

紀要『人文・自然研究』第18号

Possibilities for Psychological Support and Health Literacy
Education for Sick Children

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2024年3月25日発行

一橋大学 全学共通教育センター

人文・自然研究 第18号

Hitotsubashi Review of Arts and Sciences 18



2024年3月25日発行

発行：一橋大学全学共通教育センター

186-8601 東京都国立市中 2-1

組版：精興社

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1. Introduction: Background to the Issue

The purpose of this paper is to examine the possibilities and challenges of health literacy education in psychological support for sick children. It leads to the obtaining of clues for the content of self-care activities and learning activities that are being implemented for children undergoing ongoing treatment for illnesses, such as in special-needs schools.

In recent years, the importance of supporting the maintenance of children's physical and mental health and recovery from illness has been increasing. One example is the habituation of hygiene concepts and basic hygiene behaviors due to the spread of the novel coronavirus infection (COVID-19). The spread of COVID-19 infection has not only resulted in the maintenance of one's own health and health care but also in the maintenance of health in relation to others close by, such as family members, and in the use of masks in public spaces. The spread of COVID-19 infection has also extended the challenge of health literacy to the need to be concerned not only with one's own health care, but also with health in the public sphere at large and with the health of community members. From this point of view, it makes sense to pay attention to health literacy.

This paper is concerned with the communication activities described below. Communication activities encompass a wide range of subjects and activities. Health communication in particular will be considered in this paper. Health communication is a generic term that originally referred to communication in the field of medicine and public health. For example, it includes communication between health care providers and health care consumers (patients and their families, etc.), communication among health care providers, and communication among health care consumers, assuming team medicine, etc.

In communication between a health care provider and a health care consumer (e.g., a patient), it has been expected that the provider should explain the medical condition and future treatment plan to the consumer, encourage the consumer's understanding, and should explain the condition and treatment in the patient's own words. For example, medical staff may ask the patient, "How will you explain this to your family after you go home?" The communication includes whether the patient is able to explain his/her disorder to medical staff and whether he/she is able to acquire and maintain a lifestyle in accordance with medical staff instructions. Medication, diet adjustment, and the acquisition of rhythms such as sleep can also be considered to fall under this category. This can be considered to be a kind of patient education.

In recent years, there have also been changes in the forms and structures of information gathering and communication by health care consumers. In the U.S. health policy "Healthy People 2020," health communication using information technology was posi-



tioned as one of the pillars of the policy effort (U.S. Department of Health and Human Services, 2012). This is because “the Web now plays a central role in providing information from experts, and much of the information is provided by national professional organizations” (Nakayama, 2016, p.19). The successor “Healthy People 2030” also calls for the promotion of health communication via IT media as “Health IT” (U.S. Department of Health and Human Services, 2021).

2. Self-care Activities in Special-needs Education

In the self-care activities stipulated in the curriculum guidelines for special-needs schools, six categories and 27 learning modules are presented (MEXT, 2019, pp.199–200). For example, in the category of “health maintenance,” the content includes matters related to the formation of lifestyle habits, understanding of disease states, and life management (Ibid., p.199). Self-care activities should be implemented appropriately not only in special-needs schools but also in special-needs classes and day-care classes. It is necessary to materialize the content of the 27 modules as appropriate learning tasks according to the actual conditions of individual students. For example, in education for the sick and weak, emphasis is placed on “developing the ability to self-manage” (Takeda, 2022, p.103). In addition, it is also pointed out that “in order to respond to the diversification of illnesses in recent years, it is necessary to first select and generalize the items necessary for each of the major chronic diseases from the contents of self-care activities, and then clarify the content of instruction for each type of illness based on these items” (Ibid.). Furthermore, “Self-management of disease is of course important, but on top of that, the ability to choose one’s own activities and to communicate them to others is also necessary. It is also important for students to learn how to express themselves in order to communicate with others. It is also important to teach them to be aware of their physical condition and disease status and to acquire the ability to accurately judge what they can do and to what extent they can do it under those conditions” (Ibid., p.105). In other words, it can be noted that the content of learning related to improving and overcoming learning and living conditions caused by disabilities and diseases includes aspects of learning how the person perceives his/her own disability or disease and how to face limitations in life.

Similarly, the category of self-care activities includes “psychological stability.” In the case of children with chronic pediatric diseases, this consists of reducing distress associated with the disease and reducing anxiety due to the therapeutic environment. Furthermore, in recent years, mental instability in childhood has also become a hot topic. Psychological stability in medical communication and reduction of emotional difficulties are also important focuses of self-care activities.

3. Features of Health Literacy

Health literacy is defined as “the ability to obtain, understand, evaluate, and use information to make better decisions that lead to better health and medical care,” but “has



been defined in a variety of ways” (Nakayama, 2016, p.4). According to Nakayama (2016), organization, common to the various definitions of health literacy, signifies that “picturing information and making decisions” should be considered a priority, and that “decision-making is an action to solve a problem, and information provides the choice to solve a problem by giving information that is needed to know the options for solving the problem and to evaluate the advantages and disadvantages for each person” (Ibid., pp. 4-5).

Health literacy is positioned as a type of critical literacy, based on the theory of health promotion, to work with the wider environment to maintain or improve one’s own health, the health of immediate others, and the health of community members. Literacy can be broadly divided into functional literacy, which corresponds to basic reading and writing skills; interactional literacy, which involves obtaining and retrieving information; and critical literacy, which involves critically examining, analyzing, and integrating information and using that information in situations and contexts. Health literacy emphasizes the aspect of critical literacy. Nutbeam, one of the leading theorists on health literacy, also follows these three categories of literacy (Nutbeam, 2000).

Health literacy was developed in the 1960s in the United States as an activity to promote behavior change for health by utilizing the Health Belief Model (Nakayama, 2016, p.9). The Health Belief Model is described as “a health behavior theory that identifies ‘threat perception’ and a ‘balance of benefits and disadvantages’ as drivers of health behavior” (Sawada, 2019). The “threat perception” is defined as “feeling that one is likely to develop a disease or complication if things continue as they are” or “feeling that if one were to develop a disease or complication, the consequences would be serious (in terms of health, economics, and society)” (Ibid.). That the perceived benefits of taking health-appropriate actions outweigh the disadvantages is also considered a facilitating factor.

Health literacy is also being developed in a way that is linked to New Public Health through addressing a wide range of educational levels and a focus on the socioeconomic environment. The concept is considered important in health education. In addition, it is thought that it is also possible to obtain an implication for special education schools in considering the curriculum and learning activities for self-care activities to address students’ own health issues.

Wynia & Osborn (2010), whose subject is the relationship between health literacy and health communication, also found that limited health literacy is associated with poor health. They then point out that improving the quality of health communication is effective in maintaining and improving health.

4. Psychological Challenges and Psychological Support for Sick Children

In this section, the psychological challenges of sick children are discussed. First, three psychological challenges of sick children are identified.

The first concerns physical discomfort brought about directly from the illness. This is true not only when the child has subjective symptoms or directly feels pain, but also when the child does not have subjective symptoms. In recent years, an increasing num-



ber of children have complained of subjective symptoms, including those outside the original pathological site, as so-called complaints. These include headaches, abdominal pain, and difficulty in waking up in the morning. It is possible to focus on physical discomfort that includes these symptoms. Second, psychological anxiety, which is difficult to detect when the patient is in good health, can include, as previously suggested, anxiety about treatment, anxiety about changes in the treatment environment due to hospitalization, and anxiety about the inability to have a time perspective on one's future. Third, children are unable to verbalize their anxiety, leading some children to show physical symptoms due to this. In addition, some children may express their anxiety in the form of rejection of treatment and life, or aggressive attitudes toward those close to them due to their inability to verbalize their anxiety. In the Japanese Courses of Study, an example is given regarding children hospitalized for leukemia. "Students suffer from anemia and vomiting due to side effects of the treatment over long periods of time. This can cause psychological instability. In such cases, it is important to help the children achieve psychological stability by confiding in them and allowing them to express their anxieties."

In the following section, children's anxieties about their illnesses are reviewed. As mentioned earlier, distress concerning treatment, dietary restrictions, and decreased self-esteem are observed. In addition, anxiety surrounding physical condition and prognosis, changes in appearance due to the side effects of treatment, anxiety about maintaining friendships, and complexes about physical and psychological aspects of the disease are also possible. In addition, school-aged children may show a decreased sense of belonging to a group, such as a learning group at school. State anxiety is a temporary anxiety reaction to a specific point in time, situation, event, or object, while trait anxiety is a tendency to become anxious due to a person's personality. The latter is characterized by the fact that the former is felt differently by each person, and when the latter is strong, the person feels more anxious about a particular situation than others.

Children's social skills are also important, as previous studies have shown that children who continue to receive treatment for illnesses tend to have fewer opportunities to acquire social skills. This is due to restrictions in the living environment caused by hospitalization, frequent visits to the hospital, and other factors that limit social activities. Thompson et al. (1992) also pointed out that the risk of psycho-social problems is 1.3 to 3 times higher for children with physical illnesses than for healthy children. Children's social skills also vary based on age, developmental stage, family environment, and support from others. It can also be noted that children's social skills vary depending on the age of onset of illness, prognosis and course of treatment, and the nature of treatment (Lavigne et al. 1993).

There are four major psychological challenges for children with school-aged illnesses. The first is the delay in academic achievement and socialization due to treatment and hospitalization. Cases of school maladjustment have also been reported. Second, the influence of friendships and school maladjustment on overall psychological adjustment; Waxler-Morrison et al. (1991) point out that friendships and school adjustment are also important predictors of later psychological adjustment. Third is the influence factor of friendships. Friendships are affected by the limitation of treatment activities and changes



in appearance due to side effects (Vanneta et al. 1998). Fourth, it is difficult to form and maintain friendships. It has also been noted that changes in appearance can lead to a negative self-image (Miyagishima et al., 2017).

Next, the challenges of adolescence and young adulthood are overviewed. First, as in school age, the side effects of treatment and feelings of inferiority due to having the disease are suggested. In addition, Brownbridge et al. (1994) point out the issue of adherence, which is originally a pharmacological term that refers to the patient's active participation in determining his or her own treatment plan and being treated according to that decision. When the patient is a child, it involves a shift in the ownership of disease management from the parents to the patient. As a result, it has been noted that the child may temporarily become ill if his or her own management of the illness did not occur smoothly due to reduced support from the parents. These are developmental challenges for children in controlling their own illnesses in the future.

Support for chronically ill children can be said to provide the skill and awareness of self-control of the child's own illness. It has been noted that daily stress can exacerbate symptoms. In this regard, it is important not only to identify the site of the disease and monitor its progress, but also to identify psychological factors related to the worsening of symptoms. Self-control or self-care involves dealing with one's illness on a long-term basis. This includes not only the continuation of so-called treatment, but also diet and medication management, among others.

There are five elements of psychological support. First, the child's own understanding of the illness and its treatment must be confirmed and information gathered. This is related to the issue of truth telling. It is therefore a relatively new and recent trend in the history of medicine (Ibe et al. 2004). It is important for patients to be able to distinguish between what they know and what they do not know about their illness and treatment, in accordance with their age and ability to understand. In particular, if they have a negative perception of their illness, condition, or treatment, intervention may be necessary. Secondly, relaxation and other forms of alleviation of physical pain are also important. There are many examples of practices that incorporate artistic and cultural activities. Third, cognitive-behavioral therapy is used to alleviate mental distress. The fourth element is support for solving problems in daily life, discharge from hospital, and return to school. For school-aged and adolescent children, returning to school after discharge from hospital is an important issue. In the case of patients with recurrent childhood cancer, when they returned to school after hospitalization for the first onset of the disease, they experienced reluctance to return to school due to unpleasant comments they received about their lack of hair. When the patients were hospitalized due to a relapse, the staff carefully prepared for school acceptance by holding conferences to support their return to school, and the young people learned to explain their illness and problems to their friends by utilizing social skills training and other methods in the hospital class. In addition, the patients themselves have practiced such methods as social skills training in hospital classes to facilitate their return to school by learning to explain about their illnesses and problems to their friends. Fifth, there is also the promotion of positive life experiences. This has been seen to be effective in improving patients' own sense of



accomplishment and self-efficacy by incorporating creative activities.

The focus of this section is on psychological support for children with cancer. First, it is important to note that, due to improved survival rates, childhood cancer is no longer an “incurable disease.” However, there are still many cases that show difficulties in social adaptation, such as returning to school. In addition, Cordova et al. (1995) pointed out that it is becoming clear that the diagnostic model of PTSD is applicable to the handling of psychological difficulties in children with cancer. There have been a number of follow-up studies on this suggestion. Specifically, these studies have found re-experiencing of flashbacks, escape, emotional numbing, hyperarousal, and hypertension. Furthermore, it has been noted that the predictors of PTSD are significantly associated with subjective ratings of treatment intensity, trait anxiety, and subjective ratings of social support (Izumi 2011). Based on these findings, it is effective to encourage patients to cognitively understand the content and purpose of treatment at the beginning of treatment and to work to reduce fear. Support including family members is also important. The presence of teachers and friends at school, for example, is also important to enable a sense of a “healthy self.”

5. Psychological Support and Health Literacy

This section examines the relationship between psychological support for sick children and health literacy. Health literacy, as mentioned above, is a key concept in health education. It is a concept that can be used not only for children with illnesses, but also for healthy people at large. Health literacy is not viewed as literacy in the narrow sense, but rather as functional. Therefore, the focus is on the ability to communicate one’s problems and concerns verbally to one’s doctor and medical staff, to understand the doctor’s explanations, and to communicate these in one’s own words to family members and others. In addition, the concept of “adherence” can also be mentioned. Adherence is the patient’s ability to manage his/her medication, lifestyle, and diet in accordance with the treatment plan decided by the doctor and medical staff, as well as his/her ability to rest when necessary and to request rest on his/her own, all of which are issues to be addressed. Health literacy is a common issue for adults as well, but for children in particular, it is important to create a supportive environment for health literacy rather than relying solely on the child’s personal abilities (Nutbeam 2000).

The core content and concept of health literacy is basically the same for psychological support. However, the concept of mental health literacy, in particular, is increasingly focused on mental and emotional disorders and how to cope with them. It is important for people to use their own communication skills to proactively acquire information about their illness and treatment. In addition, the ability to adjust and change social and environmental factors related to one’s illness and health is also important. For example, it is necessary to examine what kind of changes can be expected from mental health literacy education. In an example known to the author, junior high school students commented, “I realized that mental illness and mental disorders are unexpectedly familiar to me,” and “I learned that mental illness is common during adolescence. Unawareness is



the scariest problem.” In addition, the students’ knowledge of mental illnesses and mental disorders improved, as well as their motivation to acquire knowledge, students stating, for example, “If I increase my knowledge, I can protect myself and my friends,” and “It is important to learn well because it might happen to me.” Based on a narrow definition of literacy education, this could be limited to knowledge about mental ill health. However, by examining the acquisition and application of knowledge, the perspective of taking literacy in a broader sense can be said to be more emphatic.

To examine the psychological issues of pediatric cancer patients, the following examples are found. According to Ishida (2012), the psychological concerns of children with cancer are diverse, including not only behavioral limitations due to their physical condition, but also concerns about learning at school, understanding the disease, building interpersonal relationships, and career paths. In addition, in a study of middle school students using the assumed scene method, a case in which the child was absent for six months and explained to the school only that s/he was returning to school was compared with a case in which the child explained additionally that his/her hair was falling out, that s/he would only observe physical education classes due to lack of physical strength, and that s/he had the desire to do the same things his/her friends around him/her were doing (Omi, 2020). According to the results, the latter case, with the additional explanations, tended to have smaller mean scores for the surrounding middle school students in terms of the patient’s physical discomfort and envy for observing physical education and being late for school or leaving school early ($p < .001$). Patients also indicated a desire for such additional explanations. Health literacy is effective in that it allows patients to be proactively involved in their own school environment, as well as in gaining the understanding of those around them.

6. Support for Health Literacy by Health Care Providers

In medical education, efforts are being made to improve patients’ health literacy and health communication. In parallel, communication to support patients’ health literacy is also being considered.

Models of development in medical education programs can be used as examples. For example, Kern et al. (1998) provide an example of a medical education program with individualized goal setting for medical interviewing skills. Kern and his colleagues suggests the examples clarifying the patient’s motivations and concerns for the hospital visit and using a combination of open-ended and closed-ended questions. It also recommends “avoiding leading questions and using listening, confirmation, and observation skills.” The “use of emotional relationship-building techniques” also includes “demonstrating concern, commitment, and partnership with the patient; recognizing and understanding the patient’s and physician’s feelings and responding to them in a supportive manner, without being judgmental or defensive; and using nonverbal communication and self-disclosure as appropriate.” In addition, “use of patient education techniques” includes “assessing the patient’s knowledge, beliefs, and needs, adapting the content of patient education to the patient’s needs, orally conveying information in a clear manner (avoiding jargon,



organizing information, using concise and clear language, and using an interactive format that is not one-way communication of information), writing, and using printed materials to confirm patient understanding.” The protocol also includes “confirming the patient’s understanding and consent.”

Support by health care providers is expected for the acquisition of health literacy. However, in the case of sick children, the acquisition of health literacy, the progression of the disease, and changes in the stage of treatment proceed simultaneously. In addition, there are overwhelming differences between the child and health care providers in knowledge about the disease and its treatment. It has also been noted that the relationship between care givers and patients can easily become asymmetrical. Therefore, it can be said that health care givers are required to support patients in the process of acquiring and forming health literacy in a way that does not impair their understanding or independence. This is true not only for medical staff but also for educators who teach children who are continuing to receive medical treatment. This has been applied especially to teachers in schools and classes attached to hospitals and teachers in charge of visiting hospitals. However, the same is true for teachers in regular schools when instructing children who continue to attend school while undergoing outpatient treatment.

7. Discussion and Further research

Finally, future research topics are addressed. First, the importance of health literacy is widely shared. It has been indicated in this paper that communication activities to help children develop health literacy, which is widely required for healthy and non-disabled persons, are also important for those with special needs. Considering its potential in special needs education practice, it would be useful to refer to medical practice based on health communication to focus on students’ disabilities and diseases. Health literacy is based on the theory of health promotion, and is positioned as a type of critical literacy when working with the wider environment to maintain and improve one’s own health, the health of others around one, and the health of community members. The concept is considered important in health education.

Through the examples of communication activities, it was suggested that it would be effective to utilize the methods of medical communication to provide learning and support that is tailored to the health conditions of individual students. The content of self-care activities in the national curriculum is comprehensive, covering all disabilities, and teachers and curriculum planners are required to make learning activities specific to the individual conditions of each school.

However, the health literacy education for sick children discussed in this paper involves many individual issues in conjunction with the progression of the disease and its treatment. Therefore, it includes points that differ from broadly targeted health literacy education. This has similar characteristics to patient education in health care. This cannot be explained simply by the dichotomy of being in good health or being treated for a disease. In particular, the common denominator is that instruction is based on the condi-



tion of the patient. On this viewpoint, it is necessary to survey patient education programs and to consider psychological support for children with diseases other than pediatric cancer.

The second is a consideration of the subject matter of patient education. Patient education, which has traditionally been promoted mainly in the nursing field, is often practiced in adult departments. Patient education for children can be linked to the content of school studies. For example, it can be linked to knowledge of the human body structure in science and biology, to stress management in health and physical education, and to the knowledge of food and nutrition in home economics. There have as yet been few case reports on these topics in Japan. Therefore, it would be useful to refer to the United States, where there is relatively active patient education and patient groups for specific diseases.

Third, it is important to examine differences in the developmental stages of health literacy according to the child's medical condition, differences by age of onset, and differences in the structure and content of health communication with health care professionals and school personnel. This will also be a powerful resource for curriculum development for self-care activities for children with special needs and health risks.

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Abstract

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This paper focuses on communicative activities to help children develop health literacy, which is widely required for healthy and non-disabled persons, but is also important for those with special needs. However, considering its potential in special needs education practice, it would be useful to refer to medical practice based on health communication to focus on students' disabilities and diseases.

Health literacy is based on the theory of health promotion, and is positioned as a type of critical literacy when working with the wider environment to maintain and improve one's own health, the health of others around one, and the health of community members. The concept is considered important in health education.

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