protect the rights and interests of disabled people in the context of policy-related debate in bioethics. Borgia and Griffo explain the contents and purpose of drafting each of these documents and discuss their implications for future bioethical debates.

The next paper, by Yutaka Kato, is a report on vaccination refusal. An individual's right to refuse vaccination has the potential of posing a serious threat to public health. Based on a survey of relevant literature, Kato made it clear that while people do refuse vaccination across countries, there are very few reports on the current situation, worldwide, of vaccination refusal, including the reasons why people refuse, excepting reports from the United States. Kato's paper shows that more empirical research is needed in this area, in order to investigate the justifiability of limiting an individual's right to refuse vaccination.

Keiko Hattori considers the advocacy role medical interpreters can play in the clinical setting. As the number of immigrants to Japan

increases, there is a growing demand for medical interpreters. It is sometimes said that medical interpreters can do more than act as bi- or multi-lingual interlocutors; in addition, they are increasingly expected to bridge the cultural gap between the care-giver and patient, as well as to prevent foreseeable conflicts arising from misunderstandings, thereby playing the role of a patient advocate, protecting the rights and interests of the patient who may come from a potentially socially disadvantaged group. Hattori investigates the appropriateness of such an additional role, based on her findings from interviews with medical interpreters currently working in Japan.

The paper of Ren Ino deals with the nineteenth century Japanese poet, Masaoka Shiki, who suffered from tuberculosis and was bedridden for years before he died at the age of 35. By analyzing Shiki's writings, Ino describes how the poet overcame suicidal ideation and clarified his thoughts and struggles as the poet came to accept his difficult situation and created numerous pieces of beautiful poetry about his immediate surroundings. Ino describes in detail, the last years of Shiki's life, which contain important lessons for the ethics of end-of-life care.

As I succeed Yutaka Maruhashi in the role of editor-in-chief of the Journal of Philosophy and Ethics in Health Care and Medicine, let me express my sincere gratitude to Professor Maruhashi for his help and for his thoughtful and careful work as the editor-in-chief, in the past years.

Inclusion of Persons with Disabilities in the Documents of the *National Bioethics Committee of the Republic of San Marino*¹

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Abstract

In an effort to broaden discussion and reflection on issues concerning people with disabilities, the National Bioethics Committee of San Marino (*Comitato Sammarinese di Bioetica*, CSB) has appointed Dr. Giampiero Griffo of Disabled Peoples' International (DPI), as an external expert to help CSB generate an on-going discussion about disability issues, as requested by the UN Convention on the Rights of Persons with Disabilities (UN CRPD).

This appointment constitutes the first international example of collaboration between the CSB and a representative of associations of persons with disabilities, with the specific task of identifying the implications related to the issue of disability.

The first document, *"Bioethical Approach to Persons with Disabilities"* (2013) represents the first-ever work developed by a National Bioethics Committee on the topic of people with disabilities.

In the *"Bioethics of Disasters"* document (2017), the chapter dedicated to the management of persons with disabilities, involved both in natural and human catastrophes and in emergency interventions for health conditions, also stands out.

The last document, *"Decision Making in the Care of the Sick Person at the End of Life"* (2019), considers the following topics: approaches to the condition of disability, contextual elements with which the person with disabilities relates, informed consent, and forms of support at the end of life.

Key words: persons with disabilities, UNCRPD, human rights, mainstreaming, participation.

"Nothing about us without us": this is not just a catchy slogan for associations of disabled people, but the expression represents a central theme that has allowed collaboration between the National Bioethics Committee of San Marino (CSB) and the world of people with disabilities (Disabled Peoples' International Europe).

Since its establishment in 2010, Giampiero Griffo was appointed by CSB to act as an external expert of DPI Italia⁴ in the disability field.

This inclusion represents the first international example of cooperation between the CSB and a representative of an organization dedicated to helping people with disabilities and tasked with identifying implications connected

to the subject of disability, in committee discussions.

Reasons for the inclusion of an external expert stem from two considerations: the goal of introducing in the debates and in the bioethical choices a defense of human rights of persons with disabilities, who are still often treated differently, compared to others, based on a medical/individual model of disability⁵. The second reason for inclusion comes from the UN CRPD, contained in Article 4(3): "In order to elaborate and fulfill the legislation and politics to be adopted to carry out the present Convention, as well as in the other decision-making processes concerning matters regarding disabled people, State Parties work closely in consultations,

actively involving persons with disabilities, including disabled minors, through their representative organizations.” From these same motivations, DPI Europe, the European Disability Forum, and the International Federation for Hydrocephalus and Spina Bifida⁶, have been active in passing several Assembly resolutions and promoting related research⁷. Close attention was given by Disabled Peoples’ International (DPI) Italia to the risks of discrimination connected to the condition of disabled women (Galati and Barbuto 2006). Further, even the UN Committee on the Rights of Persons with Disabilities (CRPD) highlighted, in general comment n.7, about the importance of the subject of participation for the organizations of persons with disabilities⁸.

In this article, we examine the main documents drawn up by the CSB in which the themes of disability, the effects of mainstreaming discussions of disability, and the consequences of the main documents⁹.

1. The document “*Bioethical Approach to Persons with Disabilities*”

The first and most exemplary result of this cooperation is the “*Bioethical Approach to Persons with Disabilities*” document, published in 2013, the first-ever document edited by a National Bioethics Committee concerning this theme¹⁰. The document authors strove to start a comprehensive investigation into a subject largely absent from international bioethics evaluation, for a multitude of reasons: the complexity and extent of the subject, the lack of a unanimous and shared definition of disability, the linguistic fluidity and semantic evolution that has characterized this theme over the centuries, the difficulty of facing without prejudice subjects long considered taboo, the inadequate awareness by disabled people themselves of their human dignity, all of which have persistently kept them excluded from the public debate.

The reasons listed help to explain the absence of international organizations commenting on the theme of disability, until December 2006, with the approval of the UN Convention on the Rights of Persons with Disabilities. Despite this UN approval,

bioethical organizations have been largely silent on this theme, creating, in an indirect way¹¹, a paradox: people with disabilities, among these, women, children, and older people, represent one of the most vulnerable groups, for whom members of the contemporary international bioethics community can and must act, so that the essential principles of beneficence, autonomy, and justice may be consistently applied.

The UN CRPD is an important first step in reinstating human rights to persons with disabilities as well, on the basis of a universal criterion that gives some political force to upholding human dignity. This approach is in line with the UNESCO Universal Declaration of Bioethics and Human Rights¹², but this approach had never before worked in unison with the UN Convention. CSB, along with Giampiero Griffo, decided to issue the document since the UN Convention mentioned offers a cultural frame of reference representing an historical event presaging a change in the approach to persons with disabilities, utilizing a bio-psycho-social model of disability grounded in a respect for human rights. Only after a period of decades will it be possible to assess its benefit.

In fact, a new and growing awareness of disability as an ordinary and universal condition that potentially every human being possesses, as expressed by the World Health Organization (WHO 2011), challenges us to consider disability in decisions linked to development and social organization. The protection of human rights, social inclusion policies, and the development of social environments, inspired in part by the concepts of Universal Design, affects all societies. The policies of social inclusion, designed to remove the conditions producing disabilities, refer to general policies of society and represent a new challenge of this millennium and an investment in the future.

The UN CRPD introduces a reversal of perspective in the reading of the condition of disabled people: before even knowing their needs, it is necessary to begin with the recognition of their human rights. The conceptual novelty contained in the definition of disability (“Disability is the result of the interaction between people with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an

equal basis with others.”) focuses on the social relationship between characteristics of people and the way the society takes these characteristics into account.

This new focus on social relationships means that the condition of disability is not determined automatically by health factors, a common and uncritical view still found in bioethical discussions concerning people with disabilities. In fact, the UN CRPD goes beyond the medical model of disability, which attributes the condition of disability to health and individual factors. Instead, the UN CRPD emphasizes the social model based on respect for human rights that describes how disability conditions are produced, creating barriers, obstacles and discrimination that limit privacy and respect for their human rights. In the field of bioethics, cultural and technical approaches based on the medical model are still prevalent; an example of this approach is found in the field of genetic counseling that all too often conditions and prepares family members about the likely limitations and negative conditions their baby or fetus will endure, after having been diagnosed with a significant malformation. More appropriate, instead, would be to involve other points of view, such as those professional associations that can help explain what it means to live with physical conditions and characteristics a society considers undesirable and yet still thrive. There are numerous examples of successful people who also happened to have disabilities, such as Stephen Hawking, who lived for decades with ALS, who is also considered one of the most important astrophysicists of our age, or the numerous people with Down's syndrome who have graduated from various universities and have enjoyed successful careers. Ending such lives through elective abortion or infanticide would have canceled opportunities to benefit from their contributions. This growing trend of including people with even profound disabilities stands in stark contrast to the views of Australian philosopher Peter Singer who has often argued that parents must not feel morally required to continue with a pregnancy of a baby diagnosed with Down's Syndrome.¹³

A further innovation is the concept of progressive social inclusion of people with disabilities who, included in the protective scope of respect for human rights, assume their role of

civic citizenship in a society that must look after them. The aim of the UN CRPD is to forbid all forms of discrimination based on disability and to guarantee equal and effective legal protection against discrimination. Every time a person with a disability is treated differently without justification, he/she suffers discrimination that is a violation of human rights. Further, since there are conditions that produce multiple forms of discrimination, UN CRPD pays particular attention to disabled women and children, with two specific Articles (Art.6 and Art.7). The new approach of the UN CRPD aims to overtake the traditional institutionalizing and segregationist view of treating persons with disabilities. Instead, the UN CRPD promotes the idea of everyone living in one community, with the support provided for a more independent life (Art.19 and Art.20), providing respectful treatment of human rights for people who are unable to represent themselves (Art.12) and giving access to all rights on the basis of equality with other citizens and without discrimination.

Another important factor related to discrimination against persons with disabilities is considered in Equal Opportunities (Art. 5 of the UN CRPD), precisely defined in the UN Standard Rules¹⁴. Ensuring Equal Opportunities on the basis of equality with other people requires the implementation of adequate measures and supports, so that disabled people can participate fully in society and enjoy all human rights and fundamental freedoms. Combining non-discrimination and equal opportunities representing the new framework of international legal protection means that states and societies should endeavor to identify and prevent encroachments on human rights and fundamental freedoms.

Disability, whose definition emerges from the social relation between characteristics of people and the social and physical environment, can therefore be mitigated, not just in the health sphere, by reducing the consequences of disease, accidents, and old age, but also in the social sphere, by removing obstacles and barriers, by providing technical assistance, applying helpful techniques and aids, creating the conditions for preventing discrimination and unequal treatment.

Regarding respect for human rights, we can help remove negative cultural stereotypes

and prejudices by integrating a bioethical thought to this new paradigm of disability. In fact, the protection of human rights for disabled people can be applied to a wide range of rights and activities: from those related to access to goods and services, to those related to shielding sensitive information and those connected to medical and social treatments. In protecting these rights, we find the challenges in accessing health services an important topic, as the principles of justice and equal treatment are integrated and invoked.

The idea of justice, applied to a disability in the context of the bio-psycho-social model and based on respect for human rights introduced by the UN CRPD and related policies and services, still focuses mainly on health care and rehabilitation, welfare, compensatory and protective measures. The UN Convention, however, introduces a new model of disability, framing it in a universalistic perspective, based on rights-centered arguments. This new model, previously widely made explicit with other groups in a society, revolutionizes the economic, political, cultural, and social behavior connected to disabled people.

The UN CRPD expresses a new model of justice indeed and is not a purely metaphysical form of justice. Instead, this new model or paradigm is not confined to matters of assistance, care, compensation, or protection. The new paradigm, based on equality and non-discrimination and designed to eradicate exploitation and empower discriminated and disadvantaged people, removes obstacles and discrimination for the proper support of people, facilitating the services and benefits designated for formerly excluded subjects.

The model of justice connected to the UN CRPD profoundly modifies the political view of the condition of people with disabilities. As vulnerable persons, due to functional differences, persons with disabilities have become rights-holders in the political/moral community. Within that community, a society has to provide equal opportunities and guard against discrimination. The UN Convention, considering disabled people as a part of society, acknowledges their right to benefits from all relevant policies and programs. In this new view, social and material resources must be used for all members of the

political/moral community. Mainstreaming policies is an innovative approach, and disabled members are moving from assisted to potential payers, who may need appropriate support to participate well in community life. We can monitor statistical data to see the impact of this new political approach, in such areas as the level of accessibility of a city, discrimination in access to goods and services, obstacles and barriers that prevent full participation and inclusion in the world of education, work, tourism, and leisure. This UN CRPD shows that, in order to build these new policies and to achieve the new idea of justice linked to its application, we also need to develop new areas of knowledge, a new consciousness, a new cultural approach, so that the role of persons with disabilities becomes an integral and inalienable part of this new political/moral community. An increasing concern of some international associations of persons with disabilities and their families is the quickly expanding progress of biomedicine and genetics and the moral and practical implications of this progress, especially in regard to the potential for discrimination and violation of human rights accorded persons with disabilities. As a result, many initiatives of associations championing the concerns of persons with disabilities have taken place, such as Inclusion International and Disable Peoples' International.

In the last few years and in different countries, the activities connected with biomedicine have touched persons with disabilities, highlighting discriminatory approaches that have produced great emotional impact on public opinion, since these are decisions about the quality of people's lives, of their right to exist (euthanasia, right to live) in the context of an ever-expanding array of medical technologies and methods that increase humans' capacity to influence the growth and development of offspring (medically assisted procreation, genetic therapies, genetic manipulation, cloning). Scientific development is increasingly able to influence and 'transform' human life, as researchers strive to prevent or reduce the effects of disease and old age, as well as enhance and extend human reproductivity far beyond previous conventions. The reservations expressed by associations representing the interests of persons with disabilities and their families derive from

reflections about the practical risks involved in using “the medical model” of disability as the favored approach of contemporary biomedicine and genetics, while possibly violating universal human rights. The UN CRPD offers a new approach to the condition of disability based on respect for human rights; bioethics today has to start and adapt to this new approach. The document “*Bioethical Approach to Persons with Disabilities*” acknowledges and endorses the great contributions made to society by scientific progress in general and, in particular, by the medical findings, techniques, and technologies that have allowed many disabled people to live well and to be treated fairly. Nevertheless, it is essential that research should aim to improve the quality of life for everyone and not deny the opportunity to live and make use of rights, goods and services to anyone.

Associations representing persons with disabilities are collectively concerned about the general drift of contemporary human genetics toward a form of positive or negative eugenics operating under some notion of perfection of the human being, absent in nature. In this context, disease, pain, and diversity would be read as imperfections that must be corrected. Actually, imperfection belongs to all human beings, in different forms, and functional diversity (Palacios and Romanach 2006 and Romanach 2009) is one of these diversities according to the Article 3 of the UN Convention. The notion that the perfect person exists, without genetic mutation, imperfection, or disease, is a modern myth, indeed. Every human being has a defined set of capabilities and limitations, potential, and skills that, on the basis of life experiences, of learning processes, of the challenges the person faces in order to achieve objectives and pursue wishes, represent real being, always in flux. In other words, every human being is inherently unique in shape, capacity, and potential. The document “*Bioethical Approach to Persons with Disabilities*” describes areas of potential abuse of human rights of persons with disabilities, resulting in different bioethical approaches, in light of the principles stated in the UN CRPD. The topics attest to the breadth and scope of the areas concerned: prenatal testing and genetic counselling; euthanasia; premature babies; end of life; inappropriate and segregating treatments;

equal treatment and access to health and social services; integrity of the person; informed consent; respect for private life and for sexuality; quality of life; rehabilitation and qualification; multiple discriminations; ethics and legal training on the basis of respect for human rights; and disability prevention.

Contemporary bioethical approaches to disabled people draw on theory, but these approaches are also intricately related to practical life, including but also beyond the area of healthcare. Although topics relating to persons with disabilities and such documents as the UN CRPD are studied and discussed at university, the topics are relegated to the world of health and nursing care. Actually, contemporary bioethics is ubiquitous and relates to many professions, from judge to lawyer, from teacher to architect, to engineer, to public official, to human resource manager of a company, to name just a few. The contemporary bioethics movement has much to offer us in understanding and assessing human behavior in matters of health, but also beyond healthcare, in other areas of social reality. Bioethics forums are therefore centrally positioned to discuss the theoretical and practical challenges in maintaining the rights of all people.

2. The document “*Bioethics of Disasters*”

The cooperation that CSB has enjoyed with the document, “*Bioethical Approach to Persons with Disabilities*”, has determined the starting point for a *modus operandi* of the Committee that, where possible, inserts in its documents a chapter dedicated to the perspective of persons with disabilities. This also applies to another fundamental document, which has also been innovative: *Bioethics of Disasters*, published in 2017.

The Bioethics of Disasters stands out not only for considering disasters from a bioethical perspective, never dealt by a National Bioethics Committee or in the literature concerning disaster medicine, but also for the authors’ decision to identify, in such a wide-ranging subject, those arguments of greater bioethical relevance that touch upon human well-being. Let us now consider the treatment of particular people directly experiencing a disaster: the “indirect

victim”, the journalist, the rescuer nurse, the hospital pharmacist for his/her responsibility in the management of drugs and medical devices, animals in the dual role of victims and rescuers. All of the preceding are featured in the chapter concerning the management of persons with disabilities involved in natural and human disasters, as well as in emergency interventions. These subjects, approached from a bioethical perspective, take into account the main international documents, including those by the World Health Organization (WHO)¹⁵, by the Council of Europe¹⁶, the “Sendai Framework for Disaster Risk Reduction”, adopted at the UN World Conference, held in Japan, in March 2015¹⁷, the “Charter of Inclusion of Persons with Disabilities in Humanitarian Action”, approved at Istanbul’s Global Humanitarian Summit in May 2016¹⁸, the Verona Charter¹⁹, the Charter of Disabled People’s Rights in Hospital²⁰, as well as UN CRPD.

In the management of disabled people during a crisis, first aid in its various stages is the critical element: warning systems that often exclude deaf and blind people, triage that fails to take account of disability conditions; lack of a mapping strategy that is respectful of privacy of housing conditions and people’s autonomy in the case of an evacuation; primary care that often is not made by adequately trained personnel, evacuation routes with limited access; lack of proper programming at initial admission areas to accommodate refugees and internally displaced people; facilities that rarely take into account the needs of disabled people; poor involvement by organizations in the planning, intervention, and management of various stages of the emergency; and inadequate inclusion of people with disabilities in the preventive plans for an emergency.

In its conclusion, the “*Bioethics of Disasters*” document recommends a specific plan for emergency services, so that disabled people could be included at all stages of the emergency event, ensuring non-discrimination, equality of opportunity and accessibility, and availability of spaces and services, by appropriate training of the operators, carried out by involving organizational advocates for people with disabilities.

3. The document “*Decision-making in the care of the sick person at the end of life*”

The “*Decision-making in the care of the sick person at the end of life*” document was approved in March, 2019, in the Republic of San Marino, and it constitutes an opinion drafted following an Agenda received by the Parliament of San Marino.

The drafting of the opinion is part of a process undertaken by CSB since its first mandate on bioethical reflection in the context of the end of life, starting from the first document, “*The Assessment of Human Death*” (2013), which was followed by “*Body and Body Part Donation for Therapeutic or Scientific Purposes*” (2016), “*Nursing Code of Ethics*”(2017) and “*Pain Management Nursing: Bioethical Aspects*”(2017).

The “*Decision-making in the care of the sick person at the end of life*” document focuses on the concept of caring for the dying person, a concept that is part of the fundamental rights enshrined in the UN Universal Declaration of Human Rights. In line with what was recommended in the recent international bioethics documents, the CSB examined the principles applicable to the decision-making process that must guide healthcare practitioners in taking care of the sick person in *limine vitae*, analyzing the characteristics and role of each person involved, be it a member of the care team, family member, caregiver, or trusted person.

The Palliative Care section of the “*Decision-making in the care of the sick person at the end of life*” document identifies a key element of treatment, as these last care-givers ensure respect for and dignity of the person dealing with incurability and decline of capacity. However, aware of the deep bioethical value of such a concept of care described above, the CSB wanted to deepen the scientific, bioethical, and bio-juridical aspects of the care concept, by articulating them in the various phases of a person’s life, starting from infancy to the most advanced age, dedicating special chapters to particularly topical issues such as end-of-life pharmacological support and advance indications on care choices.

Also in “*Decision-making in the care of the*

sick person at the end of life”, the CSB dedicates a chapter to persons with disabilities, confirming its continued sensitivity to this specific topic, in the wake of similar commitment expressed in *“Bioethical Approach to Persons with Disabilities”* (2013).

4. The associations of persons with disabilities and the Council of Europe

The presence of an expert in the disability sector within CSB has also allowed a cooperation at the level of the Council of Europe on some particular documents.

In particular, persons with disabilities had the opportunity to outline their position with regard to the draft of the “Additional protocol to the Oviedo Convention on human rights and dignity of persons with mental disorders, with particular attention to placement and to involuntary treatment”²¹. The work on this additional protocol is currently underway, and the possibility to converse directly with some members of the Delegations of Bioethics Committee of the Council of Europe represents a great example of inclusion and mainstreaming, rather than exclusion and side-lining.

5. The associations of persons with disabilities and the international debate

This long and fruitful collaboration with the associations of disabled people has brought to life some international publications of particular scientific standing (Borgia and Griffo 2014 and 2014b). As well, the collaboration has led to several conferences dedicated to disability and its bioethical aspects²² and the inclusion of the disability subject into the Master’s program in Bioethics at Camerino University (Italy) and at Polytechnic University of Marche, Ancona (Italy).

In conclusion, the examples of cooperation highlighted represent how effective action of multi-level mainstreaming in different fields of academia and of international institutions in the specific bioethical area can be realized. Our hope is that these examples of collaboration may be an incentive to other deeper forms of collaboration in yet other social contexts, with the knowledge

that inclusion, rather than exclusion, represents our collective future.

Endnotes

- 1 The documents are available at the following web link: <http://www.sanita.sm/on-line/home/bioetica/comitato-sammarinese-di-bioetica/documents-in-english.html>.
- 2 Deputy President of the National Bioethics Committee of the Republic of San Marino and member of DH-Bio, Council of Europe, Professor of Bioethics at the Polytechnic University of Marche, Ancona (Italy).
- 3 Co-Director of the Center for Governmentality and Disability Studies (CeRC) “Robert Castel”, University “Suor Orsola Benincasa” of Naples (<https://www.unisob.na.it/ateneo/c007.htm?vr=1>), a member of the Bioethics Committee of the Republic of San Marino and a member of the World Council of Disabled Peoples’ International-DPI (www.dpi.org).
- 4 Non-profit organization
- 5 Read Disabled Peoples’ International Europe “DPI Europe Position statement on Bioethics and Human Rights”, which is available along with other bioethical documents at web link http://www.dpi-europe.org/bioethics_issues/
- 6 International Federation for Hydrocephalus and Spina Bifida Risoluzione sulla diagnosi prenatale ed il diritto di essere differente (Toulouse, 2000), Risoluzione sull’eutanasia dei neonati affetti da spina bifida e/o idrocefalo ed il diritto alla vita (Helsinki, 2006), Groningen Protocol. Position Paper on the Disability Stereotypes, International Human Rights and Infanticide (di James E. Wilkinson 2008), see the web link www.ifglobal.org.
- 7 European Disability Forum approved (Rome, 2006) Risoluzione sulle diagnosi prenatali ed il diritto di essere differenti (Atene 2001) and Risoluzione sulla terminazione attiva della vita di neonati con disabilità e sul diritto alla vita. Recently, they published, together with the Spanish Fundacion Cermi Mujeres, the volume Ending Forced Sterilization of Women and Girls with Disabilities (2018), see the web link www.edf-feph.org.
- 8 See the web link: https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.

- aspx?symbolno=CRPD/C/GC/7&Lang=en
- 9 The documents are available at the web link: <http://www.sanita.sm/on-line/home/bioetica/comitato-sammarinese-di-bioetica.html> In Italian and English versions.
 - 10 In the document, the reader can find a vast bibliography and webography about bioethics and disability themes.
 - 11 Check the document of the Italian National Bioethics Committee “Bioetica e Riabilitazione” (2006): <http://bioetica.governo.it/it/documenti/pareri-e-risposte/bioetica-e-riabilitazione/>
 - 12 Passed at XXXIII UNESCO General Conference (2005), <http://unesdoc.unesco.org/images/0014/001461/146180E.pdf>
 - 13 See Practical Ethics, Cambridge University Press, Cambridge, 1980; second edition, 1993; third edition, 2011. ISBN 0-521-22920-0, ISBN 0-521-29720-6, ISBN 978-0-521-70768-8.
 - 14 See <https://www.un.org/development/desa/disabilities/standard-rules-on-the-equalization-of-opportunities-for-persons-with-disabilities.html>
 - 15 World Health Organization, Guidance Note on Disability and Emergency Risk Management for Health, 2013.
 - 16 Council of Europe, “Guidelines and Recommendations on Including People with Disabilities in Disaster Preparedness and Response”, 2014.
 - 17 http://www.preventionweb.net/files/43291_sendaiframeworkfordrren.pdf
 - 18 <https://www.worldhumanitariansummit.org/sites/default/files/keydocuments/SS02%20Disabilities.pdf>
 - 19 Verona Charter – about the rescue of disabled people in case of disasters (2007).
 - 20 https://spescontraspem.it/wp-content/uploads/2018/04/carta_diritti.pdf
 - 21 The additional protocol is still being written in the Council of Europe’s Bioethics Committee (DH-BIO),
 - 22 European Summit “Disability and Bioethics: The Rights, the Dilemmas”, promoted by the regional Venetian government, in the session “Genetic tests, disability and bioethics: European experiences compared”, Padova, 13-14th of November 2003; Conference of Massa e Carrara’s Azienda USL – Local Ethics Committee – Bioethical Laboratory – The Legal Medicine Unit – Operation Unit of training, Health Education, Communication and Information; “Bioethics and People with

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REVIEW ARTICLE

Conscientious Objection and Other Grounds for Vaccination Refusals Worldwide

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Abstract

Vaccination has contributed to a healthier world population. While it is often considered compulsory or recommended, people might refuse it for various reasons. According to the classification used in the United States, refusals can be made on medical, religious (or conscientious), philosophical and other grounds. Although non-medical refusals have been tolerated in some states, some think that refusals undermine infection control and lead to outbreaks of vaccine-preventable diseases. The objective of this research is to shed some light on the status quo of vaccination refusal worldwide and consider rationales and implications of different reasons which some individuals cite to refuse vaccination. This research examines literature on vaccination refusal published between January 1, 2010 and September 1, 2019, using the PubMed database. Several sets of key words were chosen to identify a sufficient number of relevant articles. Many studies in the search results sought to find out factors related to refusal/hesitancy. The articles were classified according to the country or area of primary focus. Vaccination refusers are ubiquitous, regardless of whether vaccination is mandatory or voluntary. Reports on the United States (US) accounted for the majority, and also the majority of first authors belonged to institutions in the US. As well, the proportion of US-based refusal literature is greater than that of publications in the medical field worldwide. Outside the US, there were only sporadic reports for each country. Some reports on the same countries contradicted each other. The majority of the reasons cited were non-conscientious (medical side-effects of vaccines, fatality from infections, access, financial problems, etc.). Reports of religious refusal were rare and anecdotal. There is a possibility more people will refuse vaccinations worldwide in the future, as risks of infections appear smaller. Therefore, though the numbers of articles on vaccine refusal published each year gradually increased and then began to decrease, from 2017 to the present, it is advisable to monitor more carefully the reason for refusals and to track the sources of information.

Key words: conscience, conscientious objection, vaccine, religion, database search, literature

1. Introduction

Vaccination, which is “a biological preparation that improves immunity to a particular disease,”¹ has contributed to a healthier world population. According to Martinez-Mateo et al., “Nowadays, vaccines are increasingly powerful, effective and safe. The list of vaccine-preventable diseases is expanding” and today contains such diseases as hepatitis B, measles, rubella, mumps, tetanus, poliomyelitis, pertussis, diphtheria, meningitis, and varicella. While vaccination is often considered compulsory or recommended for

some infectious diseases, across the globe, people have hesitated, delayed, or outright refused to be vaccinated for various reasons. In the case of vaccines for children, such as measles, mumps, rubella (MMR), and human papilloma virus (HPV) vaccines, parents or guardians are potential refusers. A variety of reasons are cited for vaccination refusal. For example, even though numerous scientific researchers have repeatedly denied a link between vaccination and autism², this link is still cited by refusers³. As well, the antipathy towards vaccination resulting from this false link appears to be more prevalent than ever. Such antipathy is considered a great threat

to public health. Because of “herd immunity” or “community immunity” (“... when enough people are vaccinated against a certain disease, the germs can’t travel as easily from person to person — and the entire community is less likely to get the disease.”⁴); however, not every person must be vaccinated for vaccinations to be effective in suppressing infectious diseases. Thus, the coverage goal of the World Health Organization is 90% (not 100%) by 2020.⁵

Attempts to categorize reasons for vaccination refusals have been made to help identify refusals that should be accommodated and those that should not. In the United States (US), refusals are classified along medical, religious (or conscientious), philosophical, and other grounds⁶. Medical refusals are those made based on the health conditions of refusers, such as allergies, immune system problems, etc. Refusals of this type are considered acceptable in every state in the US. Further, refusals based on religious grounds are legally permissible in 45 US states, although few major religious groups explicitly refuse vaccinations today⁷. Philosophical refusals refer to those that are based on personal reasons. Divergent risk perception, which is often considered an unacceptable reason for vaccination refusal, is usually classified as a philosophical refusal in the US (as medical exemptions refer exclusively to professionally endorsed exemptions). According to one report, “children whose parents refused for reasons of religion” accounted for 4.4%.⁸ Some medical professionals, public health experts, and policy-makers believe that philosophical refusals as well as religious refusals undermine infectious disease control and lead to sporadic outbreaks.⁹ In recent years, restrictions on non-medical refusals or exemptions have been tightened in some areas of the US. For example, according to Delamater et al., the “California Implemented Senate Bill 277 (SB277), in 2016, made California the first state in nearly 30 years to eliminate nonmedical exemptions from immunization requirements for schoolchildren.”¹⁰ Also, New York “eliminated a religious exemption to vaccine requirements [...] in the face of the nation’s worst measles outbreak in decades”¹¹ in 2019. A detailed list of US states accommodating religious and philosophical exemptions is provided by the National Conferences of State Legislatures.¹²

Instead of eliminating exemptions, in Ontario, Canada, administrators strengthened “school immunization requirements” and introduced “stiffer steps to qualify for a medical, conscience, or religious belief.”¹³

Research on vaccination intersects multiple fields, such as biomedicine, bioethics, public health, religious studies, and other related disciplines, because the characteristics of vaccines and vaccine-preventable diseases, autonomy and integrity of people, human rights, public health goals, grounds for vaccine hesitancy, along with delay and refusal, need to be considered.

Relying on the categories of vaccination refusal in the US, the author of this article seeks to understand the status quo of vaccination refusal worldwide and consider the rationales and implications of the various reasons individuals cite in their refusals to be vaccinated.

2. Methods

This study examined existing literature on vaccination refusals published between January 1st of the year 2010 and September 1st of the year 2019. Articles were identified using the PubMed database and analyzed in light of the categories of refusal found in the US¹⁴. Medical Subject Headings (MeSH) terms were used, if applicable¹⁵. Several sets of keywords were used in PubMed searches of article titles and abstracts to identify a sufficient number of relevant articles (e.g., “vaccination AND refusal OR vaccination AND refuse” and “vaccine AND refuse OR vaccine AND refusal”). Searches for “vaccination AND refusal OR vaccination AND refuse” in article titles and abstracts yielded 34 articles. Further, searches for “vaccine AND refuse OR vaccine AND refusal” yielded 267 results. Twelve articles appeared in both searches. Nonrelevant articles, such as those dealing exclusively with medical researches, were excluded. Articles without abstracts and articles written in languages other than English were also excluded. Of the remaining articles, 11 were deemed nonrelevant and excluded because of their focus on topics such as contributions in medical science and refusals of other medical procedures, etc. Only 9 articles were labeled with the MeSH term “Religion and Medicine,” which

necessitated the present study to first investigate abstracts, followed by further investigation of entire articles, as needed. The remaining articles that were ultimately reviewed for this study were then classified according to the country or region of primary focus.

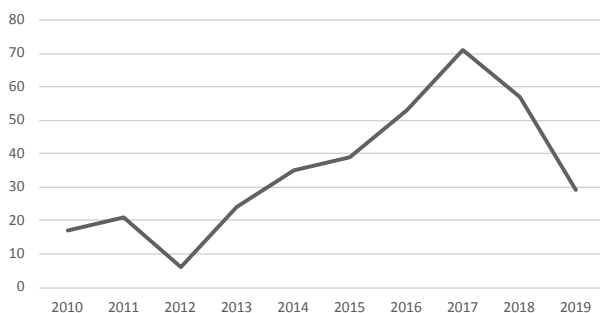
3. Results

3.1 A chronological shift

The articles were classified according to the year when those articles became available to the general public for the first time. In case more than one date of publication was recorded in the PubMed search results, the earlier date was used for this study. Table 1 and Figure 1 show the number of publications that appeared in the search results during the period. Though this study is not intended as a quantitative research, the numbers of articles on vaccine refusal published each year had been gradually increasing, but presumably started to decrease, around 2017. The reason for this decrease is unknown and hard to explain, but it is necessary to monitor publications to see whether this tendency will continue.

Table 1, Figure 1

Search results with "vaccine"		Search results with "vaccination"		Total	
2010	15	2010	2	2010	17
2011	19	2011	2	2011	21
2012	6	2012	0	2012	6
2013	23	2013	1	2013	24
2014	34	2014	1	2014	35
2015	36	2015	3	2015	39
2016	49	2016	4	2016	53
2017	59	2017	12	2017	71
2018	51	2018	6	2018	57
2019	23	2019	6	2019	29



3.2 Geographic Scope

Figures 2 and 3 show the geographic focus of the articles reviewed. Several studies were not geographically framed, exploring global or theoretical problems applicable to any country. For the sake of simplicity, articles focusing on more than one country are not included. In the search results, research on vaccination refusals in the US accounted for 64.2% (77) of the 120 articles published during 2010-2014 whose geographic areas of focus were specified and 52.2% (83) of the 159 articles published during 2015-2019 whose geographic areas of focus were specified. When Figure 2 and Figure 3 are compared, the ratio of the articles focusing on the US decreased, which suggests relatively greater interest in vaccine refusal and hesitancy outside the US in the last five years, and the total number of published articles is greater in that period.

As geography is insignificant for scientific articles, except for venues of clinical trials, this study compared the geographical distribution of articles according to locations of institutions of first authors. To simplify matters, if a first author belonged to more than one institution, only the institution listed at the top was used. According to the Scimago Journal & Country Rank, in the field of medicine from 1986 to 2018, the US (with 4,148,320 publications) accounts for 25.3% of all the publications (16,391,492 publications).¹⁶ In comparison, the predominance of articles written by authors belonging to US institutions is conspicuous in this inquiry. Figure 4 and Figure 5 show the geographic distributions according to first authors in articles whose first authors' institutions were published during 2010-2014 and 2015-2019, respectively.

There were fewer research reports on vaccination refusals by populations outside of the US. Refusers appear to exist across regulatory contexts, that is, in places where vaccination is mandatory as well as those where it is not. Many articles focused on geographic regions that attracted attention, for example, because of an infectious disease outbreak, such as the case of pertussis that emerged in California in 2010 and polio outbreaks in regions where polio remains endemic, such as India, Afghanistan, Pakistan, and Nigeria. In the near future, China may be another area of focus as a vaccine scandal ("the

Changsheng vaccine crisis”) occurred in 2018, when “unqualified DTP vaccines were reported to be used for child vaccination,” causing more people to be suspicious about the safety of vaccines.¹⁷ Of all articles considered, the author of this study found that no other country, with the exception of Canada, was reported to have intensively discussed methods of classifying acceptable and unacceptable refusal reasons as those of the US in abstracts in the search results.

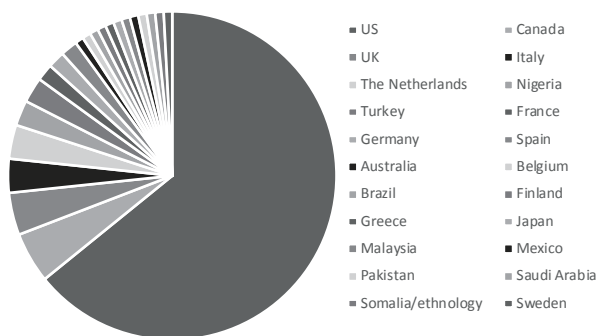


Figure 2. The geographic focus of the articles (2010-2014) in decreasing order

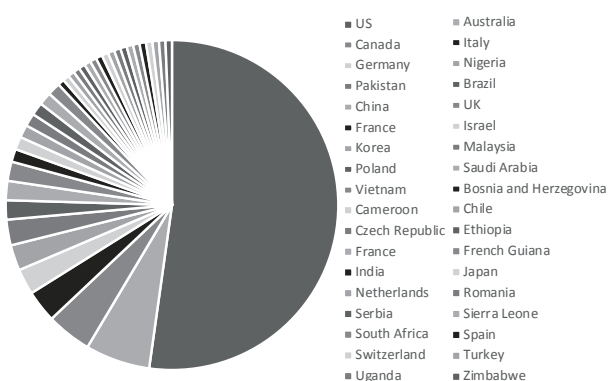


Figure 3. The geographic focus of the articles (2015-2019) in decreasing order

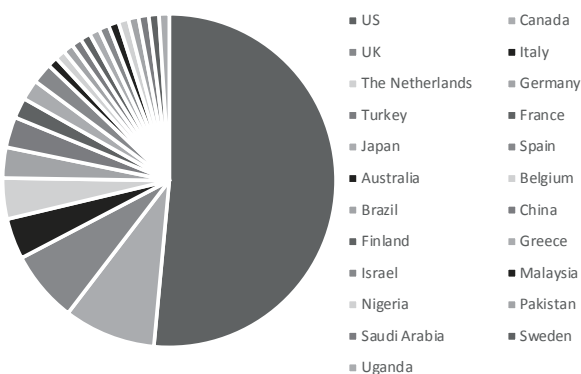


Figure 4. The geographic distribution according to first author (2010-2014) in decreasing order

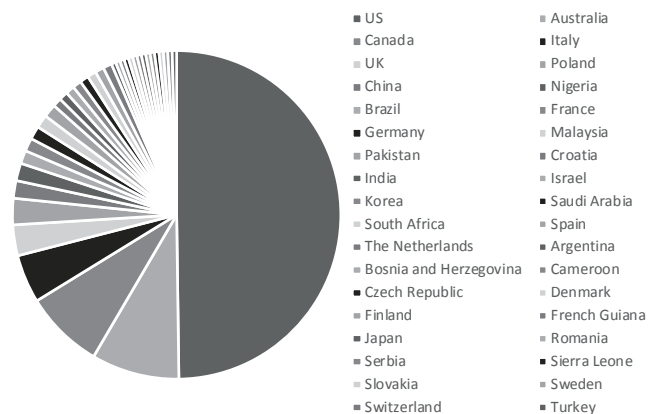


Figure 5. The geographic distribution according to first author (2015-2019) in decreasing order

3.3 Regional case studies

As qualitative research, this study did not count the numbers of articles that dealt with different grounds for hesitancy, delay, and refusal. Instead, recurring or conspicuous reasons for refusal as well as related themes in the literature were identified. Many studies sought to identify factors related to vaccination refusal or hesitancy to get vaccinated. The majority of the reasons cited by refusers were non-conscientious reasons such as side-effects of vaccines, low fatality or insignificant severity of infections that vaccinations intend to prevent, limited access to vaccine providers, and financial problems. Reports of religion-based refusals did exist, but they were rare and anecdotal. Notable cases from a geographic perspective are described extensively in the following.

Reports on some countries simply dismiss religions. To name a few, for example, in the United Kingdom (UK), while childhood immunizations are voluntary, health care staff strongly encourage participation. In London, “in 2012, a pertussis outbreak prompted a national vaccination program for pregnant women.”¹⁸ In Italy, “skepticism about the vaccine (60.4%) and its cost (34.1%) were indicated” as the primary reasons for vaccination refusal.¹⁹ Within the context of Bosnia and Herzegovina, researchers noted that “A measles outbreak with two epidemic waves involving 4,649 probable and laboratory-confirmed cases was recorded in six out of ten cantons of the Federation of Bosnia and

Herzegovina between February 2014 and April 2015.”²⁰ The authors refer to the anti-vaccination movement as “a problem with vaccine refusal resulting from anti-vaccination activities.”²¹

In Canada, morality apparently plays some roles in decision-making about vaccinations. It was reported that “91.4% of responses could be explained using the conceptual model and specifically relate to the perceived importance of vaccination (46.8%), moral convictions (19.4%), and past experiences with vaccinations services (14.5%).”²² Personal conviction was reported to be significant in France. According to Barrière et al., “Non-vaccinated HW were influenced by their family physician’s advice ($p=0.03$), personal conviction ($p<0.001$) or the media ($p<0.001$).”²³

A report on the Netherlands refers explicitly to religious aspects of vaccination refusal. According to Spaan et al., “The Netherlands experienced several outbreaks of vaccine preventable diseases, largely confined to an orthodox Protestant minority group.... Multivariate logistic regression showed that strongest predictors for vaccinating (future) children were a low or moderate level of religious conservatism (OR 10.4 [95% CI 5.7-18.9] and 4.6 [95% CI 2.9-7.4], respectively), being vaccinated themselves (OR 6.0 [95% CI 4.3-8.5]) and high educational level (OR 2.5 [95% CI 1.6-4.0]).”²⁴

In Croatia, “A sizeable minority of participants was characterized by childhood vaccine refusal (10.6%) and hesitancy intentions (19.5%).”²⁵ According to Repalust et al., “Religiosity (AOR = 1.12, $p < .05$) and the use of alternative medicine (AOR = 2.85, $p < .001$) increased the odds of vaccine refusal.”²⁶ Repalust et al. argue that “following the social contagion model, future research should move beyond individual-level approach and take into account social interaction and social network effects.”²⁷ Considering this case from Croatia, use of alternative or traditional (instead of modern Western) medicine may have something to do with both religious practices and vaccine refusals. Gleason et al. reported on the relevance of “the use of ‘folk’ or home remedies for illness prevention and treatment” among African Americans, stating that “those who use home remedies often or almost always were less likely to get vaccinated for influenza.”²⁸ This example may be related to the African American religious

traditions.²⁹

Reports on (not necessarily religious) refusal reasons in African countries were also identified in the database search. For example, in Chad, Quoc Cuong et al. found that “SID (Supplemental Immunization Days) is a special strategy intended to accelerate eradication of poliomyelitis in countries where it is still endemic (India, Afghanistan, and Pakistan, in Asia, and Nigeria, in Africa). This strategy is also applied in Nigeria’s neighbours (Cameroon, Chad, Niger and Benin). Since the poliomyelitis virus was imported from Nigeria in 2001, Chad has reported cases of poliomyelitis every year. After 30 SIDs in Chad and the inaccurate or false attribution of side-effects to polio vaccines, some groups persistently refuse polio vaccination.”³⁰

Nigeria was of importance in terms of the morbidity landscape. According to Mangal et al., “In 2012, more than 50% of the world’s cases occurred in Nigeria following an unanticipated surge in incidence.”³¹ Religiosity apparently plays a role in Nigeria. “In 2003, local Imams, traditional leaders and politicians declared a polio campaign boycott, due to the concerns about the safety of the polio vaccine.”³² This research suggests that the reason for polio vaccine objections in Nigeria is primarily safety-oriented, thus placing such reasons in the category of medical objections. However, it is noteworthy that Northern Nigeria is a predominantly Islamic country³³ and that the religious leadership exercised their influence in the campaign to boycott polio vaccines. Another body of research highlights the significant influence of religiosity. Michael et al. state that “the majority (59%) of participants believed that vaccination was either not necessary or would not be helpful, and 30% thought it might be harmful. Religious beliefs were an important driver in the way people understood disease. Fifty-two percent of 48 respondents reported that illnesses were due to God’s will and/or destiny and that only God could protect them against illnesses.”³⁴ Yet other researchers such as Taylor et al. doubt the gravity of religious influence, citing statistical evidence to support their argument. According to their latest report, “Wealth, female education and knowledge of vaccines were associated with a lower propensity to refuse oral polio vaccine (OPV) among rural households. But higher risk

of refusal among wealthier, more literate urban households rendered these findings ambiguous. Ethnic and religious identity did not appear to be associated with risk of OPV refusal.”³⁵

According to Kriss et al., in Zimbabwe, which has a predominantly Christian population,³⁶ “the apostolic faith in Zimbabwe has been historically associated with objection to most medical interventions, including immunization.”³⁷ The authors argue that “disparities in childhood vaccination coverage and availability of vaccination cards persist for apostolic [believers] in Zimbabwe. Continued collaboration with apostolic leaders and additional research to better understand vaccine hesitancy and refine interventions and messaging strategies are needed.”³⁸

Research on vaccination refusal has also examined refusal rationales in Middle Eastern countries, where, despite a popular image of religious enthusiasm in the region, refusals are not conscientious in most cases. Regarding Israel, Yitshak-Sade et al. report that “the lowest immunization coverage was found in Bedouin schools.”³⁹ The authors put forth “the hypothesis that difficulties related to accessibility constitute the main problem rather than noncompliance with the recommended vaccination protocol for school-age children.”⁴⁰ According to a survey on Israeli health care professionals (HCPs), “reasons for vaccine refusal were fear of needles (19 %); fear of side-effects (66 %) and lack of time (16 %).”⁴¹ In his article on vaccinations in Saudi Arabia, Ahmed states that “the most common reason for vaccine refusal was the impression that the disease was not fatal (25.4%, n = 32).”⁴² This reason can be classified as a refusal based on medical grounds, as this justification depends primarily on an assessment of the disease. However, this is considered to constitute a personal reason, as this assessment is regarded as divergent by health professionals. Likewise, Alabbad et al. on research on influenza hesitancy in Riyadh, Saudi Arabia, found that the most common grounds for refusal center upon risk and benefits of vaccination.⁴³

A review of the literature also finds research on the existing types of vaccination refusals in Asia. Researchers have identified a range of categories of vaccination refusal reasons in Malaysia, including justifications shaped by

religious beliefs. Wong reports that “reasons for vaccine refusal were doubts about safety and efficacy of the new vaccine (27.4%), perceived embarrassment at receiving an STI vaccine (20.7%), and perception of not being at risk of HPV infection (20.0%).”⁴⁴ Whereas “safety and efficacy of the new vaccine” and “perception of not being at risk” can be categorized as medical reasons, refusals based on “perceived embarrassment” can be affected heavily by religious traditions, as it is not embarrassing for people from other backgrounds. Chan et al. state that, in Malaysia, “the proportion of mothers who refused vaccination because of religious belief reduced from 78% between 2013 and 2015 to 67.1% in 2016 (p = .005). Overall, the finding confirms the positive impact of the educational and religious interventions introduced by the State Health Department of Kedah since January 2016.”⁴⁵ This is suggestive of a possibility of vaccination promotion by a religious authority, though religious beliefs are usually considered to be difficult to change and leave little room for persuasion; this possibility was reported by Dutch researchers⁴⁶.

In Pakistan, research suggests that “parents refuse to immunize their child because of lack of immunization visit knowledge and also because of their doubts regarding vaccine potency and side-effects.”⁴⁷ Nevertheless, another group saw differently the problem in a country that was established when Muslims across the Indian sub-continent separated from British-controlled India. Murakami et al. report that “local interpretations of these facts (perceptions that OPV contained birth control or pork, that OPV was a foreign/central plot against Muslims, and that the vaccination was against the Hadith and the fate determined by God) and different manifestations of OPV refusal...of other injectable vaccines [were] almost equally prevalent for reasons that were very similar.”⁴⁸ The reference to “a foreign/central plot against Muslims,” is, in this case, an example where the hostility or antipathy toward other religious traditions can be relevant.

Likewise, research on vaccine-hesitant and vaccine-refusing parents in Australia identifies parental rejection of Western medical epistemology as a common cause for hesitancy and refusal, a rejection that can also be influenced by hostility/antipathy toward or

disagreement with other religious traditions.⁴⁹

As for China, religiosity does not appear as a relevant factor shaping vaccine refusal or hesitancy. In areas of China, such as Shanghai, concerns about vaccinations are reported to be predominantly medical in nature: “Among 618 caregivers, 64% were concerned about vaccine co-administration and 31% were concerned about vaccine administration to infants <6 months of age).”⁵⁰ In the communist country, where religion, likened to opium, is prohibited, there seems to be little room left for religiosity. “In December 2013, this success was threatened by widespread media reports of infant deaths following HepB administration ... [resulting in] [s]eventeen deaths and one case of anaphylactic shock.”⁵¹ Also in Hong Kong (China), according to Cheung et al., “significant predictors of vaccination ... [include] age, smoking status, comorbidity, previous hospitalization, perceived susceptibility, perceived severity, and psychological flexibility.”⁵² In the above figures and table, Hong Kong is counted along with China. Nevertheless, considering the importance of traditional remedies in China and a recent report on a possible link between use of alternative medicine and lower vaccination (as in Australia⁵³), quasi-religious aspects of Chinese traditional medicine can be worth considering in future researches.

As the above review suggests, the characteristics of the particular subgroups one belongs to can have a greater influence on reasons underlying vaccination refusals than the characteristics of one’s country of domicile. For example, the US comprises groups of diverse racial and religious backgrounds. Somalis in Minnesota is a case in point. “In 2011, an outbreak of measles in Minnesota was traced back to an unvaccinated Somali child.”⁵⁴

3.4 Thematic analysis

This review of existing literature on vaccination refusal finds that reasons for refusal involve issues with ethical implications that can be classified according to several predominant themes, including risk perception (such as side-effects of vaccines and fatality of infections), informed consent, conflicts of interests, and free-rider problems.

3.4.1 Risk perception

With regard to risk perception and future prospects, Bégué states that “the fear of adverse effects is now stronger than the fear of infectious diseases. The benefits of vaccination for vanishing infectious diseases can be hard to perceive.”⁵⁵ Oraby, Thambi, and Bacuh argue that “mathematical models that couple disease dynamics and vaccinating behavior often assume that the incentive to vaccinate disappears if disease prevalence is zero. Hence, they predict that vaccine refusal should be the rule, and elimination should be difficult or impossible.”⁵⁶ A closer look at risk perception finds that refusers are also concerned about “the number of vaccines given in the first 2 years (25%, CI 22 to 29), vaccine ingredients (22%, CI 19-25), allergies (18%, CI 15-21), weakening of the immune system (17%, CI 14-20) and autism (11%, CI 8-13).”⁵⁷ Non-refusers also share similar concerns - nearly half of Australian parents have some concerns, and a quarter lack vaccine decision-making confidence regarding childhood vaccines. Vaccination can be refused because of fear of needles or lack of time.

3.4.2 Informed consent and human rights

One concept that was featured in refusal reasons was that of informed consent.⁵⁸ Martinez et al. noted that in Granada, Spain, “Non-vaccinators ... ask for informed consent.”⁵⁹ One of the preconditions for autonomy or self-determination is that a person is best-positioned to judge his/her own welfare, avoid harm, and protect rights and integrity of one’s own body. However, vaccination’s communal dimension places it beyond this precondition, as individual decisions looking to advance one’s own welfare may negatively impact the welfare of an entire community.

3.4.3 Reasons for suspicions of vaccination science

In researches on vaccination, collaborations with and assistance from pharmaceutical companies may be indispensable in some cases. In the search results, most of the articles declared no conflicts of interests, which is understandable since the present study excluded purely scientific researches reporting results of clinical trials. Only three articles made it clear that they

had conflicts of interest.⁶⁰ According to the research of Martinez et al., refusers “believed that vaccination programs are moved by biased studies and interests other than prevention.”⁶¹ This suspicion is only natural because clinical trials are usually led by those who wish to promote the drug, which constitutes a conflict of interest.

3.4.4 The free-rider problem

An individual’s utility is maximized when everyone else has been vaccinated and the individual has not: that is, when an individual engages in free-riding. Such free-riders can be protected by herd vaccination, with no possibility of adverse effect. Bутtenheim and Asch refer to “participation mandates, exclusion, incentives, and social norms” as “four conventional responses to the free-rider problem.”⁶² They find that “some health care providers have adopted the policy of refusing to accept into their practices families who refuse to vaccinate their children according to the standard vaccine schedule.”⁶³ Whereas some may expect such a penalty to urge the general public to receive vaccinations, this exclusion policy can have negative consequences for the welfare of the broader population, as “many pediatric practices have adopted vaccine policies that require parents who refuse to vaccinate according to the ACIP [Advisory Committee on Immunization Practices] schedule to find another health care provider. Such policies may inadvertently cluster unvaccinated patients into practices that tolerate non-vaccination or alternative schedules, turning them into risky pockets of low herd immunity.”⁶⁴

4. Discussion

The majority of the articles in the search results did not include religious refusals and the majority of the reasons cited were non-conscientious (i.e., risk perception, access to vaccines, financial problems, etc.). Reports of religious refusal were rare and anecdotal. Religious refusal can be based on Christian, Islamic, or other religions, and religiosity-influenced vaccination behavior in various ways, as shown in the Results section. The first authors of the articles whose first authors’ institutions were specified in the PubMed search results were based predominantly

in the US; this predominance may be due to fewer cases of vaccine refusals, but may otherwise reflect lower attention to the issue.

4.1 Religious refusals

According to the literature identified by the database search process, religious refusals were not necessarily religious in a strict sense. For example, religions may provide networks for exchanging and disseminating secular information that can result in refusal/hesitancy, with religious leaders maintaining an influence on secular issues such as public health. The Islamic religion serves as a prime example. Reportedly, Muslims have refused vaccination in Nigeria and other countries. Compared to other religious traditions, the Islamic religion apparently leaves little to the secular dimension (considering the roles of Sharia and the authority of the imam). Other quasi-religious refusal reasons include preference to traditional or folk remedies and antipathy toward other (especially Western) traditions. The aforementioned report by Gleason et al. suggests a possibility that religions are disguised in other practices because, in some areas, folk remedies may be closely related to religious practices and beliefs.

In cases where vaccination refusal is not religious in a strict meaning, religions may still function as a catalyst for non-religious refusals, but religious participation also may influence the problem surrounding vaccinations. As clerics can mobilize and motivate people, suggest more virtuous paths, religions may actually function for the betterment of public health.

If refusers cite medical reasons, it is more likely that health care professionals (HCPs) with their greater expertise on the subject, could possibly persuade potential refusers to be vaccinated. On the other hand, if refusals are made on religious grounds, it may be more difficult for HCPs to understand their motivation and consequently persuade refusers effectively. This suggests that the possibility of persuasion (i.e., decision reversal) varies based on different grounds of refusal. This seems consistent with the report that “Different reasons for refusal are associated with different patterns of vaccination behavior.”⁶⁵ For HCPs, understanding refusers’ attitudes towards vaccination and health can be made more difficult when refusals are based on

values foreign to HCPs. If the refusal makes little sense to HCPs, it might be simply dismissed or not be recorded or reported properly.

A lack of reports on religiously based refusals may be interpreted in a variety of ways. In developing countries, this gap may be attributed to less attention paid to non-medical factors such as human rights, including the principle of informed consent. Some countries may not be well-prepared to evaluate religiosity in public policy. They need to consider how to deal with potential religious refusal, for few studies on reasons for refusal in countries outside of the US discussed criteria as sophisticated as those used to categorize such reasons than those used by researchers in the US. Moreover, some authors in the search results were not based in areas targeted in their research. Unless they come from the targeted area, there remains a possibility that some authors are not knowledgeable about the religio-cultural practices and beliefs in the area. Also, partly because PubMed was used for the present study and articles listed in the database were written mostly by those trained in scientific fields related to health care and also because much attention to religions may undermine chances of being published in medical journals, due attention may not be paid to religio-cultural aspects of people's behaviors.

4.2 Contradictory research reports

A number of case studies reporting on vaccination refusals within the same country produced results that were incoherent and contradicted each other. Such examples include contradiction in the reports on religious refusals in Nigeria and Pakistan. These contradictions and incoherence may have arisen for a number of reasons. One explanation is that conflicting reports on the same country may reflect differences in the region or sample populations studied or differences in the time in which vaccination refusal in a given country was examined. Another possible explanation for contradictory results is a lack of attention, by some researchers, on the religious aspects of vaccination refusal. Again, HCPs are usually not knowledgeable about religious teachings or traditions and they are not cultural anthropologists. One conspicuous and relevant trend found in the literature, relating to

contradictions and incoherence, is that reasons for refusal are used and measured by scholars in very different manners. For example, survey and interview questions that ask about a refuser's "lack of confidence" rely on a rather superficial and vague construct in need of further clarity, as perceptions of "confidence" may concern the safety and effectiveness of vaccines, their readiness (i.e. they feel they have enough knowledge to move forward to take vaccinations), and so forth. To prevent such inconsistencies of wording in asking about the reasons for refusal considered by researchers, well-designed qualitative surveys should precede quantitative surveys that typically feature questionnaire surveys, so that the latter form of research, in building on the factors identified by qualitative surveys, can develop survey questions and possible answers in a way that is more relevant to a given context. In this way, quantitative survey results will be more meaningful. Given the broad spectrum of reported grounds for refusal, without prior insight into specific grounds for refusal, sound quantitative analysis is hardly feasible. Further inquiry into the cause of contradictory results will be necessary to reach any conclusion about the independent or combined role of the above factors in producing contradictory results across case studies on the same countries.

4.3 Informed consent, integrity of body, and harm to others

As a conceptual instrument, informed consent has been developed and applied to avoid harm to persons through integrating autonomy and self-determination in health care. Vaccination involves minimal but actual invasiveness to the human body. Thus, it may appear to the eyes of each person receiving the vaccination as a form of medical intervention involving potential harm analogous to other health care procedures. In healthcare, avoiding harm to the body or protecting the integrity of the body is of paramount concern. However, vaccination as a collective intervention has derived from a distinct context which is foreign to the notion of informed consent. To achieve public health goals, we need to reconcile the concepts of informed consent and public health goals. Moreover, within the context of vaccination, there are nuanced

relations between individual choice and the harm principle.⁶⁶ In another wording, John Stuart Mill's Harm Principle stipulates that "... people should be free to act however they wish unless their actions cause harm to somebody else." One problem is that a vaccination refusal of one person does not necessarily constitute direct harm to others because of "herd immunity" or "community immunity." When generalized, however, a vaccination refusal can pose a threat to the public health and thus constitute harm to others. From this viewpoint, sporadic refusal by individuals seems more justifiable than consistent refusal by groups of individuals. When vaccination refusal is exercised by people belonging to the same group, tolerance is less likely, contrary to regulations in some American states that require affiliation to religious groups⁶⁷.

4.4 Risk perception and the free-rider problem

As perceived risks of infections become smaller, other rationales for refusing vaccinations such as religious beliefs may become more prevalent. There is a possibility that more people worldwide will refuse vaccinations in the future, as risks of infections appear smaller and informed consent or other rights are perceived as more important. This suggests that it is advisable to monitor more carefully grounds of refusals and to track the sources of information.

With regard to risk perception in particular, while low risks (probabilities) of harm may appear insignificant to policymakers, the general public may interpret such risks in a very different – and not necessarily illogical – manner. For example, in Japan, approximately 20 persons die annually because of being hit by lightning strikes. Despite this small number of deaths, this risk is well-known among golfers and anglers, with such groups taking precautions. They avoid standing in a field or near a very tall tree. There is nothing illogical about being concerned with risks, even if they are unlikely and rare. Refusing vaccination may be rational in terms of risk perception as long as they can believe that they will be protected by "herd immunity" or "community immunity" (or they may simply believe that the targeted infection will remain insignificant as in the cases of some influenza vaccine cases), but

such refusal may be perceived as free riding.

As far as the free-rider problem is concerned, free-riders take advantage of herd immunity. To put it another way, free riding is made possible by herd vaccination. Thus, when free riding occurs because of religious beliefs shared by groups of people who gather in one place, religious beliefs may negate the protection afforded by herd vaccination by increasing the number of unvaccinated individuals in a given religious community. On the other hand, clerics can mobilize and motivate people and make followers behave in a new way. One possibility is that organizations of health professionals attempt to persuade religious leadership, as those leaders, possibly being older and having no young children, may not be usual targets of persuasion by health professionals. And successful cases (exemplified in reports by Chan et al. and Ruijs et al.) do exist. Religious beliefs may influence free riding by promoting virtuous behaviors that promote vaccination.

4.5 Implications for Japanese society

As the number of immigrants and foreign residents has been growing rapidly, with some of them possibly retaining their religious and cultural beliefs,⁶⁸ due attention to the potential factors that can affect health behaviors of those from other countries must help predict refusal or hesitancy behaviors and consider measures. Nevertheless, as discussed in this study, without sensitivity and attention, factors underlying people's vaccine hesitancy and refusal, including religiosity, can elude the attention of health care professionals.

5. Conclusion

Despite the great contribution of vaccination to humanity, people worldwide refuse vaccination for various reasons. Antipathy against vaccination today can pose a great threat to public health in the area. Relying on the classification used in the US, this research examined articles using PubMed. The numbers of articles on vaccine refusal published each year has been gradually increasing, but presumably has started to decrease around 2017. From a geographic perspective, the present study found that refusers are ubiquitous and are found in

countries where vaccination is both mandatory and voluntary. However, with regard to the geographic focus of research, there were lower ratios or reports on vaccination refusers in places outside of the US, compared to publications in the medical field in general. One possible explanation for the scarcity of reports outside the US may be that the international community does not share enough information on the vaccination status quo elsewhere. This absence of geographically consistent conscientious objection arguments apparently has contributed to public health goals.

As a qualitative research study, the numbers and ratios of articles associated with each reason for refusal were not counted. Instead, the nature of refusals and related themes that recurred in the literature were identified and categorized. The majority of the reasons cited were not religious or philosophical, with reports of religiously based refusals rare and anecdotal. The dearth of reporting on religious refusals can be interpreted in multiple ways, including an inability to evaluate religiosity in public policy. Future research needs to consider how the international community should deal with religious refusals. It is recommended that researchers monitor more carefully the grounds for refusals and track the sources of such rationales. There is a possibility that more people will refuse vaccinations in the future, as risks of infectious diseases appear smaller and informed consent and other human rights rise in importance. Religions can function as a catalyst for non-religious refusals. On the other hand, religious affiliation and clerics may help mitigate the free-riding problem, for example. Although the number of publications on vaccination shows a sign of decrease in recent years, consistent and close attention to the reasons for vaccination hesitancy and refusal can help improve the public health situation, while paying due attention to the religio-cultural aspects of people's behaviors.

The limitation of the study

The low availability of relevant articles significantly limited feasible research designs.

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RESEARCH REPORT

Healthcare Interpreters' Advocacy for Patients in Japan

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Abstract

The purpose of this study is to discuss the boundary of the healthcare interpreter's role in the conduct of patient advocacy in Japan and consider problems with the healthcare interpreter's role as an advocate for patients with insufficient fluency in Japanese.

Interviews were conducted with people in the healthcare interpreting field relating to the Japanese standards of conduct for healthcare interpreters compared with the Japanese codes of ethics for healthcare providers, with the focus on patient advocacy.

Relating to patient advocacy conduct, some differences were found between the codes of ethics for healthcare providers and the standards for healthcare interpreters. The interviews demonstrated that the healthcare interpreters have not actively performed a patient advocacy role.

Although the standards for healthcare interpreters mention patient advocacy, the standards do not specifically allow positive advocacy by the interpreters. One reason for this lack of enforcement is that, at present, healthcare interpreting is not an officially qualified profession in Japan, and only a limited number of untrained or volunteer interpreters are currently working in various healthcare settings, in Japan. Also, not all healthcare providers have a clear understanding of the healthcare interpreter's multiple roles. The boundary of the healthcare interpreter's role as a patient advocate has been ambiguous. Healthcare providers also need to recognize the boundary of the interpreter's patient advocacy role.

Keywords: advocacy, foreign patients, code of ethics, healthcare interpreting, interviews

1. Introduction

The number of foreigners coming to Japan to seek work or other visas has been increasing since the latter half of the 1980s, and 2.5 million registered aliens, including permanent alien residents, are presently living in Japan (Immigration Services Agency of Japan, 2018). Communication difficulties are often an unavoidable part of daily life of a foreign resident, in Japan. In particular, communication in medical settings is very difficult for patients and family members without basic fluency in Japanese. Due to such communication difficulties, many such patients forgo access to care, even though they want or need medical care (Nishimura, 2011). Language barriers

often compel some patients with an insufficient command of Japanese to compromise the quality of healthcare provided them. The fact that these patients cannot sometimes receive good medical care in Japan when their health or life is at risk indicates that their human rights to treatment and consideration are at risk. To overcome the communication problems for such patients in the medical setting, a demand for healthcare interpreters has been increasing, and the Japanese government has striven to establish the position of 'healthcare interpreter' as an integral part of the healthcare setting. The 2020 Tokyo Olympics is thought to be a large contributing factor, further increasing a demand for healthcare interpreting. Healthcare interpreters have to be equipped with sophisticated skills, not only in interpreting different languages, but also by

being sensitive to differing cultures, historical traditions, and expectations of both healthcare providers and patients, and, as a result, healthcare interpreters play a difficult and complicated role in the medical setting (Haffner, 1992).

Some studies demonstrate, through participant observation, discourse analysis, and interview survey, that the healthcare interpreter not only serves as a verbal conduit, but plays various other roles, such as a facilitator, positively participating in the conversations between the healthcare provider and the patient for their mutual understanding, as well as helping participants understand the differences in cultural beliefs and values. (Angelelli, 2004; Wadensjö, 1998; Nadamitsu, 2008). When a healthcare interpreter encounters relevant cultural differences, cases report how a healthcare interpreter explains to a physician the cultural background of a patient and asks the physician some supplementary questions when the interpreter knows that the patient does not understand the physician's explanation, due to differences in cultural beliefs (Kaufert & Putsch, 1997). In a study of Wadensjö (1998) on dialogue interpreting of healthcare interpreters, the healthcare interpreter is recognized not only as a language interpreter, but also as a facilitator of interactions in the communication. In fact, Angelelli (2004) conducted an interview survey with healthcare interpreters who were working for a hospital in California; interviewees described how healthcare interpreters facilitate between Latin-American patients and American healthcare providers. The healthcare interpreters facilitated the differences in medical culture to achieve a smooth communication as a liaison between the two parties. Bischoff (2012) investigated the roles of the interpreters working in a women's hospital. It is pointed out that the interpreters have the function of building and supporting an effective patient-provider relationship by careful intervention, to avoid the conflicts between patient and healthcare provider. Some examples of empirical evidence show that healthcare interpreters provide patients and healthcare providers with supplementary information about cultural backgrounds of each participant and act as facilitators in the conversations between the two parties (Kaufert & Putsch, 1997; Wadensjö, 1998; Angelelli, 2004;

Bischoff, 2012). Some research suggests that interpreters and sign-language interpreters can be justified in adding supplementary explanations about the cultural values and practices, in order to obtain mutual understanding among participants in asymmetrical power relationships, such as the patient-provider relationship in the medical setting. Other studies show that the interpreter's roles vary, depending on the purpose of interpreting (Angelelli, 2004; Kaufert & Putsch, 1997; Roy, 2000).

Issues such as "accuracy," "neutrality," and "confidentiality" are common in the ethical codes of practice for interpreters in various fields, e.g., community interpreting. The ethical code for healthcare interpreters refers to the issue of "advocacy", in addition to the above issues (Mizuno, 2008). In this sense, the ethical code of the International Medical Interpreters Association (IMIA), i.e., an American organization for healthcare interpreters, is typical because it defines the conduct of advocacy not as impairing neutrality, but rather making such advocacy necessary for patients' health and well-being. The term "advocacy (of rights)" is defined as 'proposal', 'support', 'pleading', 'speaking' on behalf of someone. The term "advocacy" in the ethical code refers to a process in which a particular expert stands by the socially disadvantaged person to support actively, when needed, and sometimes speak on behalf of patients, as well as take the initiative in arguing against any potential for social inequalities, unfairness and injustice (Registered Nurses Association of British Columbia, 1995). Namely, advocacy strives to protect the rights and benefits of others such as socially disadvantaged persons who find it difficult to claim and fight for their rights by themselves. In healthcare and welfare settings, special attention has been paid to the conduct of advocacy to protect the rights of the socially disadvantaged, i.e., terminally ill patients, handicapped persons, bedridden elderly persons, older patients with dementia and child patients (Takayama, 2006).

Through discourse analysis of videotaped hospital settings involving native Canadian patients, healthcare providers and interpreters, Kaufert & Koolage (1984) conclude that the healthcare interpreters not only serve as language interpreters and cultural mediators, but also

as patient advocates, by explaining what the healthcare providers say to patients in such a way that the patients can understand. This research is considered to be the first one referring to the patient advocacy role of the healthcare interpreter. Roat (2010) emphasizes that healthcare interpreters should function as patient advocates for deepening mutual understanding between the patient and healthcare provider and providing appropriate healthcare information to the patients.

Mizuno (2005) describes that it is too early to incorporate the role of patient advocacy into the code of ethics for healthcare interpreters, in Japan, because the measures for the relief of the victims of human rights violations are less developed in Japan than in the United State. Mizuno insists that healthcare interpreters should keep their neutral positions and strive to interpret accurately, while patient advocacy should not be added to the ethical codes of conduct for healthcare interpreters. Oshimi (2010) suggests that the issues concerning when and how patient advocacy should be conducted by healthcare interpreters is still under discussion, and the interpreters' additional role of patient advocacy has not yet been established internationally and academically. Hale (2007) states that patient advocacy by healthcare interpreters has not always been positive for patient and medical provider, even though the basic goal of both healthcare provider and healthcare interpreter is the same: to assist and save patients.

On the other hand, according to Takahashi (2009), it is natural that the healthcare interpreter should stand on the side of the patient lacking sufficient fluency in Japanese, to protect the person's rights and benefits, rather than remain neutral. Iida (2012) points out that healthcare interpreters may encounter many medical care situations requiring their intervention and coordination, deviating from "neutrality" and "impartiality." Roat (2010) states that the healthcare interpreter may be justified in being a patient advocate when patient's health, well-being, and dignity are at risk.

As mentioned above, discussion is currently underway for and against the healthcare interpreter's conduct of advocacy (Roat, 2010). The healthcare interpreter's role of advocacy is, indeed, a controversial issue, and knowing

how presently active healthcare interpreters in Japan feel about the additional role would be instructive. How do the healthcare interpreters themselves recognize the role of advocacy in the Japanese medical settings? To find out, the author collected and investigated descriptions relating to advocacy in the Japanese standards of conduct for healthcare interpreters. At the same time, the author collected and compared the codes of ethics for healthcare providers dealing with patients of other countries with the standards for healthcare interpreters, focusing on the way of dealing with the issue of advocacy. In addition, the author tried to collect opinions and thoughts about interpreter's advocacy from the people actually involved in healthcare interpretation.

2. Purposes

This study considers the healthcare interpreter's role of patient advocacy as well as the scope and boundary of that role. In addition, the study highlights the problems related to the healthcare interpreter's role as patient advocate for patients without sufficient fluency in the Japanese language, by examining the results of an interview survey the author conducted with people actually currently involved in the medical interpreting field. Finally, codes of ethics for healthcare providers are compared in terms of how such patient advocacy was or was not conducted by healthcare interpreters.

3. Methods

3.1 Comparison of advocacy-related items between codes of ethics for healthcare providers and standards of conduct for healthcare interpreters

For analysis, the author considered the following Japanese codes of ethics for physicians, nurses, and medical social workers as well as the Japanese standards for healthcare interpreters, focusing on the conduct of advocacy.

- 1) Professional Ethics Guideline for Physicians (Japan Medical Association, 1998)
- 2) Code of Ethics for Nurses (Japanese Nursing Association, 2003)
- 3) Code of Ethics for Medical Social Workers

(Japanese Association of Social Workers in Health Services, 2005)

4) Standards for Medical Interpreters (Committee to Review Standards for Medical Interpreters, 2010)

The Standards for Medical Interpreters 2010 were formulated by the Committee to Review Standards for Medical Interpreters (established in May 2010), with the aim of indicating the desired levels of facilitation of the professional healthcare interpreters (Nishimura, 2011). The author paid attention to the codes of ethics for healthcare providers and the standards for healthcare interpreters because clinical ethics is today a required subject for healthcare professionals in Japan, and studying clinical ethics is also essential for the healthcare interpreter trainee. Moreover, three categories of healthcare professionals - physicians, nurses, and medical social workers - were selected because they were found to be most closely related to patients with insufficient fluency in Japanese and healthcare interpreters, as mentioned in the Standards for Medical Interpreters 2010.

3.2 Interviews with people involved in healthcare interpretation

To consider the patient advocacy by the healthcare interpreter, the author found it necessary to collect the opinions from various people actually involved in the healthcare interpreting field.

3.2.1 Subjects

The author sent e-mails to the healthcare interpreting organizations listed on the home page of the National Association for Medical Interpreters (NAMI) to ask for interviews. Then, interviews were individually conducted with the following four persons, (labeled A, B, C, and D), who approved the purpose of this study.

(A): A physician, holding a position of the director of a healthcare interpreting organization and currently using healthcare interpreters in the medical setting.

(B): A director of a healthcare interpreting organization.

(C): A healthcare interpreter (Portuguese

- Japanese), also acting as the chief of an organization for supporting foreign patients.

(D): A healthcare interpreter (English - Japanese) belonging to a healthcare interpreting organization.

3.2.2 Summary of interview survey

The interviews were conducted between August and September 2013. Only the author (i.e., interviewer) and each interviewee gathered at the place designated by the interviewee (i.e., the interviewee's workplace or a meeting room in the community). A semi-structured interview was conducted over a period of 40 minutes to one hour, based on the interview guide, which included the following questions: (1) What kinds of medical settings afford the healthcare interpreter chances to act in the role of patient advocate? (2) What do you think is the purpose of being a patient advocate? (3) How does your organization deal with the challenges of patient advocacy in terms of healthcare interpreter training? and (4) What do you think is the future of patient advocacy by the healthcare interpreter? The dialogues were recorded after obtaining the interviewee's consent. After the recorded data were transcribed, the transcribed data were then confirmed by each interviewee, to ensure accuracy.

The author explained in advance to each interviewee that the interview results would appear in a published article and that the interviewees would be indicated only by the corresponding alphabetical letter, so as not to identify the individuals, the right to privacy would be guaranteed, and the consent to participation in the survey could be withdrawn at any time.

4. Results

4.1 Advocacy stipulated in codes of ethics for healthcare providers and healthcare interpreters

A code of ethics is a guide for the professional because it stipulates how to conduct oneself as a professional. A code of ethics also has social significance because the mission and the role of the professional will become known in the healthcare community and society at large.

The author strove to clarify the scope of the healthcare interpreter's and healthcare provider's patient advocacy, by comparing the standards for healthcare interpreters and the codes of ethics for healthcare providers, such as physicians, nurses and social workers. Those standards of conduct for healthcare interpreters and healthcare providers, each stipulating the mission, duty, and ethics of the professional to indicate what they should aim at and what they should not do to moderate their behaviors, are also significant pledges to the healthcare community and society at large. Thus, the author thought that the comparison of those standards of conduct for healthcare professionals could define and clarify the scope and the boundary of the role in the advocacy conduct of each healthcare professional. Specifically, using the keywords such as "right to self-determination," "rights of patients" and "advocacy," the author extracted the advocacy-related items from the codes of ethics for physicians, nurses and social workers closely related to patients without sufficient fluency in Japanese.

4.1.1 Professional ethics guideline for physicians

Medicine and medical care shall be used to maintain and promote people's health as well as to treat sick people. The physician shall recognize the significance of his/her own responsibilities and serve all people based on a love and concern for humanity.

(Respect for and advocacy of patients' rights)

The physician shall put the highest priority on the patients' benefit and strive to respect and advocate patients' rights. Patients are entitled to receive impartial medical care, to obtain information and choose medical care based on self-determination, to refuse medical care, and to seek a second opinion. Every patient has a right to privacy.

(Explanation of information about a patient's disease and the state of the disease to the patient and the patient's families)

In an accurate, honest, and understandable manner, the physician is obligated to inform patients of the results of diagnosis, including what the disease may be, how the disease will progress, what kinds of examinations, and

treatments should be provided.

4.1.2 Code of ethics for nurses

The nurse respects the life, dignity and rights of all human beings.

In an equal and fair manner, the nurse provides care to recipients in need of medical assistance, irrespective of the recipients' nationality, race and ethnic group, religion, belief, age, sex and sexual orientation, social status, economic status, lifestyle, and health problems.

The nurse establishes a relationship of trust with the individual recipient in need of nursing care and provides nursing care based on that trusting relationship.

The nurse respects patients' right to know and right to decide, and acts as an advocate for each patient's rights.

The nurse safeguards recipients in need of nursing care and ensures recipients' safety in cases where nursing care for the recipient is hindered and the recipient is at risk.

4.1.3 Code of ethics for medical social workers

(Dignity of human beings)

The social worker respects the unique and intrinsic worth of all people, irrespective of their origin, race, sex, age, physical and psychological state, religious and cultural background, social status, economic status, and the like.

(Respect for a client's right to self-determination)

The social worker upholds a client's self-determination, and helps individual clients more thoroughly understand their rights and how best to make good use of them.

(Coping with clients' decision-making abilities)

The social worker always finds the best way to advocate the rights and benefit of clients with incomplete decision-making abilities.

(Preventing violation of clients' rights)

The social worker serves as an advocate for clients to prevent clients' rights from being violated in any case.

The social worker always finds the best way to advocate the rights and benefit of those clients

lacking sufficient decision-making capacity. The conduct of advocacy for clients' benefits and rights by medical social workers is widely extended to clients' decision-making situations in healthcare settings (including informed consent and choice of alternatives) to clients' social problems, such as poverty and abuse that may be associated with sickness and disability. The social worker always makes an effort to be well-acquainted with the laws and systems concerning advocacy of those with incomplete decision-making capacity and to protect those clients from suppression and theft as an appropriate advocate. Members of our society may not always be aware of people without sufficient capacity for self-determination. It is not only the legal and healthcare systems, but also the medical social workers' keen sensitivity to human rights and the courage to take action, when necessary, that is needed to advocate for a person's rights and benefits. The social worker always strives to be sensitive to and a guardian of human rights in the healthcare field.

4.1.4 Standards for Medical Interpreters 2010

4.1.4.1 Roles of the healthcare interpreter

The healthcare interpreter stands as a language interpreter and a cultural mediator between the healthcare provider and the patient who often does not share the same language and may come from different cultural and social origins. As well, the healthcare interpreter supports patients so that patients can make decisions based on their own intention and be provided with information in a culturally sensitive and easy-to-understand manner.

The healthcare provider sometimes communicates with the healthcare interpreter as if the interpreter were one of the patient's family members. As well, the patient sometimes implicitly expects the healthcare interpreter to act as an advocate for the patient. However, advocating either for the healthcare provider or the patient is not an inherent, but an acquired, role of the healthcare interpreter.

4.1.4.2 Healthcare interpreter's role as advocate

The fundamental role of the healthcare interpreter is to serve as a language mediator. The healthcare

interpreter, however, may act as an advocate for the patient, when aware of the fact that the patient's human rights are flagrantly violated.

The healthcare interpreter acts as an advocate for the patient when some problem remains unsolved and the patient's rights are subject to suppression, even after the interpreter assists in bridging the cultural gap between the patient and the healthcare provider by means of "accurate interpreting" and "explanation in consideration of cultural differences."

4.2 Interviews with people involved in healthcare interpretation

Various ideas about the healthcare interpreter's conduct of advocacy were extracted from the semi-structured interviews with the four persons (A, B, C, and D). The author classified the transcribed data into the following three categories: 1) interpreter's conduct regarded as patient advocacy; 2) negative views of the interpreter's advocacy; and 3) prospects for the interpreter's advocacy.

4.2.1 The interpreter's conduct regarded as patient advocacy

- (A): "The interpreter may act as an advocate in settings where the physician cannot understand the patient's situation without receiving vital information about the patient through the interpreter. In our organization, for example, interpreters are trained to obtain the patient's consent and tell the physician that the patient is, for instance, obligated to fast during the month of Ramadan" as a requirement of Islamic faith.

- (C): "After a physician saw a Japanese woman infected with HIV, the physician said in Japanese to her partner, who was a South American, 'You must have infected her with AIDS.' I promptly asked the physician for confirmation, 'May I translate what you said?' The physician answered, 'You may not translate what I said.' I usually try to ask physicians for confirming what they mean if their words imply prejudice about the patients, the patients' nationality, and the like. I think it may be ... an example of patient advocacy, although it's trivial."

- (D): "I ask the male physician to leave his seat when the female patient is prohibited from contact with the male physician for religious

reasons. The interpreter also pays attention to the patient. If the patient does not say anything, I always try to be attentive.”

- (D): “The healthcare interpreter is admitted when the patient has some different cultural background or such a situation may be disadvantageous to the patient. This is the conduct of patient advocacy, I think.”

4.2.2 Negative views of the interpreter's advocacy

- (B): “In addition to interpretation, the interpreter is allowed to confirm only the patient's and his/her family's statements, and the physician's statements. The interpreter should not speak or act on the interpreter's own initiative. Most of our interpreters are not at a professional level [of proficiency], and they need some assistance or support in the actual settings. That is the reason why patient advocacy is not committed to the interpreter.”

- (A): “The interpreter should neither persuade nor induce the patient to do something because such actions will not necessarily be advantageous to the patient. The interpreter should support what the patient is going to do. It is strange that the interpreter should take the initiative in the conduct of advocacy. Properly, the interpreter should cope with the advocacy of the patient in accordance with the patient's intention.”

- (A): “The interpreters... [in] our organization are not able to cope with patient advocacy without the social worker. Our organization does not deny patient advocacy, but it prevents interpreters from acting as the advocate, at the individual interpreter's discretion.”

4.2.3 Prospects for the interpreter's advocacy

- (A): “Our organization requests interpreters to introduce the patient to the person in charge of advocacy, that is, the social worker, when necessary.”

- (A): “Definitely, patient advocacy is very important. I wonder how to divide patient advocacy between the healthcare interpreter and the healthcare provider. The healthcare provider should know how to use the healthcare interpreter. Advocacy of foreign patients' rights is an important problem. So, it's difficult to determine how the two parties share the task of

advocacy. The presence of the interpreter is in itself the conduct of advocacy, I think.”

- (B): “We should first pay attention to accurate interpretation and then think of patient advocacy. In light of the current situation of healthcare interpretation, this argument is too premature in Japan. To talk about patient advocacy now may confuse the priority.”

- (C): “With certain practical training of how to act as the advocate, specifically for patients with HIV and terminal cancer or infant patients, not all, but some, of the trainee interpreters can learn to act as advocates, I think.

5. Discussion

5.1 Advocacy by healthcare providers

The code of ethics for physicians stipulates that they should assign top priority to the benefits of the patients, and they should be responsible for patients' self-determination, by explaining matters to the patients in plain language. The codes of ethics for nurses and medical social workers also stipulate not only that they should respect and advocate the patients' self-determination, but also that they should advocate for the patients when patients are at risk. According to the ethical code for social medical workers, social workers shall listen to the suppressed cries of the patient which are too faint to hear and advocate for the patient's benefit and rights. The ethical code for medical social workers also stipulates that they shall continually make an effort to maintain a keen awareness of human rights and be guardians of human rights in the healthcare field.

As mentioned above, the Japanese ethical codes for physicians, nurses and medical social workers deal with advocacy in different expressions. This is because the position, the role, and the relation with patients vary, depending on the profession. In particular, medical social workers act as consultants and advisors about patient's everyday concerns and economic problems. Medical social workers stand so close to patients that they can become the most familiar advocate for the patients. Medical social workers have a role in protecting patients with an insufficient fluency in Japanese when their human rights are suppressed or violated.

5.2 Advocacy by healthcare interpreters

5.2.1 Advocacy stipulated in the standards

The standards for healthcare interpreters formulated by the Japanese Association of Medical Interpreters do not specify advocacy as the healthcare interpreter's role and mention that it is left to the judgment of individual healthcare interpreters, whether to act as an advocate or not.

The Japanese standards of practice for healthcare interpreters do not recommend that interpreters play an active advocacy role. One of the reasons for this view is that the current healthcare interpreters have not yet reached professional levels, as a whole, in Japan. There is no official qualification system for healthcare interpreters and many untrained interpreters and volunteer interpreters are currently working in various medical settings. As indicated by Roat (2010), there is also an idea that the primary role of the interpreter is to interpret accurately, while the advocacy of patient's rights is not included in the occupational scope of the interpreter.

The healthcare interpreter has not yet been recognized as a professional position in Japan, and the Japanese standards of practice for healthcare interpreters stipulates that the healthcare interpreter should avoid serving as an active advocate for patients. In contrast to this, some healthcare interpreter organizations outside of Japan stipulate the role of advocacy for patients as one of the interpreter's roles, consistent with his or her professional ethical code. The ethical code formulated by the National Council on Interpreting in Health Care (NCIHC), one of the organizations for healthcare interpreters in the United States, stipulates that when the patient's health, well-being, or dignity is at risk, the interpreter may be justified in acting as an advocate. The ethical code (1986) by the International Medical Interpreters Association (IMIA), another American organization for healthcare interpreters, specifies advocacy as the interpreter's role, stipulating that the interpreters will engage in patient advocacy and in the intercultural mediation role of explaining cultural differences or practices to healthcare providers and patients only when appropriate and necessary for communication purposes, using professional judgment. Although there is a subtle difference in the way of viewing the conduct of advocacy

between the two codes, these two ethical codes similarly describe that the healthcare interpreter may, and even should, act as the advocate, depending on the medical setting.

Using an example of patient advocacy by a medical interpreter, let us consider the guideline described by the NCIHC suggesting the interpreter may advocate on behalf of a party or group to correct mistreatment or abuse. For example, an interpreter may alert his or her supervisor to patterns of disrespect towards patients. The above-mentioned interpreter's conduct of advocacy is to alert the authority, on behalf of patients, to protect them when patients' human rights are violated. In this case, the interpreter stands on the side of the patient, that is, on the opposite side of the healthcare providers. Judgment in such a case is considered difficult.

In the United States, there are facilities for training healthcare interpreters and official qualifications for professional healthcare interpreters. Further, the professional healthcare interpreters in the United States are requested to attend ongoing training programs to keep their knowledge and skills up to date and at the desired levels. While training, healthcare interpreters learn when, where, and how best to conduct themselves as advocates in a professional manner. Thus, in the United States, healthcare interpreters can work as medical professionals, together with other healthcare providers. Accordingly, healthcare interpreters in the United States are expected to conduct themselves as advocates, as would other healthcare providers, when the patients are found to be at a disadvantage.

In contrast to the United States, healthcare interpreters in Japan are not recognized as professionals. The Japanese standards for healthcare interpreters describe that the healthcare interpreter acts as an advocate for the patient when the problem remains unsolved and the patient's rights are subject to suppression, even after the interpreter assists in bridging the cultural gap between the patient and the healthcare provider. As mentioned above, when acting as the advocate for the patient without sufficient fluency in Japanese, the interpreter's neutral stance with respect to the healthcare provider will, inevitably, be broken. Namely, the conduct of advocacy conflicts with the

interpreter's role of "neutrality." Therefore, professional training is needed, to learn when, how, and in what manner the healthcare interpreter should act as an advocate. According to the report of Hale (2007), an untrained healthcare interpreter acted as an advocate for a patient without regard to "neutrality" and "accuracy," and consequently, the interpreter's conduct did not help the patient; in fact, the relationship of trust with the healthcare provider was impaired, leading to a medical mistake. Hale (2007) shows that a healthcare interpreter's *ad hoc* patient advocacy that compromises neutrality and accuracy may place the patient at a disadvantage.

5.2.2 Healthcare interpreter's advocacy conduct found in interviews

In the interview survey, the interviewee (C) said: "After a physician saw a Japanese woman infected with HIV, the physician said in Japanese to her partner, who was a South American, 'You must have infected her with AIDS.' I promptly asked the physician for confirmation, 'May I translate what you said?' The physician answered, 'You may not translate what I said.'" Interviewee (C) regarded the above-mentioned actual interpreter's conduct as advocacy for the patient. Interviewee (C) acted as a Portuguese interpreter and was the leader of an organization supporting HIV patients. Interviewee (C) thought that patient advocacy was essential for the interpreters belonging to his organization because they specialized in interpreting for HIV patients. All the interpreters of his organization were experts with 10 years' or more experience in this field, and they had a common understanding of cases where active advocacy was needed, through the training system his organization had prepared. In the case given by interviewee (C), the interpreter advocated for the patient by raising his voice against the physician's discriminatory remarks to the patient. This kind of advocacy by the interpreter is regarded as similar to the advocacy of the medical social worker who actively advocates for the patient, to protect the patient from the physician's accusatory remarks, and the like.

Interviewees (A) and (D) mentioned advocacy challenges related to a patient's religious affiliation. Interviewees (A) and (D)

identified a justified advocacy role where some cultural gap between the healthcare provider and the patient was thought to be disadvantageous to the patient. The healthcare interpreter is actually required to work as an advocate for the patient without sufficient fluency in Japanese, by alerting the healthcare provider of communication difficulties relating to language and cultural differences, to ensure that the patient receives appropriate medical care.

As demonstrated by the interview results, interviewee (B) pointed out that support of the coordinator was necessary in the actual settings for the majority of interpreters belonging to B's organization, and accurate interpretation was a top priority for those interpreters at the present stage. Interviewee (B) insisted that *ad hoc* patient advocacy by untrained healthcare interpreters should not be conducted. Interviewee (B)'s remarks can be supported by the fact that B's interpreting organization is composed largely of non-Japanese staff who are adequately fluent in Japanese, living expat communities in Japan, a situation that also applies to other healthcare translation organizations. In Japan, a considerable number of foreigners from expat communities have a good command of Japanese and play a vital role in interpreting in their communities in Japan. Yet some of them have little experience of working as the interpreters and others undergo little training for accurate interpreting. Even children of the expat communities are often recruited as interpreters, because of their command of Japanese. The interviewee (B) insisted that it was still too soon to argue over the advocacy conduct by untrained interpreters who still had difficulty in translating verbatim. In light of the interpreters of (B)'s organization, the interviewee (B)'s opinions seem reasonable.

The results of the interviews show the ambiguous scope of the healthcare interpreter's advocacy conduct. Specifically, the advocacy conduct of the healthcare interpreter varies, depending on the interpreter's organization, for example, whether to interpret a healthcare provider's statement or not, explain or fill in the cultural gap, or act as a patient advocate.

5.2.3 Different views on the healthcare interpreter's advocacy conduct

Roat (2010) describes that the healthcare

interpreter should not conduct advocacy when the point in question is based on the physician's professional opinion, such as diagnosis, when there is no oversight or misunderstanding; when the patient no longer wants advocacy; when the conduct of advocacy may lead to abuse of confidentiality; or when the interpreter's agent or organization specifically prohibits the interpreter from serving as an advocate. Further, according to Roat (2010), it is most important that the healthcare interpreter be recognized as one of the professional members of the medical team, not an outsider, so that the healthcare interpreter can learn when and how to conduct advocacy. Hale (2007) states that the healthcare interpreter can understand cultural differences between the healthcare provider and the patient to cope with diversity in the medical setting, if the interpreter is entitled to participate in the team conference as a member of the medical team and obtain information about the patient in advance.

As stated by interviewees (A) and (B) in the interview survey, one of the reasons why they do not approve healthcare interpreters' advocacy for patients is that the majority of existing healthcare interpreters are still insufficiently trained to judge by themselves. An unskilled healthcare interpreter's actions as an advocate for a patient without sufficient fluency in Japanese may help to cause medical mistakes and entail a risk to the patient's health. For this reason, Japanese standards for healthcare interpreters do not admit the interpreter to conduct advocacy.

Even so, even extensive training cannot always adequately prepare interpreters for patient advocacy. Hattori (2017) conducted a questionnaire survey of healthcare providers' awareness and healthcare interpreters' awareness of the interpreter's roles. According to the survey, the healthcare providers were aware that healthcare interpreters had the function of speaking on behalf of patients and explaining, in simple terms, physicians' intended meaning to patients (Hattori, 2017). As demonstrated by the survey results, the healthcare providers ask the interpreters not only to interpret the dialogues accurately, but also act as advocates. There is a gap in awareness of the healthcare interpreter's roles between the healthcare providers and the healthcare interpreters. Therefore, it becomes unclear in the medical setting who should

conduct advocacy for patients without sufficient fluency in Japanese or when and how such advocacy should be performed.

In some cases, healthcare providers ask healthcare interpreters to act as advocates for patients without sufficient fluency in Japanese. According to the Japanese standards, on the other hand, the interpreter's advocacy is left to each interpreter's discretion. Moreover, according to interviewees (A) and (B), for instance, the directors of the healthcare interpreting organizations insist that advocacy for patients with insufficient fluency in Japanese should be avoided and done only at each interpreter's discretion. In brief, the healthcare interpreter's advocacy is viewed differently, depending on the healthcare provider, the standards of conduct for healthcare interpreters, and the persons concerned in healthcare interpretation.

5.2.4 Future tasks related to the healthcare interpreter's advocacy

With the increase in demand for healthcare interpreting in Japanese society, healthcare interpreters will likely encounter a greater need for advocacy in the medical setting. Coping with this situation requires strengthening the official qualification system and improving the training system for healthcare interpreters as well as guaranteeing and upgrading their levels and skills in all relevant areas. As pointed out by Ohno (2014), if the current Japanese standards for healthcare interpreters are supplemented with the items relating to the professionalism and scope of the role, such as existing standards of various countries, the Japanese standards will be more consistent with the international community's standards. Doing so would contribute to the recognition of healthcare interpreting as a profession, which in turn would improve the healthcare interpreter's standing in the Japanese healthcare system and society at large. Also, healthcare providers should cooperate to meet these challenges. Even when the current healthcare interpreters reach a professional level, through the introduction of an official qualification system and an effective training system, advocacy for patients without sufficient fluency in Japanese may still be compromised. To counter this possibility, healthcare providers must understand the healthcare interpreter's roles

and how best to utilize the healthcare interpreter in the medical setting. Kumamoto (2006) insists that advocacy in healthcare settings should be conducted by some professionals, in relation to a patient's rights. Such advocacy should be done in consideration of the following three points: (1) what the patient's rights are; (2) how the patient's rights may be violated under the current circumstances; and (3) what kind of action should be taken to advocate the patient's rights.

In addition to the obligatory training to be designed for healthcare interpreters, certain training programs are also necessary for healthcare providers so that the providers can learn how to use the healthcare interpreter in the medical settings and understand the scope of the healthcare interpreter's role. After that, healthcare professionals, including healthcare providers and healthcare interpreters, should discuss and decide how best to share the conduct of patient advocacy.

5.2.5 Advocacy for patients with insufficient fluency in Japanese

The author believes that advocacy should benefit the patient without sufficient fluency in Japanese in such a way that the thoughts, concerns, and questions of the patient reach healthcare providers and that the voice of the healthcare provider is adequately understood by the patient. In this manner, the patient can enjoy the same level of medical care and the implicit right of self-determination and other rights afforded patients with sufficient fluency in Japanese.

The healthcare provider's advocacy for patients without sufficient fluency in Japanese is intended to provide patients with the best medical care and benefit, by making the best use of all the healthcare provider's knowledge and skills. The author argues that advocacy for patients without sufficient fluency in Japanese should not be committed to healthcare providers only; the healthcare interpreters as well should be advocates. Ishikawa (2010) mentions that all medical staff in contact with a patient are implicitly regarded as advocates for the patient, so long as they respect and pay attention to the patient and the patient's needs. As well, the physicians and the nurses should tackle the patient's health problems in cooperation with other professionals, to decide what is in the best

interests of the patient.

Although accurate interpretation and maintaining a neutral position are important for the healthcare interpreters as a matter of course, healthcare interpreters are also required to consider patients' needs and protect patients' rights and dignity in the medical setting. In this sense, healthcare interpreters are implicitly regarded as advocates. Unlike the healthcare providers' advocacy, however, the healthcare interpreters' advocacy is to fill the cultural gap between healthcare providers and patients lacking sufficient fluency in Japanese by eliminating patients' language barriers and providing information about patients' cultural backgrounds to healthcare providers. The author contends that healthcare interpreters should be advocates for such patients by siding with the patient and protecting a patient from any reduction, avoidance, or suppression of any of a patient's full array of rights in the context of Japanese society. Although the manner of acting as an advocate may differ, healthcare providers and healthcare interpreters are required to cooperate for the same purpose, that is, for the best interest of the individual patient in their care.

6. Conclusions

Healthcare providers and healthcare interpreters approach the advocacy for patients without sufficient fluency in Japanese in different ways. In respecting patients' intentions, supporting patients' right to self-determination, and protecting the patients' rights generally, healthcare providers should conduct advocacy, with a focus on the best benefit to the individual patient. In particular, medical social workers engage in advocacy to protect the patient from anyone who may want to reduce, avoid, suppress, or actively violate the patient's rights. Healthcare interpreters, for their part, fill the cultural gap between healthcare providers and patients and conduct advocacy, when required. Further, healthcare interpreters can raise concern and protect a patient from a healthcare provider, for example, when recognizing the patient's rights as being reduced, avoided, suppressed, or actively violated that may lead to compromised medical care. However, active advocacy by healthcare interpreters has not yet been officially permitted

in Japan. The reasons for this are the following: the healthcare interpreter has not been officially certified and a considerable number of untrained interpreters are currently working in various medical settings; the scope of the advocacy conduct by the healthcare interpreter is currently not clearly defined in the Japanese standards of conduct for healthcare interpreters; and the healthcare providers do not recognize what the healthcare interpreter's advocacy for the patient entails.

For patient advocacy, the healthcare interpreters need sufficient knowledge, skills, and experience as professionals in their field. In light of the current circumstances of the healthcare interpreters, the author concludes that it may be premature for the healthcare interpreters to be tasked as patient advocates for patients. Most importantly, we need to establish an official qualification system for creating professional healthcare interpreters and improve the training systems for increasing the professional skills of healthcare interpreters. Training is necessary, not only for the healthcare interpreters, but also for healthcare providers. Healthcare providers are also required to understand the roles of the healthcare interpreter, learn how to use the healthcare interpreter in the medical settings, and explore the challenges of advocacy of patients. It is an urgent challenge for all professionals treating patients without sufficient fluency in Japanese, and it is incumbent on all parties to discuss and cooperate, to recognize each other's respective roles relating to advocacy for such patients. We will then need a further discussion on the role of advocacy, to be shared by healthcare providers and healthcare interpreters, specifically concerning the boundaries of the role between the two parties and the respective manner of advocacy for patients.

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RESEARCH REPORT

Masaoka Shiki's Last Days and His Creations: Notes on a Poet Who Suffered from Tuberculosis and Spinal Caries

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Abstract

Once, tuberculosis was said to be a disease that made us acknowledge death, as cancer might today. Masaoka Shiki (1867-1902), a pseudonym for Masaoka Tsunenori, died of tuberculosis at 35, with complications from spinal caries. One of the most famous and important poets in modern Japanese literature, Shiki expressed, through his last poems and thoughts, the poignancy and challenges of his debilitated state, offering us a rare glimpse into a highly active and poetic mind at the edge of death, still able to find beauty, even within severe restrictions of illness. The continual and thoughtful care he received from family and friends offers us insight and chances for reflection on how best to support a dying person.

As literary historian Reginald Horace Blyth wrote of Shiki, "By the end of his short life, he had found some humanity, but no religion, no pantheism, or mysticism, or Zen." This article asserts that Shiki's self-discovery of a sense of 'humanity' is deeply related to the poet's epiphanies of objective self-awareness, *satori* [enlightenment], and *kaigyaku* [humor], all of which represent fundamental qualities of his writing, especially his later writing. This article focuses on the philosophical concepts of Shiki's thinking, but also serves as a brief introduction to the life and literary work of the artist, who is not so well known outside of Japan.

Keywords: thanatology, Masaoka Shiki, *haiku*, *tanka*, *satori*, *kaigyaku*, objective self-awareness, pulmonary tuberculosis, spinal caries, end-of-life care

Preface

Once, tuberculosis was said to be a disease that made us realize and acknowledge death, as cancer might today. In her ground-breaking book, *Illness as Metaphor*, philosopher Susan Sontag wrote the following about tuberculosis as metaphor:

Two diseases have been spectacularly, and similarly, encumbered by the trappings of metaphor: tuberculosis and cancer. (Sontag 1983: 7)

TB [tuberculosis] is thought to be relatively

painless. TB is thought to provide an easy death, while cancer is the spectacularly wretched one. For over a hundred years TB remained the preferred way of giving death a meaning - an edifying, refined disease. (Sontag 1983: 20)

The Romantics moralized death in a new way: with the TB death, which dissolved the gross body, etherealized the personality, expanded consciousness. It was equally possible, through fantasies about TB, to aestheticize death. (Sontag 1983: 24) (Omission by research author)

Sontag's literary characterizations of

tuberculosis differ starkly from those expressed by Shiki, who suffered both from tuberculosis (TB) and, near the end of his life, spinal caries. In fact, Shiki found the experiences of his illnesses much less romantic, refined, and ethereal. Ironically, writer and philosopher Tokutomi Roka (1868-1927) published a novel titled *Hototogisu* [*The Cuckoo*] which has the same meaning as Shiki's pen name. *The Cuckoo* was released in serial form, from 1898-1899, as Shiki began suffering more acutely from TB, shortly after, around 1900 [Meiji 33], and was hugely popular throughout Japan and abroad, later published in multiple translations. The novel depicts the death of its heroine, Namiko, by TB, in a romanticized way consistent with Sontag's description. In his last poems and other expressions, Shiki presents a prosaic and unromantic experience with TB, one that shows how he suffered, but was able to come to terms with his illness, while at the same time use the experience as a catalyst for some of his finest writing.

Despite his serious condition, which left him largely bedridden during the last six years of his life, Shiki was still a prolific writer who managed to leave a tremendous amount of quality work over a short lifetime. Shiki is one of the most famous and important Japanese poets in modern times. In his book *A History of Haiku*, Reginald Horace Blyth, a specialist in Zen and haiku, describes Shiki in the following manner:

Shiki, 1867-1902, is considered to be the restorer of haiku, which had been falling off since the time of Buson. Basho walked his Way of Haiku; Buson his Way of Art; Issa, though he did not speak of it, his Way of Humanity. What had Shiki? He had no Way of any kind, unless perhaps a Way of Beauty, like Keats, but ill-health and beauty do not go well together, and by the end of his short life he had got some humanity, but no religion, no pantheism, or mysticism, or Zen. (Blyth 1964: 21)

Shiki's "humanity", which Blyth mentions, is related to objective self-awareness, '*satori*' [enlightenment] (or at least his own form of it), and '*kaigyaku*' [humor]. Japanese historian Donald Keene also describes Shiki's sense of humanity, in relation to the poet's cultural

background (see, Keene 1998: 36, or Chapter 2 of this article).

This article considers the concepts of objective self-awareness, *satori*, and *kaigyaku*, concluding with reflections about whether Shiki benefited or was comforted by any of his personal epiphanies, as expressed in his writing. Providing some biographical context will help us place these concepts. First, he was a reformer of *tanka* and *haiku*. Shiki succeeded in composing literary works in modern colloquial Japanese, rather than using highly formalized Japanese. Shiki also lived a life that expresses an additional bioethical meaning. That is, Shiki was a real-life example of end-of-life care, where no alternative was possible. He became infected with pulmonary tuberculosis at the age of 21, and later contracted spinal caries at the age of 28. He became largely bedridden for the final six years of his life, requiring the continual care of doctors, his younger sister Ritsu, and friends.

Nevertheless, Shiki continued to create art until the day he died at age 35. His body of work, overwhelming, both in quantity and quality, offers many entry points for explication and discussion, to learn about his life and art. We can frame some of these entry points as questions with brief references to their relevance to medical ethics:

1. *What did Shiki think about his own death and that of others?* Considering this question teaches us about coming to terms with death.
2. *How did he resist the urge to commit suicide, which had haunted him many times?* Considering this question leads us to think about related topics, such as euthanasia, dignity in death, assisted suicide, and end-of-life care.
3. *How did his younger sister Ritsu support him through his difficulties?* This question teaches us about terminal home care and pain control in Tokyo, over 115 years ago (see, *Document: Morphine Administration Record*).

Shiki was the patriarch and the sole earner of the house. It was both his pride and responsibility, and he always suffered from his inability, or lack of power (social pain) to do more. Ritsu had to turn her heart into a demon's, in order to replace his bandages, as he

experienced continual and severe pain, as well as regularly clean his bedding and bedpan. The value of Ritsu's efforts to comfort Shiki through his ailments as well as his mental anguish and loneliness cannot be overstated. At the same time, we are invited to consider how such palliative care and pain care can be solved in contemporary society.

1. Shiki and his impending death.

1.1 Objective self-awareness and transcendent sensitivity

In early May of 1902, four months before his death, Shiki began writing his final essay series, *Byosho Rokushaku* [Six-Foot Sickbed], which was serialized in the newspaper *Nippon*, for which he was a staff writer. The title of the series is described in such a memorable form that it has become, for many contemporary Japanese, a familiar image of sickness and impending death:

A six-foot sickbed - this is my world. And this sickbed six feet long is too big for me. Sometimes I have only to stretch my arm a bit to touch the *tatami*, but at other times I can't even relax by pushing my legs outside the covers. In extreme cases, I am relaxed but am tormented by such terrible pain that I'm unable to move my body so much as an inch or even half an inch. Racked by pain, anguish, shrieks, morphine, I search for a way out, helplessly craving a little peace on a road that leads to death. All the same, as long as I stay alive, I intend to say whatever I feel like saying. Day in and day out, all I ever see are newspapers and magazines, but often I am in such pain I cannot read them. When I can, they make me angry or irritated; but once in a while something makes me so happy, I forget my pain. Feeling like someone who has been sleeping for six whole years and knows nothing of the outside world, I write this preface by way of introducing myself.

(*Byosho Rokushaku*, no. 1, June 5th, 1902 (Not the date of writing, but the newspaper date. Same as below). Translated by Keene, Keene 2013: 171-172)

The idea of his bed being 'six-feet'[6尺] has a philosophical meaning of its own. In Japan, both *fusuma* [sliding screen] and *tatami*-mats (also *futon*-mattresses) are made to be approximately six feet in length. There is an old proverb that says, "Standing takes half a *tatami*, and sleeping takes but one," which means that human beings do not require any more space than a *tatami* (about 180cm by 90 cm; 6 by 3 feet) to live.

Nevertheless, even this size was too wide for Shiki, just four months before his death. Here, Shiki claims that certainly the size of a *tatami* is too wide for his sick body, but his *spirit* can spread out from there. This spirit can be restated as imagination. For example, Shiki imagines himself leaving his body and objectively looking at himself on the six-foot sickbed. This is not necessarily astral projection (out-of-body experience), but rather the sign of an untethered imagination.

The description of his sickbed informs us about Shiki's objectivism. Objectivism once had just been Shiki's technique to write poetry, but later, especially as his illness worsened to the point of being incurable, it became part of his lifestyle. To describe this technique, he called it '*shasei*.' Beichman translates this word as "to sketch from life" (Beichman 1982: 54). Shiki used the term *shasei*, which was influenced by Nakamura Fusetsu (1). Certainly, this way of thinking was part of the realism already expressed in modern Japanese literature, in accord with other profound changes, such as the felt national need for rapid industrialization (*Bunmei-Kaika*). However, it is worth noting that Shiki tried to tackle 'everything' objectively, through his ailments. Naturalism (rather natural scientism) in Western literature in the 19th century also promoted realism in modern Japanese literature. Shiki's *shasei* is one such expression.

1.2 Shiki and Chomin

Much of Shiki's commentary on his literary contemporary Nakae Chomin (1847-1901) may best be understood as a literary rivalry of sorts, near the end of their lives. Chomin died on the 13th of December, while Shiki died less than a year later, September 19th, 1902; both of them were gravely ill. In characteristically stark and

realist language and image, Shiki thought that 'everything' is included in the body itself. Shiki criticized Chomin, a pseudonym for Nakae Tokusuke, a journalist and statesman of the Meiji era, a famous Enlightenment thinker whose last work *Ichinen Yu-han* [*One Year and a Half*], chronicling his physical decline from esophageal cancer, brought him unexpected acclaim and some material success as well, while Shiki's writings about his last days experienced little material success.

On the literary attack, Shiki criticized Chomin's lack of objective observation of his own illness, even though Chomin was also a teacher of Shiki's uncle, Kato Takusen, one of the largest benefactors of Shiki. In a somewhat reckless manner (See, Fukumoto 2017: 107), Shiki criticized Chomin and his final days which were described in Chomin's best seller essay *Ichinen Yu-han*. Shiki criticized Chomin as "not beautiful" in his unpublished essay *Gyoga Manroku* [*Stray Notes While Lying On My Back*, including *Morphine Diaries*] and three series published essays titled "Rest of Life" (1901). Both Shiki and Chomin are examples of terminally ill patients who painfully chronicled their condition and decline in their writing. In the following illustration, in a soft but direct rebuke of Chomin's view of dying and death, Shiki, who had always used 居士 'koji,' the Japanese traditional honorific title in referencing 'Chomin', omits all honorifics;

[Written in the old style of Japanese] He [Chomin] still doesn't know anything about *beauty* [美], and in this point, his view is inferior to mine. If he understands *reason* [理], he will give up, but if he understands beauty, he can enjoy the rest of his life. He must enjoy it when he buys apricots and eats them with his wife [as Chomin says in *Ichinen Yu-han*], but there is some reason behind it. The scorching daytime heat is gone, and the white flowers of calabash [夕顔] sway in the evening breeze; what kind of *reason* is there? (*Gyoga Manroku*, Oct. 15th, 1901)

Shiki's chiding of Chomin, might derive from Chomin's unexpected literary fame, something that apparently surprised Chomin

himself.

However, this critique by Shiki was still unpublished at the time; only the three series essays, titled "Rest of Life", were published before Shiki's death. Therefore, no one at the time knew of Shiki's critique and reflections in *Gyoga Manroku*.

Though the second essay of *Rest of Life* describes Shiki's writing philosophy, the first essay of the series gives us a better sense of his thoughts on how the dying Chomin failed to go far enough, in coming to terms with the ending of his life. Shiki states his opinion, which he also stated in *Gyoga Manroku*:

However, in the point that Chomin can't understand the pleasure beyond *Gidayu* [Japanese traditional play performed by dolls], it is inevitable that Chomin is a secular person. He was able to give up on death from his theoretical reasoning because he had an education [culture]. If Chomin was able to live a little more, he may have been able to reach more than "giving up." ("Rest of Life," in: *Shiki Zenshu* [*Shiki Complete Works*], XII: 534-539, especially 536. Omission by research author)

In other words, Shiki criticized Chomin for never surpassing the stage of "giving up". Chomin is unaware of beauty, and on this point, his view is inferior to Shiki's epiphanies about dying and death. Shiki thinks that if Chomin understands reason, he will give up; but if he understands beauty, he would be able to enjoy his life, even if he is on his deathbed. Surely, apricots and time spent with his wife can bring joy, but there is reason behind them (thus no true joy, thought Shiki). Shiki asks if reason is really necessary to feel the wind in the evening after the whiteness of the sun. Shiki, as he faced death, was able to find joy, without or beyond reason, in experiencing *nature*, even in his debilitated state.

Shiki's dissatisfaction lies in the fact that Chomin went to see *Gidayu* and ate apricots with his wife. Shiki, who was bedridden could not go out, and he gave up on ever having a wife and children. As the heir of the Masaoka family name, this lack of both wife and children apparently led to his feeling of disaffection. He could eat apricots only with his disciples,

mother, and sister. Concerning Shiki's critique of Chomin, writer Masamune Hakucho thinks that "there might have been an envy" (Hakucho 1983: 7; Chomin 2016: 321), but Tsurugaya also notes that Shiki had long before accepted and come to terms with not having a wife and children and money as well. If we accept Tsurugaya's description, Shiki had already conceded the impossibility of marriage, children, fame, and money. However, in contrast to Chomin, who, in Shiki's mind, still clung to rationality and worldly considerations, Shiki broke through to a higher, non-rational level, shown in his *Byosho Rokushaku* and other last writings.

This higher level of being can be characterized as objective self-awareness. By being able to take a more objective view of his painful life, Shiki was able to reach a level, beyond rationality, where even a miserable life could not inhibit laughter. Shiki reached the point where he could simply love nature and sketch in words and paintings, what seems mundane and unnoticed and bring the humble images of life into high relief and visible in a new light.

Shiki's deepest feeling as a terminal patient (2) is starkly depicted in his last essay, "The Morning of September 14th", and the poet's literary epiphany (3) occurs in the *Jisei* "Hechima Saite" (Both will be addressed further on in this article).

1.3 Shiki's viewpoint

Despite being bedridden and unable to move without great pain and much discomfort, faced with the fact of terminal illness, Shiki was able to move to a new level of consciousness, beyond reason and the worries of life. At this level, Shiki sees, smells, feels, thinks, and writes (at times with the help of a scribe or interpreter), transcending his situation, although at the same time acutely aware that he feels himself as a physical body. Consider the following *tanka*, written a year before his death;

kame ni sasu
fuji no hanabusa
mijikakereba
tatami no ue ni
todokazarikeri
[the sprays of wisteria

arranged in the vase
are so short
they don't reach
to the tatami]

瓶にさす藤の花ぶさみじかければたたみの上にと
どかざりけり

(*Bokuju Itteki* [*A Drop of Ink*], April 28th, 1901. Translated by Brower, Brower 1971: 403)

This is one of the most famous of his *tanka*, widely known in Japan and part of the literary canon taught at school. This *tanka* is also widely considered to be one of the most difficult works to understand and interpret. Generally, works created with Shiki's motto of "*shasei* objectivism" are likely to raise questions. Most Japanese junior high school students would probably think, 'Of course, the short sprays of flowers do not reach the tatami. So what?' However, we must remember Shiki's words;

Even if I was lying on the sick-bed year-round, day and night and always enjoy looking up even at a *bonsai* tree that is three-shaku high [about 3 ft.], when I was a little distressed by morphine, I want to laugh at myself who was bothered a while ago. (*Byosho Rokushaku*, no. 42, June 23rd, 1902. Research author's emphasis is added)

In other words, the true meaning of this work cannot be understood unless it is seen from Shiki's point of view. Many of Shiki's important works cannot be understood without sharing the viewpoint of Shiki, the bedridden patient.

The same can be said for the next unpublished haiku, created at the same time as *Byosho Rokushaku*, in the summer of 1902, probably one of his final works.

ikita me wo
tsutsuki ni kuru ka
hae no koe
[will it come to peck,
at living my eyes
voice of fly]
活きた目をつつきに来るか蠅の声
(*Shiki Zenshu*, vol. III: 460)

At that time, Shiki is thinking of himself as

if he were a soldier dying on the battlefield. He expects that crows would come to peck the body, especially the eyes, even though he is not dead! However, it is not the crow but the fly that comes. Further, it is its sound, not its figure. Even so, how sensitive he is to hear the fly's voice! No, of course, Shiki does not hear the fly's voice. No one can hear the voice of an insect that cannot speak. Shiki feels the change in the air in the room and feels that change has reached his open eyes.

1.4 Awareness of death and the pen name 'Shiki'

Shiki wrote the following tanka one year before his death (dated May 4th, 1901):

ichihatsu no
hana saki-idete
wagame ni wa
kotoshi bakari no
haru yukan to su
[the wall iris
opens its buds:
before my eyes
the last spring
begins to fade]

(Translated by Beichman, Beichmann 1982:
138)

Shiki despised May because his physical condition worsened every year, in the midst of spring. Also, in this verse above, we can see that he is terribly irritated and pained. But, in fact, he was able to see the spring of the following year. In this way, in his later years, Shiki always understood that death was coming for him. However, he struggled most when he reread the oldest *kanshi* [Chinese poetry] he wrote, when he was in his twenties:

聞子規 子規を聞く
一声弧月下 一声、弧月の下
啼血不堪聞 血に啼きて聞くに堪えず
半夜空欹枕 半夜空しく枕を欹つ
古郷万里雲 古郷、万里の雲

[Listen to The Cry of Shiki [Little Cuckoo]

One cry under the lonely moon;
It coughs blood, I cannot bear to listen.
Halfway through the night, I strain my ears

in vain, Ten thousand *ri* of clouds over my
old home]

(Translated by Keene, Keene 2013: 24.
Originally, *Shiki Zenshu* VII: 16)

Long before Shiki became ill, as an adolescent, he wrote of the cry of the little cuckoo or 'shiki.' It seems that the poet unwittingly intuited his future as a tuberculosis patient. In poems of east Asia (China, Japan) *shiki* (*hototogisu*) is a symbol of a dying poet. The pronunciation of this 'shiki' also leads to another word 'shiki [死期], which means "time of death" in Japanese.

Historian Donald Keene explains the significance of the bird metaphor:

This early mention of the *hototogisu*, a bird whose cries suggest it is coughing blood, has an ominous ring as the work of an eleven-year-old, seeming to foretell Shiki's death twenty-four years later. "Shiki" was the Sino-Japanese name for the *hototogisu*. The image of the *hototogisu* would run through Shiki's writings. (Keene 2013: 206, note 36).

In contrast, Keene quotes a haiku written by *Hozumi Eiki* (1823-1904), who is almost forgotten by contemporary Japanese.

chi wo nagasu
ame ya orihushi
hototogisu
[Rain washes away
The blood: just at that moment
A nightingale sings.]
(Translated by Keene, Keene 1984)

The poem is based on Ueno, the battlefield of the Meiji Restoration. In this haiku, the *hototogisu* (Keene translated it 'nightingale' here) is just a bird which spits blood, without philosophical import.

However, the connection between one of Shiki's earliest works and his pen name is still a matter of theory. The decisive change in his philosophical and literary outlook occurred as his condition worsened from pulmonary tuberculosis and, later, spinal caries. Shiki later recalls that immediately after hearing the diagnosis, he felt that time had stopped for about five seconds (See,

a letter to *Kyoshi*, March 17th, 1896; *Shiki Zenshu*, XIX: 16-19).

2. Preparedness to die

2.1 Shiki's ambitions and despair

As early as 1895, Shiki wrote the following in the same letter to *Kyoshi*, one of his most gifted disciples in haiku, as well as a fraternal figure:

Many people in this world have great ambitions, but none so great as I. Most people are buried in the earth still embracing their dreams, but no one will ever go beneath holding fast to as many as I. No matter how great my achievement in haiku, it will be as zero compared to the infinity of my dreams.

(Translated by Beichman, Beichman 1982: 60. Originally *Shiki Zenshu* XIX: 18)

Shiki was a very ambitious man. He was a student at the Imperial University (*Teikoku Daigaku*) in the 1890s. This was the first and only university in Japan at that time, so the classes had only a few dozen students, including Shiki. They were expected to become senior government officials or to serve as teachers at educational institutions that were established one after another on behalf of foreigners who were hired at very high salaries.

Tsubouchi Shoyo, an upperclassman of Shiki's at the university and from whom Shiki had learned English, was exceptionally well-established in literature, and as a result, Tsubouchi felt himself, along with other graduates at the time, as someone who would be responsible for the establishment of the Faculty of Literature at Waseda University, as well as becoming a leader in spreading Western theater to an increasingly modern and urban Japan.

By contrast, Shiki had quit university, though almost everyone had encouraged him to change his mind. Shiki was greatly ashamed of having betrayed his family and hometown expectations. As a scholar from Matsuyama City, formerly Matsuyama *Han*, a local area of the Edo period, he defamed his family name, *Masaoka* (former *samurai*). This failure to complete his degree is an early example Shiki facing and

confronting limits.

However, it was his incurable disease that became the fatal limit for him, as evidenced by his last two published essays both named after his literary and physical limitations, *Bokuju Itteki* [*A Drop of Ink*] and *Byosho Rokushaku* [*Six-foot Sickbed*].

So, as Beichman states (Beichman 1982: 60), "[By] this time Shiki made his statement, he seems to have adjusted to the limits of his world. The title of the diary itself, with its implication that his world was contained within the boundaries of a six-foot sickbed, would indicate as much, as does the title of the diary he had written the previous year, *A Drop of Ink*. Both suggested that he had scaled down his expectations to the point where they no longer created needless frustrations."

So, in his despair, it is likely that he would have considered suicide. However, no matter how hard he looked at his younger cousin, Fujino Kohaku, who had committed suicide, or some acquaintances - the first one of which was Shimizu Noritoo, who died at the age of seventeen, Shiki's university roommate for whom he had served as a chief mourner on behalf of Shimizu's father in distant Matsuyama - who died without being able to commit suicide, Shiki could not kill himself.

2.2 Suicidal impulse and acceptance of suffering

However, Shiki must have had no desire to commit suicide, though he had thought of it. In a famous description dated October 13th, 1901, in *Gyoga Manroku*, he writes with tears that he had nearly succumbed to a suicidal urge, but he could not die because of the suspected pain before his own death; it wasn't that he decided not to die, but rather felt he was unable to die. This description is memorable:

The house had become silent. Now I was alone. Lying on my left side, I stared at the writing set before me. Four or five worn-out brushes and a thermometer and on top of them, lying quite exposed, a blunt little knife a couple of inches long and a two-inch eyeleteer. The suicidal feeling that sometimes sweeps over me even when I

am not in such a state suddenly surged up. The thought had already flashed through my head while I was writing the telegram message

But I could hardly kill myself with that blunt little knife or the eyeleteer. I knew a razor was in the next room if I could only get there. Once I had a razor, cutting my throat would be no problem, but sad to say, I can't even crawl now. If no other way existed, cutting my windpipe with the little knife would not be impossible. Or I could pierce a hole in my heart with the eyeleteer. I could certainly kill myself in that way, but I wondered if I would die immediately if I drilled three or four holes.

I thought over every possibility, but to tell the truth, fear won out, and in the end, I couldn't bring myself to do it. I wasn't afraid of death, but of the pain. I thought that if I found the pain of my sickness unbearable, how much more horrible the pain would be if I botched my suicide. But that was not all. When I looked at the knife, I felt something like a current of fear flowing from it and welling up inside me. (Translated by Keene, Keene 1998: 370-371. Omission, paragraphing and emphasis by research author)

At the end of his diary, Shiki drew pictures of the knife and the eyeleteer, and wrote four Chinese letters 古白曰来 [*Kohaku iwaku* 'kitare,' *Kohaku* calls to come]. The Voice of *Kohaku* from hell tormented Shiki. *Kohaku* tried to kill himself with a pistol seven years ago, but he could not die for days in a hopeless situation. Also, in the next year, the last months of his life, he often expressed his desire to die. Unable to commit suicide, because he lacked the ability to do so, Shiki, it seems, wanted some form of assisted suicide. From June 19th to 22nd (newspaper dates), 1902, Shiki wrote these consecutive essays (*Byosho Rokushaku*):

No. 38 (June 19th)

[Written in the old style of Japanese (4)]
Here is a patient. He is in so much pain and weak to the point that he can hardly move. His mind is confused and can't read books or newspapers because his eyes are

crumbling. Even worse, writing a sentence with a brush can never be done. So, there are neither nurses nor visitors to talk to. How can he spend his day? How can he spend his day?

No. 39 (June 20th)

When I took to my sickbed, as long as I could still move, I didn't find my sickness too hard to endure, and I lay there quite serenely. But when, as of late, I have become unable even to stir, I am prey to mental anguish, and almost every day, I feel pain enough to drive me out of my mind.

I have tried my utmost to bear it, but I have reached the point where I can endure no more, and my patience is at last exhausted. A person who gets into such a state is no use for anything. Screams. Howls. More screams, more howling. I have no way to describe the pain, the agony. I think it would be easier if I turned into a real lunatic, but I can't even do that. If I could only die, that would be more welcome than anything else. But I cannot die and no one will kill me.

The suffering of the day is finally reduced at night, and when I am slightly drowsy, the pain of the day ends and the pain of the next day wakes up already. There is no time when it hurts as much as when waking up. Isn't there anyone to save me from this pain? Isn't there anyone to save me from this pain? (Paragraphing and emphasis by research author. See, Keene 1998: 368)

So, who can help Shiki? How about religious grace? Apparently not, as the following diary entry describes:

No. 40 (June 21st)

"How can I spend my day?" "Isn't there anyone to save me from this pain?" To get here, religious people will say that I have arrived at a religious issue. But for me who does not believe in religion, religion is useless. God's helping hand cannot reach those who do not believe in Christianity. For those who don't believe in Buddhism, it is impossible to spend the day repeating Buddhist prayers.

In the extreme, even my breath was dominated by the breaths of others and it became very painful. It has become much more difficult to harmonize with myself and my surroundings. When morphine is working well, this harmony is a little easier, but these days it no longer works. I fall into this kind of boundary.

If a compassionate soul comes to my bed and tells me something interesting, I will be grateful that it will save me some pain.

The only thing I want to refuse is a person who sits face to face and says nothing. (Omission, paragraphing by research author)

Because Shiki is “educated according to rationalist, Confucian principles” (Keene 1998: 368), religion could not bring comfort to him. Finally, he was also kept from speaking, as if being unable to write was bad enough.

No. 41 (June 22nd)

Today the suffering was severe.

I was administered morphine twice.

(Omission by research author. But in fact, it seems to be that, in the day like this, Shiki can hardly think of anything)

In these consecutive entries, it is apparent that Shiki was barely able to write no. 38 by himself. After that, he had to rely on dictation. And the pain was especially severe the day he wrote no. 41.

2.3 A letter from a religious person with lung disease

At that time, a letter was delivered to Shiki who suffered such a disease. He wrote in the same essay:

No. 42 (June 23rd)

When I got up this morning, I received a letter. It is from an anonymous sender in *Hongo* [Tokyo] and he is a stranger to me. This letter is roughly as follows:

Sincerely, I read your Byosho Rokushaku and felt something, so I'll give you some advice.

First, rest assured that the Heaven King or Nyorai are always with you.

Second, if you can't believe in the former, just be patient with your current situation, progress of the situation, leave it to pain, leave everything as it goes, leave Heaven and Earth and let everything appear and disappear to you because of the limit of human power.

Third, if you can do neither, cry in confusion, only to die.

Once I was on the verge of death, and inevitably bothered and confused about my body, I could get a mental rest by that second way. This was my saving grace, so I can't say that it will help relieve your pain or not. I beg you to try to think if your pain is a bit softer.

This kind, clear, and plain letter has caught my heart and my thoughts are almost completely covered.

However, in me, the mental illness is physiologically generated, and when I am in pain, I can't do anything. Even if it is physiologically worrying, there is no other way than to leave it to “the current progress.” There is no other way than crying, feeling annoyed, and dying at last.

But as long as it is a physical pain, when it is mild, I can't give up but say that there is no means of comfort. When it comes to advanced pain, I can't just be comfortable, but I feel like I can't give up. Probably, I can still not give up.

Even if I was lying on the sick-bed year round, day and night and always enjoy looking up even at a *bonsai* tree that is three-shaku [3 ft.] high, when I was a little distressed by morphine, I want to laugh at myself who was bothered a while ago.

If I knew that I was the same person when I laughed, those who laugh at my annoyance would all be laughed at by me if each changed their position and could not escape. Having a hearty laugh. (Written on June 21st (5) (Omission, paragraphing and emphasis by research author)

The sender of this letter is probably Kiyozawa Manshi, a reformer of *Jodo-Shinshu*

[Buddhism] during the Meiji era. Kiyozawa's disciple Akegarasu Haya studied and composed haiku and tanka under Shiki at the same time. In addition, Kiyozawa had shown his respect for Shiki's works for several years. Kiyozawa noted Shiki's huge appetite, which was mentioned in Shiki's later essays. Shiki's gluttony was one way to cope with his lung disease. One medical scientist Fujimoto Shigefumi, President of Sendai Aoba Gakuin Junior College, speculates that Shiki ate more than 3000 or 4000 kilo calories a day (cf. Fujimura 2011: 56). The anonymous letter was supposed to be sent to Shiki, to encourage him. Of the three ways to be saved from suffering, Kiyozawa recommends the second. However, Shiki is most sympathetic with the third suggestion, "Cry in confusion, only to die." It seems that Shiki could live only this way, as Shiki's own *satori* [enlightenment, epiphany].

2.4 *Satori* for Shiki himself

Before this letter, Kiyozawa was asked by another disciple, Ando Shuichi, "What do you think about the *satori* of Masaoka Shiki's thinking?" (cf. Ando 1904) Kiyozawa praised Shiki's view of *satori*. This actual conversation between a master and a pupil was triggered by a famous essay of Shiki, an excerpt of which follows:

Up to now, I have always misunderstood the *satori* of Zen. I mistakenly supposed that *satori* was a way of dying in a tranquil state, regardless of the circumstances, but *satori* is actually how to live in a tranquil manner, regardless of the circumstances.

(*Byosho Rokushaku*, no. 21, June 2nd in 1902. Translated by Keene, Keene 2013: 232, note 27. Originally *Shiki Zenshu* XI: 261)

Although Shiki had little good to say about religion per se, he did express a kind of affinity for *satori* in Zen. However, this *satori*, in the sense Shiki describes it, is, as Blyth says (Blyth 1964: 21, and in the Preface of this article), different from religion, pantheism, mysticism, and Zen; instead, it is related to '*kaigyaku*.'

2.5 *Jisei* [farewell/resignation haiku]

Shiki wrote three *haiku* as his *jisei* on the day

before his death. The first of them is the most relevant for this article.

hechima saite
tan no tsumarishi
hotoke kana

[The sponge gourd has bloomed;
See the Buddha
Stuffed with phlegm]

(Translated by Keene, Keene 2013: 188)

糸瓜咲て痰のつまりし佛かな

During this time, near the end of life, Ritsu and disciple Hekigoto both supported Shiki in his writing. In later years, Hekigoto recalled that Shiki was out of breath as he wrote three verses, including this first one with his brush. The final state of Shiki, which Hekigoto describes in his *Shiki no Kaiso* [*Reminiscence of Shiki*], is very touching. As many critics have explained, it is strange that Shiki compares the dying self here to a Buddha (in old Japanese grammar, 'shi' of 'tsumarishi' is an auxiliary verb of the past tense in the first person). The Japanese word '*hotoke*' can also stand for 'corpse,' but his intended meaning is not necessarily religious because religious figures or divinities such as the Buddha or God do not struggle, suffer or die.

Here, Shiki is about to die. In Japanese custom, it is said that water of the *hechima* soothes the throat of a sick person, but it actually does not work. It is too late. Like the old proverb '*yamai koumou [koukou] ni iru*' [When the disease spreads too far, it is no longer curable]. However, even as he was dying, Shiki looked at himself objectively, even portraying himself humorously. His sense of humor, *kaigyaku*, is what Shiki had consistently, as he could not help but laugh at his tormented self (See, No. 42 of *Byosho Rokushaku*, and above, 2.2 of this article). Shiki eventually died, but he did so by retaining his essential character.

Conclusion: Pain, Care, and Thanks

As he was the patriarch and sole earner of his own house, Shiki was also the patriarch of the literary association with his name *Hototogisu*. As well, he was surrounded by many disciples and shared a fraternal bond with many of them.

However, during the years leading up to

his death, Natsume Soseki, the most famous writer in modern Japanese literature, and Shiki's lifelong friend, was in London, so Shiki could not meet with him. Shiki wrote several letters and confessed his deep sadness and despair, which he could tell only to his friend. Shiki himself was aware of his impending death, and the surroundings he starkly describes express this awareness. His last days and last creations, including three *jisei haiku*, were composed when he was no longer able to speak well enough, so people who cared for him could not know his last words. However, he gave them a lot, and they returned the favor; Shiki must have been grateful for all the things that he was given.

Swiss-American psychiatrist Elizabeth Kübler-Ross mentions a poem as an example of the last stage in her five-stage model of encountering dying: 'acceptance' (cf. Kübler-Ross 1969). The poem, translated from Bengali to English by the poet himself, was written by Rabindranath Tagore (1861-1941), winner of the Nobel Prize for Literature, in 1913, and the first such winner who hailed from Asia:

I have got my leave. Bid me farewell, my brothers! I bow to you all and take my departure.

Here I give back the keys of my door - and I give up all claims to my house. I only ask for last kind words from you.

We were neighbours for long, but I received more than I could give. Now the day has dawned and the lamp that lit my dark corner is out. A summons has come and I am ready for my journey. (*Gitanjali*, 93)

Tagore's poem aptly expresses how Shiki must have felt: acceptance of his impending death.

Let us conclude this article with Shiki's own words. The *jisei* [farewell] haiku has already been mentioned, and the following are some lines from his last essay, "The Morning of September 14th." It was written five days before his death and published in "*Hototogisu*" magazine, dated September 20th, 1902, a day after his death, with a note stating that "Shiki died; he made a distant trip at 1 am." In prose, Shiki adds his own description:

My condition suddenly worsened from 4, 5 days ago; although from before my legs that had been hardly able to move, suddenly swollen like water, I can't move at all.

Until now, I have suffered from various pains, but this is the first time I have experienced such pains. Therefore, for the past few days, my hospital room has become a kind of disturbing atmosphere due to my suffering, the hustle and bustle of my house and my friends coming to visit.

.... When I woke up this morning, my feet remained the same as the previous day, but my mind was very calm, probably because I had a good night's sleep only last night different from usual. Although my face was slightly southward, I was unable to move it at all, but I looked quietly outside the glass *shoji* [window]. [Looking to cloudy silent sky, *yoshizu* [reed screen], about 10 fruits and a few flowers of *hechima*, *ominaeshi* [golden lace], *keitou* [cockscorn], *shukaidou* [begonia]] Since I got sick, I have never seen this garden as quietly with a peaceful heart as this morning. [Talking with Kyoshi, hearing a voice of an about 6-year old child living in a house opposite south, reading a textbook, and a *natto* seller comes to Shiki's house in the back of the alley, so asked to buy because of contributing sales; actually he didn't want it much....].

.... When I talk with Kyoshi about the morning at Suma [where Kyoshi went to visit when Shiki's condition worsened enough to die, in 1895], the *hechima* leaves fluctuate one by one as if they had fallen, even by dew. Every time, the coolness of autumn seemed to permeate my skin, and it was a good feeling. It seemed strange that I felt so painful that I didn't feel sick for a while, so I wanted to write it in a sentence and spell it with my mouth. I asked Kyoshi to write it down. (Cf. *Shiki Zenshu* XII: 570-572. Omission, paraphrasing and emphasis by research author)

It may not have been romantic, but this saved moment before his final moments was characterized by a tranquility after his long journey of suffering from tuberculosis and spinal

caries. We know that Shiki's death was possible only with his essential character, and with care of those around him.

Document

Morphine Administration Record (by Shiki himself, in *Gyoga Manroku*, II, cf. *Shiki Zenshu* XXI: 489-493).

Period: 1. From March 10th to 12th, 1902.

Period: 2.-3. From June 20th to July 29th, 1902.

1. March, 1902

10 th 8:40 am	11 th 1:30 pm, past 11 pm	12 th Noon
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2. June, 1902

20 th Noon, 9 pm	21 st 5:45 pm	22 nd 9:05 am
23 rd 2:15 am	24 th 9 am, 6:20 pm	25 th 8:35 pm
26 th 8 am	27 th 6 am, 10 pm, 37.8 C (body temperature)	28 th 10:20 am, 8:25 pm
29 th 9 am	30 th 9 am, 37.2 C	

3. July, 1902

1 st 8:30 am, 5:25 pm	2 nd 8:30 am, 7:15 pm	3 rd 7 am, 3:30 pm
4 th past 4 am, 4 pm	5 th past 7 am, 7 pm	6 th around 8 am, ar. 7 pm
7 th 8:30 am, pm (lack of time)	8 th 7:30 am, 5:30 pm	9 th 9:15 am
10 th not drunk	11 th twice (lack of times)	12 th 8 am, 4:40 pm
13 th 4 am, past 3 pm	14 th 2 am, 3 pm	15 th 2 am, 1:30 pm, 9:30 pm*
16 th 0:35 pm	17 th 1 am, 0:30 pm, 8:30 pm*	18 th 9:30 am, 5:30 pm
19 th 9 am	20 th not drunk	21 st 10 am
22 nd 9:30 am	23 rd 10 pm	29 th 10:35 am

(From 24th to 28th, no record)

* He drank three times despite the doctor's limit of twice a day. Perhaps he and others were guilty of it, but judging from current standards, we can appreciate that he increased the medication rather than to suffer from unbearable pain.

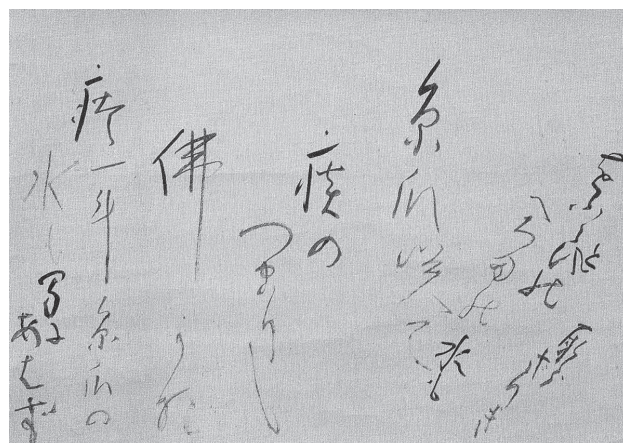


figure 1

Shiki's autograph of three haiku as his *jisei*, written on 18th September, 1902, just a half day before his death (from right to left, 4th-7th lines: 糸瓜咲て [*hechima saite*] 痰の [*tan no*] つまりし [*tsumarishi*] 佛可奈 [*hotoke kana*])

Endnotes

- 1 Fusetsu was Shiki's very important friend, who had learned from *Asai Chu*, one of the leading Western-style painters of the Meiji era at the government-run *Kobu Bijutsu Gakko* (Technical School of Art, established in 1876). Also, a famous writer and doctor Mori Ogai praised Fusetsu, and it is known that Mori requested Fusetsu write the calligraphy inscribed on his own (Ogai's) grave.
- 2 Even Tsurugaya, an excellent researcher and translator of Chomin, admits that "Certainly, the depth of the shadow of death in Shiki's final essays *Gyoga Manroku*, *Bokuju Itteki* and *Byosho Rokushaku* elevate them above Chomin's *Ichinen Yu-han*..." (Tsurugaya's explanation; see, Chomin 1995: 317-323, especially 322-323). In addition, Tsurugaya praises Shiki's final essay "The Morning of September 14th" as it evokes feelings of "clear tranquility and peace" (his explanation; Chomin 1995: 322-323).
- 3 In describing these three *haiku* of the *jisei*, a famous haiku poet Yamamoto Kenkichi (see, Yamamoto 1962: 36) praised them, stating that "[they are] complete final words and also singing," "It can be said that his life as haiku poet is to get these three phrases." These are generally highly acclaimed as Shiki's masterpieces. I agree with these opinions. Ironically, the one exception was Shiki's gifted disciple, Kyoshi, who gave the last works of Shiki a low rating. Kyoshi wrote, "I don't think these *haiku* of the *jisei* are as good

as Shiki's [other] works, and I think that they are not particularly good enough to represent Shiki's objective attitude towards life" (Naito et al. 1916: 42. Emphasis by research author).

- 4 Like many other languages, Japanese has two styles of writing: the old style or written language was used mainly until about 1900s (Meiji 30s), some years after the death of Shiki. Shiki is the person who introduced a new style of Japanese writing which expresses spoken language. Because Shiki, in his last years, could not use the pen (Japanese brush) well enough, he had others (mostly his sister Ritsu, or disciples (Kyoshi, Hekigoto, and others) write down his spoken words. With his rich knowledge of Chinese and old Japanese, Shiki became one of the best writers of his era. His supervising manager, Kuga Katsunan, President of the Newspaper Nippon; his uncle Kato Takusen; his elder friend, Mori Ogai, are also such people, deserving of the title of experts.
- 5 Noted by Shiki himself. This date of writing is different from the newspaper date and is a message to the sender of that letter, Kiyozawa, although Shiki pretends not to know in the text.

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