

〔実践報告〕

UCLAメディカルセンターでの研修報告： 出生前検査の提供に関するカリフォルニアと日本との違い

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Practical report of nursing exchange program in UCLA Medical Center:
The differences in access to prenatal testing between California and Japan

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要 旨

私は2017年9月に千葉大学大学院看護学研究科とUCLAメディカルセンターが行うアメリカの看護を学ぶ研修に参加した。そこでの私の目的は、UCLAメディカルセンターでの出生前検査の在り方と職種間連携について学ぶことであった。本著では、日本での出生前検査の現状と異なる三点について論じる。まず1つめに、UCLAメディカルセンターでは妊娠初期に全妊婦がカリフォルニア州の出生前スクリーニングプログラムについて情報提供され、ほとんどの妊婦が何らかのスクリーニングや出生前診断を受けていた。2つめに、アメリカは日本より医療専門職の種類が多く、それぞれの専門性も高かった。またそれらの専門職は独立して妊婦やその家族に対する意思決定支援を行い、その情報は電子カルテで他職種に共有され、互いに連携がはかられていた。3つめに、アメリカは対象となる妊婦の人種や経済的背景、宗教などの個別性が大きかった。カリフォルニア州ではメディカルと呼ばれる公的な医療保険制度があり、それに認定された低所得世帯はこの制度を利用して、出生前スクリーニングやそれに付随する支援を無料で受けることができた。またインフォームドコンセントを得る際に、英語を話さない患者には公的な通訳サービスを用い、自律的な意思決定ができるよう配慮されていた。諸外国と比べ、日本の出生前検査の普及率はとても低い。しかし近年、妊娠中に胎児の情報を得たいというニーズは増加している。また胎児期に出生前検査によって得られる胎児の状態も増えている。そのため看護職が出生前検査の情報提供に関わることが求められている。妊婦の出生前検査に関するインフォームドコンセントや意思決定を支えるには、看護職の更なる役割の高度化や連携が必要であると考えた。

Key Words：出生前検査，出生前スクリーニング，UCLA，意思決定支援，医療専門職連携

Abstract

A nurse exchange program between Chiba University Graduate School of Nursing and UCLA Medical Center was conducted in September 2017. The purpose of my participation in this exchange program was to learn how prenatal screening or diagnosis is offered and how inter-professional occurs cooperation in UCLA Medical Center. There were three major differences between testing in UCLA Medical Center and Japan. First, the implementation rate of prenatal screenings in UCLA Medical Center was higher than in Japan. All pregnant women were offered the opportunity to enter the program in the California Prenatal Screening Program at the early stage of pregnancy. Secondly, the healthcare staff at UCLA Medical Center was generally more diverse and specialized professionally when compared to Japan. Each healthcare professional supported pregnant women and their families' decision-making and shared information related to prenatal tests were shared among all involved experts by using electronic medical records. Lastly, the American population features a broad spectrum of socioeconomic and ethnic backgrounds. The California public insurance (Medi-Cal) covers the cost of prenatal screening program for registered low income patients. When giving informed consent, standardized translational service is used so that pregnant women autonomously make a decision. Although fewer prenatal screening or diagnosis is performed in Japan compared to other countries, the number of pregnant women requesting these screenings to detect fetal abnormalities is increasing. Furthermore, the range of conditions identified by genetic variants during pregnancy is expanding. Finally nurses and midwives should become more active in supporting pregnant women's decision-making. More advanced qualification and practical cooperation among Japanese nursing professions are needed to support informed decision-making regarding prenatal testing.

Key Words : prenatal testing, prenatal screenings, UCLA Medical Center, decision-making support, cooperation of healthcare professionals

I Introduction

Over the past 20 years, prenatal screening has become widespread in the world¹⁾. In Japan, the number of prenatal screening was much smaller than in other countries. A survey showed prenatal testing (screening followed by diagnosis) was performed in fewer than 3% of all pregnancies in 2008²⁾. However, the recent availability of Non-Invasive Prenatal Testing (NIPT) in 2013 generated a steady increase in demand for prenatal testing among Japanese pregnant women^{3) 4)}, which also increased the risk of poorly informed decision-making^{5) 6)}.

Chiba University Graduate School of Nursing has performed a Nurse Exchange Program with University of California, Los Angeles (UCLA) Medical Center since 1993. In 2017, the program was held on September 18th to 22nd. It was a precious opportunity to learn about how prenatal testing was offered in the USA. My purpose was to learn about prenatal testing and the support to pregnant women and their families provided by cooperating healthcare professionals in UCLA Medical Center. The

perinatal Unit Director of nursing selected departments at UCLA Medical Center or affiliated hospitals for me to compare access to prenatal screening or diagnosis in Japan and the USA. These institutions are listed in Table 1.

II Findings of offering prenatal screenings and diagnoses in UCLA Medical Center

1. Access to prenatal screening in UCLA Medical Center and Japan

There were some differences regarding prenatal screenings between UCLA Medical Center and Japan.

The Table 2 shows prenatal testing options in UCLA Medical Center. Most pregnant women in there accepted screenings from the end of the first trimester. The American College of Obstetrics and Gynecologists (ACOG) published guidelines recommending screening for all women regardless of age in 2007^{7) 8)}. Then, in 2009, the California State Genetic Disease Branch introduced a state-wide prenatal screening program⁷⁾. This program aims to ensure that prenatal screening services and

Table1. Insitutions visited during the program

Institutions	Learning contents
Ronald Reagan UCLA Medical Center: Outpatient clinic, Birth place	Genetic counseling by Genetic Counselor, Prenatal check up by CNM*3
OBGYN*1 at West Medical (Westwood) : Medi-Cal (state insured) accepted	Family planning, STD*4 treatment, D&C*5 caring and patient education by RN*6
UCLA Medical Center, Santa Monica: Birth place, High risk OB*2 clinic	High-risk pregnancy care by NP*7, Maternal Fetal Medicine by a physician

*1OBGYN: Obstetrics and Gynecology, *2OB: Obstetrics, *3CNM: Certified Nurse-Midwives,

*4STD: Sexually Transmitted Disease, *5D&C: Dilation and Curettage, *6RN: Registered Nurse,

*7NP: Nurse Practitioner

**Table2. Prenatal genetic risk assessment and testing options in UCLA
(Modified after UCLA David Geffen School of Medicine)**

		Ultrasound	California Prenatal Screening Program	NIPT	Diagnostic testing	Carrier screening
GENETIC SCREENING AND TESTING OPTIONS	1st Trimester	Nucal translucency [11-14weeks]	1st Trimester Screening [11weeks 2days-13weeks 6days] PAPP-A&HCG1 Trisomy 21, 18	>9weeks Trisomy 21, 18, 13, Monosomy X, Triploidy, gender [microdeletions]	Chorionic Villus sampling (CVS) Chromosome analysis, Microarray, -Miscarriage -Mosaicism	-Cystic fibrosis -spinal muscular atrophy -Sickle cell -Thalassemia -Ashkenazi Jewish panel
	2nd Trimester	Complete anatomy [18-22weeks]	2nd Trimester Screening [15-20 weeks] AFP, HCG, uE3, INH Trisomy 21,18, SLOS, Spina bifida		Amniocentesis chromosome analysis, AF-AFP, Microarray, -Miscarriage	

follow-up diagnostic services are available to all pregnant women in California. For women with screening results indicating a high risk of a birth defect, the program provides free follow-up diagnostic services. Participation in the testing and follow-up services is voluntary⁹⁾. During the early stage of pregnancy, all pregnant women were informed about the prenatal screening program. Subsequently, pregnant women have the right to decline participation. Genetic counseling is available to women who show high risk of chromosome abnormalities such as advanced maternal age or family history. Invasive procedures (amniocentesis and chorionic villus sampling) are covered by public or private insurance⁹⁾. Low income households have access to state insurance Medi-Cal⁷⁾¹⁰⁾. Medi-Cal covers medical expenses including prenatal screening or genetic counseling for high risk patients. For others, the cost incurred for genetic counseling or prenatal diagnosis varies depending on

insurance coverage. All pregnant women were offered participation in the California Prenatal Screening Program. They are able to decide which test they choose, using genetic counseling or other resources as reference.

In Japan, there is no governmental law ruling availability of prenatal screening or diagnosis. As a result, an expert committee including members of Japan Society of Obstetrics and Gynecology (JSOG) made the decision to not recommend the use of maternal serum marker screenings¹¹⁾. Therefore, prenatal screening or diagnosis options differ according to areas and institutions in Japan. Therefore, not all pregnant women are offered prenatal screenings such as serum screening or Nuchal Translucency (NT) measurement during first and second trimesters. However ultrasound checkups are not considered prenatal genetic screenings, and are performed routinely without requiring consent¹²⁾¹³⁾. Regarding the cost, the lack of governmental support prevents public or

private insurance from covering the expenses for prenatal screening or genetic counseling. Japanese pregnant women need to pay for their own tests if they want to undergo prenatal screening, diagnosis or genetic counseling. In Japan, prenatal testing is less accessible than at UCLA Medical Center.

2. Specialization of healthcare professionals

In the USA, the diversity of healthcare professions is higher than in Japan. For example, Registered Nurses (RNs), Nurse Practitioners (NPs), Clinical Nurse Specialists (CNSs), Certified Nurse Midwives (CNMs) commonly collaborated at UCLA Medical Center and affiliated hospitals. Not only physicians but also CNMs and NPs can order prenatal screenings and tell women the result of the tests in case of normal result. In case of abnormal result, they can introduce the patient to a genetic counsellor, an Obstetrics and Gynecology physician or a Maternal-Fetal Medicine (MFM) specialist. Then, the information about the nature of counseling and the test result are shared among all healthcare professionals by means of electronic medical records. In UCLA, nurses or midwives are able to function independently for prenatal checkups, patient education, medication, or follow-up of surgery. Routine procedures, such as examination by interview, measurement of vital signs, urine tests, room cleaning and preparation before prenatal checkups are usually performed by Medical assistants. In Japan, NPs and CNSs started in the past several decades, and the population is still small. Nurses including NPs and CNSs, and midwives cannot order screenings nor prescribe a medicine without a doctor's prescription. Japanese NPs and CNSs are referred to 'koudo na kango' which means as 'advanced nurse', however their responsibilities are no different from those of nurses and midwives in practice. They mostly have similar duties as American RNs and CNMs, they are also in charge of routine procedures usually assumed by American Medical assistants. The role of each nursing profession is therefore more ambiguous in Japan than the USA.

Besides, access to prenatal testing usually

involves specialized professionals in UCLA Medical Center. Genetic counselors are in each clinical department. Genetic counseling was available for pregnant women and their families when they needed it. Genetic counselors also could order prenatal screenings or invasive tests. Results were disclosed by the healthcare professional who ordered it. In most normal cases, genetic counselors informed patients by e-mail or telephone instantly. In Japan, there are 226 certified genetic counselors as of 2017¹⁴⁾ and most of them belong to a limited number of larger hospitals. Therefore, pregnant women who wish for a consultation with a genetic counselor need to go to the nearest hospital where a genetic counselor is available. A first difference between the USA and Japan is that genetic counselors were rarely involved before amniocentesis in Japan⁶⁾. Most information about the invasive diagnosis was provided by local doctors⁶⁾. Another different point was that Japanese nurses and genetic counselors are unable to order tests and communicate their results without a doctor's prescription.

3. Diversity of ethnic and socioeconomic groups

In the USA, society is composed of various ethnic groups and healthcare providers need to consider each patient's background. A Video Tele-Interpretation system was officially used for non-English speakers at no cost. This is a translation and interpretation system using the TV phone, available through partnership with the healthcare interpreter network. It allows face-to-face interaction ensuring high quality and timely patient care¹⁵⁾. To obtain official informed consent, the system must be used by non-English speakers so as to avoid misunderstanding. In California, this system is used within 30 hospitals¹⁵⁾. In Japan, hospitals have various ways to provide translational services. Standardized translational services are rare and generally provided by volunteer or patients' families.

As for the cost, medical care including prenatal testing for low income patients was fully covered by Medi-Cal in California⁷⁾¹⁰⁾. On the other hand, all prenatal screenings and

invasive procedures are not covered by insurance in Japan. Therefore, low income patients cannot undergo expensive prenatal testing.

As for chromosome analysis, carrier screenings, such as for thalassemia, cystic fibrosis, sickle cell or other genetic diseases are performed in the USA more than in Japan. The purpose of carrier screening is to screen one or few genetic variants in targeted populations. In the USA, the number of fetal carrier screening during pregnancy is increasing¹⁶⁾. Genetic counselors order them and target specific conditions depending on patient's race because the risk of carrying the diseases is different according to ethnicity. In Japan, the main reasons to undergo amniocentesis are advanced maternal age which accounts for over half of the procedures, abnormal results of maternal serum screening, and ultrasound findings¹⁷⁾. Because Japan is a mostly mono racial nation, and the Japanese population does not usually carry the conditions targeted by carrier screenings, these screening are not common in general amniocenteses.

III Discussion

In UCLA Medical Center, a large number of pregnant women underwent prenatal screenings, and specialized healthcare professions facilitated women's decision-making regarding prenatal testing.

From the point of view of historical difference, ACOG recommended not only screening tests but also invasive diagnostic testing to be available to all women regardless of maternal age in 2007^{7) 8)}. Consequently, the California State introduced the prenatal screening program. On the other hand, JSOG and the expert committee did not support the implementation of prenatal testing.

Regarding the termination of pregnancy, the US Supreme Court confirmed that women's right to choose an abortion was protected by the US constitution in 1973 (Roe v. Wade)¹⁸⁾. In Japan, the Eugenic Protection Law established in 1948 to prevent the birth of inferior descendants was changed to the

Maternal Protection Law in 1996 to protect the lives and health of pregnant women. Organizations advocating for handicapped persons took the lead against the eugenic¹⁹⁾.

According to the Maternal Protection Law, abortion is possible in case of pregnancy resulting from rape or when the pregnancy may significantly damage the woman's health or cause her distress for economic reason. Abortion due to fetal abnormalities is not included in the conditions covered by the law. Nishiyama et al. mentioned two reasons deterring pregnant women from receiving prenatal testing: one is a 1999 statement by the expert committee and JSOG not recommending prenatal screening, and another is the absence of legal permit for abortions due to fetal abnormalities⁶⁾. In addition, some disability organizations feel that aborting fetuses for fetal abnormalities may be similar to eugenics, owing to the connection between the Maternal Protection Law and to the Eugenic Protection Law in the past.

Tsai et al. showed that cultural factors such as lack of available resources (medical support, financial support, or emotional support), social pressure and stigma influenced attitude toward prenatal testing and abortion among the Asian population²⁰⁾. Therefore, more individually tailored support is needed for autonomous decision-making regarding prenatal testing. There is also possibility of unequal access to genetic counseling and prenatal testing due to its high cost and availability in Japan. Only wealthy families can access prenatal tests, in the present situation. Furthermore, limited recognition of the importance of genetic counseling among obstetric professionals is a concern in Japan⁶⁾ as women do not have the means to informed decision-making. At present prenatal screening is not recommended, however it is increasingly demanded by Japanese pregnant women³⁾ and has potential to expand the spectrum of detectable conditions thanks to recent technological advances^{16) 21)}. Expanded carrier screening allows for identification of a greater number of genetic changes and conditions without limitation to

specific ethnic groups¹⁶⁾. This would allow screening for hearing impairment or color-vision deficiency that are more common in the mostly mono-racial Japanese population. Ames et al. mentioned that decision of whether to accept screening resides with the individual and it is therefore important that the decision is informed, based on correct knowledge and free of coercion from others.²²⁾ Not only doctors should share the role of supporting pregnant women and their family's decision-making about prenatal testing. In Japan, nurses and midwives assume the role of interacting and connecting with patients. Thus nurses and midwives in Japan should play a more active role in supporting pregnant women's decision-making. Allowing them to shoulder more diverse responsibilities, like in the USA, in response to the increasingly accessible commercial genetic screening.

IV Conclusion

UCLA Medical Center is technologically advanced regarding prenatal genetic testing. High implementation rates and larger range of tests were supported by specialized healthcare professionals. In Japan, more qualified nurses and midwives are needed to inform women's decision-making. Distinguishing between health providers who manage routine procedures like American Medical assistants, and those who have high qualification like CNSs or NPs is desirable. It is also important for nurses and midwives to recognize that they should generally be more aware of being the first contact to pregnant women and their interface with prenatal care. There are many differences between prenatal testing in the USA and Japan regarding health services, law, history, culture, ethnic groups, and financial affairs. Overall, prenatal testing is more accessible in the USA. Changes are needed to improve access to screening in Japan. Such changes may include the recognition of the qualifications of 'advanced nurses' and a better definition of the responsibilities of each respective nursing profession towards the promotion of informed decision-making regarding prenatal testing.

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VI Declaration of interest

The author reports no conflicts of interest.

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