

## 変化する健康の概念と教育

### —当事者主体の参加モデルの構築に向けて



研究ノート

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Changing health, changing education: Towards participatory models of action

Key Words : Health, Education, Prevention, Participant-centric, Rare disease

#### <日本語要約>

教育と健康は私たちの社会生活の根幹を成す2つの要素です。グローバル化、人口動態の変化、持続可能な発展への懸念、情報技術と人工知能の進歩は、教育と健康の分野において新たな課題と可能性を生み出しています。ここでは、社会変化に対応する当事者参加型モデルの作成を通して健康の概念と健康教育の見直しを行うために、現在私が関与している2つのプロジェクトを概説します。

1つ目は学校における予防と健康教育です。  
2つ目は、医学研究および医療出版における当事者（主に患者）主体の参加モデル（Participant-centric Initiatives : PCI）の創設への取り組みです。

#### <学校における予防と健康教育、ヘルスプロモーション>

WHOは1986年のオタワ憲章において、人々が自らの健康をコントロールし、改善することができるようにすることを目指す「ヘルスプロモーション」の理念を示しました。こんにちでは教育と健康が密接に関係していることが明らかになっており、ヘルスプロモーションの場としての学校の役割はより重要なトピックになっています。健康状態と教育面に

おける成功との密接な関係のために、健康は、医学的な視点からだけでなく教育的な関心の対象として取り組むべきものになっています。健康状態が悪いと学習が阻害されます。まさしく、「良い健康は良い教育成果とつながっている」のです。

また、学校におけるヘルスプロモーションと健康教育は重要な倫理的・認識論的問題を投げかけます。すなわち、健康な人とは誰か？そもそも健康とは何か？それらを実施することで、か弱い人や健康でないと思なされた人たちが烙印を押されてしまわないだろうか？一部の人々は、健康教育を「健康ファシズム」と呼び、豊かな医療資源にアクセスできるエリートによる持たざる人々への価値観の押し付けであるとして批判すらしています。

私は4年以上に渡って、科学研究費補助金プロジェクト「EU諸国等における学校基盤の包括的健康教育カリキュラムの研究—地域と共同する学校」（基盤B:26301039）の一員として、ヘルスプロモーションとヘルシー・スクールの概念がどのように国や地域の政策、学校において解釈され、実践に取り入れられているか、フランス、カナダ、イギリス、ドイツ、スイス等の現地調査を通して明らかにしようとしてきました。



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同科研に関連して過去3年間、予防と健康教育に関する課題に対して専門家であるDidier Jourdan教授と共同で研究を行っています。Jourdan教授は現在、JSPS外国人招へい研究者プログラムにより、招へい教授として2か月間人間科学研究科に滞在中です。我々は、予防と健康教育に関する国際的な研究コンソーシアムを創設し、政策から学校における実践へ転換のための「翻訳プロセス」(Callon, 1986)の

プロジェクトを実施するための科研費を申請しました。また、Global Health and Educationのユネスコ・チェアとUNITWIN（大学間ネットワーク）プロジェクトにも取り組んでいます。既往の研究では、さまざまな文化や政策の場面で健康を尊重する学校の義務、健康教育カリキュラムの内容と構成（誰に、どのように、誰が、何を、どのように、いつ、誰に教えられるのか）、そしてコミュニティ・パートナーシップに関する課題と要件。また、ヘルスプロモーションと健康教育に関する広範な政策、カリキュラムへの組み込み方、学校での実践方法を観察しました。

### <当事者主体の参加モデルの創設 (PCI) >

私が取り組んでいる研究のもう1つの分野は、希少疾患患者のアドバカシーと、患者や介護者の生活の質 (QOL) を高めることです。私は希少疾患の領域、特に特定の希少疾患である遺伝性血管浮腫 (HAE) の分野で、患者に関わってきました。ここでは、患者/介護者、医師、産業界の間での平等なパートナーシップの創出を通じて、治療環境と疾患に対する知識と実践方法を向上することが最大の目的です。患者と医師の間の平等なパートナーシップの実現のため、患者団体の在り方を提言しました。臨床前の実験室レベルの研究から立ち上げまで、その薬が患者に適用可能であれば、「全体の医薬品開発プロセ

ス」に患者を巻き込んで薬の開発を行う動きが始まっています。例えば、研究範囲、研究デザイン、採用、安全監視、研究成果の普及（非専門家を含む）、臨床試験以外の環境での医薬品の使用経験を記述したモデルケースがあります。(Hoos et al, 2015)。一方、医療専門家以外の方が医療専門家とどのように協力できるかについて、倫理的かつ実践的な問題を含みます。これまでの医療研究に対する倫理審査では、患者が保護されているか、ということに焦点が当てられていました。しかし「保護」という焦点のみにすると患者のエイジェンシー（行為主体性）を妨害する恐れもあります。最新の概念では、研究に参加することによって患者がエンパワーされるか、ということも問われるようになっていきます。

### <おわりに>

ここでは2つの角度から健康という問題に取り組んでいる研究プロジェクトを紹介しました。1つは学校を対象とするヘルスプロモーションに関する研究。もう1つは一般的な定義では「健康を持っていない」希少疾患患者に関する研究です。両方とも、プロセスへの当事者の参加とエンパワーメント、そしてそれによって浮かび上がってくる倫理的、認識論的な問題に焦点が当てられています。私はこれらの現代的かつ意義深い研究に関わることができることに感謝しています。

## Changing health, changing education: Towards participatory models of action

### はじめに

Education and health are two institutions central to social life. Both face challenges in the 21<sup>st</sup> century around funding, mission and practice. Globalization, demographic changes, the so-called 'epidemiological turn', the extension of schooling, concerns about sustainable development, as well as advances in information technology and artificial intelligence, create new challenges and possibilities within the fields of education and health. In this short research note I will outline two projects that I am currently

involved in that are focused on innovation through the creation of participatory models of action. One is focused on health promotion and health education in school settings. The other concerns participant-centric initiatives (PCI) in medical research and medical publication.

### Health promotion

The World Health Organization defined health promotion in its Charter on the subject as 'the

process of enabling people to increase control over, and improve their health'. Here 'health is 'a resource for everyday life, not an objective of living' (WHO, 1986). As such, health is 'a positive concept emphasizing social and personal resources, as well as physical capacities' (WHO, 1986). Responsibility for health promotion lies not only with designated health professionals, but many other actors including schools and leaders in schools settings.

Schools, while tasked primarily with education, have always played a role in health especially around monitoring, prevention and hygiene. Today schools are regarded as important sites for health promotion and health education that takes a whole school approach. This takes into account social and physical settings, the ethos of the school, community partnerships and development of personal health schools or health literacy (see IUHPE, 2008). The legitimacy of schools as sites of health promotion is an important and sometimes controversial topic. Health can be framed as an educational concern due to the close relationship between health and education status. Poor health status can inhibit learning and 'good health is associated with positive educational outcomes' (Warwick, Mooney & Oliver, 2009).

Schools are also regarded as appropriate settings for health promotion and education due to universal reach. Programs and curriculums targeting compulsory years of schooling can reach most children and young people in a given population, where there is universal access. This, nevertheless, creates important epistemological and ethical issues about the status of the message and the means of implementation. Who or what are the models for good health and does this result in the stigmatization of those who are vulnerable or with poor health? Some regard health education as 'health fascism' imposing the values of an elite with a myriad of health resources on those less affluent with fewer resources (Fitzpatrick & Tanning, 2014).

There is evidence that those from affluent backgrounds benefit more from health education messages and skills training than those from deprived backgrounds (Marmot et al., 2010). As such, health education activities could exacerbate health inequalities and by extension educational inequalities if not sensitive to context and message. I have a personal interest in quality of life for people living with rare genetic diseases. Questions about how we create teaching and learning around health that is inclusive and respectful of those living with pre-existing health conditions is another issue that is of considerable importance.

Over the past four years I have been a member of a team carrying out a study (JSPS Grant-in-Aid for Scientific Research # 26301039) of how the health promotion and healthy schools concepts are translated into policy and practice at a country and/or provincial level. We have carried out fieldwork in, Canada (Ontario and Québec), England, Scotland, Switzerland (the Canton of Vaud), Germany, the Netherlands and France. In this project we have sought to better understand the mandate of schools regards health in different cultural and policy settings, as well the content and organization of health education curriculum (What is taught, by whom, how, when and to whom?), and issues and requirements around community partnership. We also asked questions about how broader policy around health promotion and health education, how it is incorporated into curriculums, and observed how it is practiced in schools. As a result of this process, we have begun to explore epistemological and ethical issues involved in knowledge creation and dissemination around health in educational settings. The results of this research will be disseminated in an English language publication co-edited by Professor Didier Jourdan, and myself. Professor Jourdan is a full professor at Blaise Pascal University in France. Former Dean and Vice President at his university, he also served as Director of the Prevention and

Health Promotion Division of the French National Public Health Agency and is one of European's leading experts in public health.

Over the past three years Professor Jourdan and I have been engaged in a productive collaboration on prevention and health education. As I write this research note, he is an invited professor at Osaka University under the JSPS Fellowship scheme. We have created an international research consortium on prevention and health education and applied for funding to carry out a major project on the translation process (Callon, 1986) from policy to practice in schools. We are also working together on the UNESCO Chair and UNITWIN Network on Global Health and Education. The twin aims of the Chair are to strengthen the relationship between universities, policy makers, practitioners and civil society and make a contribution to policy and practice development' in the field of global health education (Jourdan, 2017).

### Patient-centric initiatives

Another area of research I am engaged in is linked in with rare disease patient advocacy and enhancing the quality of life of patients and care givers. I have been involved directly in patient advocacy in the area of rare disease generally and especially in terms of one specific rare disease, Hereditary Angioedema (HAE). At the level of practice, a major goal is to improve treatment environments and knowledge creation through equal-partner engagements between patients/ care givers, physicians and industry. I have co-authored a paper with Dr Naomi Kitano, Senior Lecturer at Wakayama Medical University, where we theorize the transformative potential of patient advocacy organizations, arguing that they potentially create a space for the practice of equal partnership between patients and physicians without the contractual and symbolic constraints encountered in a clinical setting.

As a result of the practice of patient advocacy I have increasingly become involved in related research. For the past two years I have been collaborating with Professor Kazuto Kato, Department of Biomedical Ethics and Public Policy in the Graduate School of Medicine here at Osaka University to develop the Japanese version of a participant-centric patient registry called RUDY. This registry has been developed by a team led by Associate Professor Kassim Javaid at the Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, Medical Sciences Division, Oxford University. RUDY allows not only patient input of data on a real time basis, but also through the creation of a Patient Forum has allowed patients to lead in the development of the registry. We are now moving to create a Patient Forum for the Japanese RUDY and have high expectations of this kind of patient-centric tool.

In addition, Professor Kato and I are currently carrying out a scoping review (see Arksey & O'Malley, 2005) of participant-centric initiatives in medical research with Professor Jane Kaye and her team at HeLEX, University of Oxford. In the protocol that has been developed, Participant Centric Initiatives (PCI) are defined as 'tools, programs, and projects that empower participants to engage in the research process' using digital technologies (Anderson et al., 2012). PCIs take different forms but they all 'place patients and research participants at the centre of decision making, providing an interactive information technology (IT) interface to engage and communicate with participants' (Kaye et al., 2012). The reported outcomes of PCIs include improved quality and relevance of research outcomes, greater willingness of patients to be participants in research and increased retention; and improved healthcare delivery (Anderson et al., 2012; Kaye et al., 2012). The scoping review aims to identify the extent and range of PCIs that are designed to facilitate medical

research in three national settings: UK, USA and Japan

The emphasis on patient involvement and equal partnership in medical research goes beyond the research process itself. Recently, the British Medical Journal (BMJ) has created a 'patient-included' criteria for research and co-publication (see for example, Richards, et al, 201; Richards et al., 2014; Richards et al., 2015). We are at the beginning of a move to include patients over the 'entire medicines development pathway — from preclinical laboratory-based studies to launch, and beyond launch to ultimate withdrawal from the market — for as long as that medicine is available to patients. Examples are in research scoping, study designs, recruitment, safety monitoring, understanding, and dissemination of research results (including lay summaries for non-experts) and in describing their experiences with the use of medicines in settings outside of clinical trials' (Hoos et al, 2015). Nevertheless, involvement raises important ethical and practical questions about how non-medical experts can work with medical experts. It can also conflict with compliance regulations put in place to 'protect' patients. Depending on jurisdiction, compliance regulations can infantilize patients and result in their exclusion from the medicines development pathway and more generally in the production of knowledge in the field. Recently a conversation has started over the need to think beyond simple patient protection in the field of bioethics to include the question of whether the research process empowers the patient as a participant.

### 終わりに

I have introduced here two projects that approach the issue of health from two very different angles: one is concerned with a general population, school children, and the other on a very clearly defined population who by conventional definitions lack health, rare disease patients. Research is not only linked by the key word 'health', but also with

epistemological and ethical concerns, the role of key actors in processes that affect them in corporal as well as intellectual and emotional ways. Whether school children or rare disease patients the research explores ways for key actors to work together to achieve health in a dynamic sense of the word. I feel very privileged to be engaged in these two areas of work and to be able to work with co-researchers who are focused on improving health and the environment in which we make decisions about our health.

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