

【原 著】

# 慢性疾患患児に対する復学支援の研究動向

村上 理絵 大守 伊織

Trends in Research Concerning School Re-entry Support for Children with Chronic Illness

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原 著

## Trends in Research Concerning School Re-entry Support for Children with Chronic Illness

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The principle aim of the present study was to elucidate research trends and issues related to school re-entry. We reviewed past studies concerning school re-entry support for children with chronic illness. A total of 36 papers were analyzed for the keywords of "school re-entry," "support," "pediatric cancer," and "chronic illness." The results revealed that the concerns regarding the children and school re-entry support roles of legal guardians, healthcare providers, teachers, etc., and specific examples of collaboration with other occupations. "Guaranty a right to learn" and "relationship maintenance" were noted as issues, and ensuring a system that can establish certain learning opportunities even if the enrollment status of the child changes, continued maintenance of relationships of the patient before the onset of disease, and support to maintain the relationship of healthcare providers and teachers who are involved after onset of the disease are necessary even after school re-entry.

Keywords : school re-entry, support, chronic illness

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### I Introduction

Along with advances in medicine, as a result of the annual progress of cancer diagnostic and treatment technology, the relative survival rate of childhood cancer as a whole has gradually improved since 1993, and it has been indicated that the 5-year and 10-year relative survival rates are approximately 80% and 70%, respectively<sup>1)</sup>. This has increased the number of pediatric patients who after treatment, can return to their previous lives before onset of childhood cancer without dying. However, there is no systematic support system in place to ensure learning after school re-entry after discovery of the illness and provide support to maintain previous human relationships, which are currently performed only at the discretion of legal guardians, teachers of the original school and hospital school, healthcare providers, etc.

Children with chronic illness are separated from school life by being hospitalized for therapy and are forced to break their relationships with friends and teachers. Outside of the home, school is the place where children perform the majority of activities of daily living; issues such as

whether it is possible to continue relationships with friends and teachers after hospitalization as before and whether it is possible to keep up with studies are important issues that comprise the foundation of daily living of children. Moreover, childhood cancer also has late complications that affect growth, development, and secondary cancer, and there are late complications in which symptoms continue even after conclusion of treatment. Children who experience these issues or are repeatedly hospitalized for short periods of time need continuous long-term support depending on the individual situation, but no support system has been established. Ishida<sup>2)</sup> reported that the results of an employment status survey administered to 239 persons who had experienced childhood cancer (mean age: 24 years [16-42 years]) indicated that the unemployment rate was 16% (31 persons), which was influenced by late complications and school withdrawal; characteristics of persons who find it difficult to obtain employment were indicated to be lack of academic achievement, lack of social skills, loss of social and physical self-confidence, and low self-esteem. Thus, the disadvantages that arise as a result of being unable to receive sufficient support due to an insufficient support system affect the subsequently lives of children.

The present study focused on the need to improve school re-entry of children with chronic illness, and in view of issues such as enhancement of a support system and content, clarified research trends and related issues by summarizing past studies on school re-entry support.

## II Methods

Target literature was searched using CiNii and Ichushi Web Database Ver.5. The keywords were set as "school re-entry" and "support" and "childhood cancer" or "school re-entry" and "support" and "chronic illness." Because Hiraga et al.<sup>3)</sup> clarified trends in research on school re-entry support for children with childhood cancer until 2010, of the papers published after 2011, excluding those published in conference proceedings and papers published in academic papers, we analyzed 36 suitable papers.

In the analysis, as a first step, in order to understand the trends of research on chronic diseases, we analyzed focusing on year of publication, target disease, and paper type. As a second step, we attempted analysis by focusing on descriptions related to papers related to school re-entry of children with childhood cancer or chronic illness.

## III Results

### 1 Trends in the number and types of papers

An examination of publication year revealed that the number of papers

increased from 2014 to 2016. Because the literature search was performed in 2017, trends subsequent to the search were not examined. The types of papers of the search period were as follows: 5 review articles, 14 surveys, 11 reports, and 6 case studies; and there were more surveys and reports than case studies and review articles. The forms of the surveys were as follows: 6 questionnaire surveys, 4 semistructured interviews, 1 interview, 2 qualitative inductive studies, and 1 qualitative factor exploratory study. With regard to target disease, of the 28 cases with listing, cancer, including childhood cancer, was the most common (19 cases). The types of subject were as follows: 11 pediatric patients or former pediatric patients, 5 teachers or nursing teachers, 3 legal guardians, and 4 healthcare providers (22 in total; overlap present) (Table 1).

## 2 Trends in research seen by paper types

### (1) Review articles

Among the review articles, there were papers that examined the trends of research on the guaranty a right to learn in regular classes of children receiving treatment for illness, issues concerning school re-entry and nursing support, and the experiences of adolescents with chronic childhood illness and their parents<sup>3)~7)</sup>. All papers indicated that while the survival rate of children has increased due to medical advances, there are issues related to school re-entry following hospital discharge and various services. With regard to support and issues facing children with illness, legal guardians, healthcare providers, teachers, etc., confusion concerning school transfer, difficulties in procedures, delays in learning, estrangement with friends and teachers, response to classmates after school re-entry, response to infectious disease, and poor physical condition were shown from disease onset to hospitalization, before and after discharge, and at the time of school re-entry<sup>4)~7)</sup>. Ikari<sup>3)</sup> focused on the recent shortening of hospitalization and the progress of home medical care allowing pediatric patients to attend regular school, and reported the necessity of support for behavioral disorders such as refusal to attend school and psychosomatic disorders.

### (2) Surveys

Of the surveys, most studies examined the role of support for pediatric patients by legal guardians, physicians, nurses, teachers, nursing teachers, etc., with regard to school re-entry<sup>8)~14)</sup>. Regarding cooperation, various types of cooperation is made among legal guardians, doctors, healthcare providers, teachers, and nursing teachers upon school re-entry, but it

was indicated that in order to respond to the anxiety and difficulties of support experienced by teachers after school re-entry, healthcare providers need support to create direct collaboration with teachers<sup>8)</sup>. Regarding cooperation-related issues, although legal guardians, healthcare providers, and teachers cooperate, communication between healthcare providers and teachers is heavily dependent on legal guardians, and the burden of legal guardians was noted<sup>11)</sup>. Next, in a study that investigated the awareness of teachers and nursing teachers concerning illnesses, they investigated knowledge concerning illness, support for persons who have experienced the illness, and collaboration for providing support to children with illness<sup>15) ~ 18)</sup>. These findings indicate that teacher had little knowledge concerning the prognosis of childhood cancer, suggesting the necessity of obtaining knowledge concerning prognosis in supporting recovery<sup>17)</sup>. Regarding cooperation, a certain degree of cooperation was achieved and support was provided, but as seen from teachers, there were issues regarding the difficulty to understand the role of nurses as compared with physicians, the difficulty to cooperate with nurses, and the request for nurses to coordinate healthcare providers and the school<sup>15)16)</sup>. In addition, there were studies that attempted to support school re-entry through elucidation of the decision-making process and structure of resilience of pediatric patients and studies or clarification of how to disclose information about the self<sup>19) ~ 21)</sup>.

### (3) Reports

Among the reports, topics included current status of education and treatment of cancer patients in other countries<sup>22)23)</sup>, current situation and issues regarding guaranty a right to learn specialized for high school students<sup>24)25)</sup>, hospital schools, what sort of role NPOs and clinical psychotherapists play to support hospitalized children<sup>26) ~ 28)</sup>, current status of school re-entry support, key points for smooth school re-entry, and actual medical care and independence activities at schools for special needs education<sup>29) ~ 32)</sup>. In studies on adolescent/young adult cancer patients<sup>23)</sup>, measures taken already in other countries were given as examples, and the necessity of education and work programs in Japan and the problem related to school transfer were mentioned. Moreover, in Japan, because the school registration status of students is changed as a result of hospitalization, discussion on how to support hospital schools at the time of school re-entry and how to transmit information to the original school was discussed, suggesting that the creation and operation of individual educational support plans and individual guidance plans may solve the aforementioned

Table 1. Subjects and types of paper of each studies

Paper number	Subject	Subjects number	Disease	Types of paper
3		Chronic illness	Review	
4		Hospitalized for lengthy period	Review	
5		Childhood cancer	Review	
6		Chronic illness	Review	10
7		Chronic illness	Review	
8	Teacher	Childhood cancer	Surveys	12
9	House staff	Childhood cancer	Surveys	12
10	Father	Childhood cancer	Surveys	39
11	Professional staff	Chronic illness	Surveys	22
12	Medical institution	Childhood cancer	Surveys	287
13	Mother	Childhood cancer	Surveys	5
14	Patient, Guardian, Teacher, Nurse	Childhood cancer	Surveys	10
15	Teacher, Nursing teacher	Childhood cancer	Surveys	517
16	Teacher, Nursing teacher	Childhood cancer	Surveys	441
17	Teacher	Childhood cancer	Surveys	205
18	Teacher, Nursing teacher	Childhood cancer	Surveys	441
19	Patient	Childhood cancer	Surveys	10
20	Patient	Childhood cancer	Surveys	6
21	Patient	Childhood cancer	Surveys	11
22			Report	
23		Cancer	Report	
24		Childhood cancer	Report	
25			Report	
26		Chronic illness	Report	
27	Clinical Psychologists		Report	
28			Report	
29			Report	
30	Female		Report	
31		Childhood cancer	Report	1
32	Male	Higher brain dysfunction	Report	1
33	Male (Age; 7)	Pediatric brain tumor	Case Study	1
34	Male (Age; 14)	Spinal Cord Injury	Case Study	1
35			Case Study	1
36	Male	Hospitalized for lengthy period	Case Study	
37	Patient	Hospitalized for lengthy period	Case Study	3
38	Patient	Brain tumor	Case Study	2

issues to enable unbroken support<sup>23)</sup>. Regarding support for school re-entry support of high school students, the problem of advancing to the next grade or school was mentioned, as high school and higher education are not part of the compulsory education stage<sup>24)25)</sup>. Regarding learning support of high school students, it is possible to receive visiting education of special support schools in hospitals in the local school district, but in such a case, it was necessary to drop out of the original school and to change school enrollment status, so the influence on advancement to university and employment was also mentioned as a problem.

#### (4) Case studies

Among the case studies, cases in which school re-entry support was actually carried out using support booklets, pamphlets, and contact cards, and school re-entry support meetings with persons of different occupations were reported<sup>33) ~ 37)</sup>. Information provision tools such as brochures and pamphlets were shown to be effective to introduce specific knowledge and procedures for pediatric patients and their legal guardians to create a prospect for school re-entry<sup>35)37)</sup>. With regard to contact cards, physicians, homeroom teachers, and children can fill in each field, and even after leaving the hospital following discharge, the cards were effectively utilized as a long-term tool to connect the three parties<sup>36)</sup>. School re-entry support meetings provided a place where persons with different occupations can simultaneously share information, and the importance of the meetings was shown in several studies<sup>33) ~ 35)38)</sup>.

## II Conclusion

In this study, we found the most studies focused the role of support for pediatric patients by legal guardians, physicians, nurses, teachers, nursing teachers, etc., with regard to school re-entry. The major issues of school re-entry are indicated to be "guaranty a right to learn" and "relationship maintenance." Improvement of the school environment and system is essential for guaranty a right to learn. Every students should be provided the opportunity to learn even if he or she is in high school or transferee to a different school. Especially in the case of high school or higher education students, it may be directly connected with advancing to the next grade, going on to university, and obtaining employment. Thus, it is necessary to support the situation of learning during hospitalization so that there is no influence on subsequent life. Sato<sup>25)</sup> indicated that in order for students to feel secure in transferring to hospital school, whether or not the original school allows them to re-enter if treatment is completed

even if they drop out is a key factor. In order for high school students to obtain opportunities for learning while hospitalized, it is necessary to drop out of the original school and to change the student enrollment status to a special support school, but it is necessary to devise measures such as adapting the learning content and progress to the original school in order to realize school re-entry; the role of hospital schools and nonprofit organizations (NPOs)<sup>26)</sup> is anticipated. Regarding relationship maintenance, Hatae et al.<sup>5)</sup> indicated that relationships with friends of the original school after school re-entry constituted a source of anxiety, but it is necessary to provide support for children with illness to maintain relationships with friends from before onset of the disease in addition to healthcare providers and teachers who are involved after onset as well as provide support to maintain the relationship between healthcare providers and teachers. By maintaining human relationships that remain unchanged after treatment, it may be possible to live a fulfilling life both physically and mentally after school re-entry.

In order to solve these issues, it is important that other occupations collaborate to support children. The results of summary of past studies revealed that legal guardians, healthcare providers, teachers, etc. currently cooperate and provide support to a certain extent, but it was shown that there are issues such as the fact that after school re-entry, teachers are less likely to collaborate with healthcare providers, and both teachers and healthcare providers depend on the legal guardians. In order to solve such issues, it is desirable to devise appropriate countermeasures such as cooperating while being conscious of school re-entry from the hospitalization period, using concrete tools to effectively connect each party, and discussing the cooperation system after the school re-entry at the school re-entry support meeting where the related parties can gather.

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## 慢性疾患患児に対する復学支援の研究動向

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本研究では、慢性疾患患児の復学支援に関する研究を概観し、研究の動向と課題を明らかにした。「復学」「支援」「小児がん」「慢性疾患」をキーワードとする36文献を分析した。その結果、保護者、医療関係者、教師など、患児に関わる人たちの思いや復学支援における役割、他職種連携、連携の具体例、高校生や思春期における復学支援の現状と課題などについて研究されていた。課題としては、「学習保障」および「関係維持」を挙げることができ、患児の学籍が変更になっても一定の教育機会を設けることのできるシステムの確保と、患児が発病前からつながっている人間関係を維持し、発病後に関わることになった医療関係者や教師と復学後もつながり続けられるような支援が必要と考えられた。

キーワード：復学、支援、慢性疾患

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