

**PERCEPTIONS OF BARRIERS TO SUITABLE
EDUCATION FOR CHILDREN WITH MEDICAL NEEDS
IN ENGLAND AND JAPAN**

by

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Abstract

This study investigates the difficulties of ensuring a suitable education for children with medical needs. The aims are to identify barriers to education and to suggest possible areas for improvement. The research questions are: (1) What are the educational needs of children with medical needs? (2) How do the systems function to respond to the child's needs? (3) What are the barriers to suitable education for children with medical needs? The study reports on two case studies undertaken in England and Japan, in which data were collected from a range of stakeholders (people who experienced hospitalisation in childhood, parents, teachers of hospital and mainstream schools) through face to face interviews and email interviews. The findings identify the children's academic needs, their health condition and medical care related needs, as well as their social emotional needs. Hospital school, home teaching and main school maintain continuity of education in both cases. As obstacles to education, regional differences in available support were identified in both countries. Teacher's lack of awareness of the child's education, insufficient knowledge and skill, lack of communication, lack of information about the child's illness, and unsupportive school leadership were identified as barriers. This study suggests 1) to improve teachers' knowledge of teaching ill children, 2) to improve their knowledge of the available support systems, 3) to improve communication, 4) to obtain sufficient information about the child's difficulties and illness, and 5) to improve supportive school leadership. Further developments may be needed in inadequate systems, teacher training, and social emotional support for children.

Declaration

This thesis is as a result of my investigations and research and it has never previously been accepted in substance for any degree.

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Abbreviations

CAMHS	Child and Adolescent Mental Health Services
DfCSF	Department for Children, Schools and Families
DfES	Department for Education and Skills
GCSE	General Certificate of Secondary Education
GSU	Guidance and Support Unit
ICT	Information and Communication(s) Technology
IEP	Individual Educational Plan
LA	Local Authority
MEXT	Ministry of Education, Culture, Sports, Science and Technology, Japan
NHS	National Health Service
Ofsted	Office for Standards in Education, Children's Services and Skills
PPS	Parent Partnership Service
PRU(s)	Pupil Referral Unit(s)
PSHE	Personal, social and health education
SEN	Special educational needs
SENCO	Special Educational Needs Coordinators
SNS	Social Network System
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organisation
WHO	World Health Organisation

Chapter One

Introduction

1.1. Introduction

This chapter presents the general background of the study and the context of the research. It explains topics of investigation, followed by the aims and research questions, the significance and limitations of the study. It finally explains definitions of key words.

1.2. Background to the study

1.2.1. Topics of investigation

Because of advances in medical treatment, more children are surviving life-threatening diseases with long-term and health related needs (Brown, *et al.*1993). Taking example of childhood cancer, 1500 children in the UK are diagnosed some kinds of cancer each year. Eight out of ten of those children survive five years or more. This survival rate is twice what it was in the 1960s (Cancer Research UK, 2011). However, it is likely that children who experienced serious health problems have difficulties to access education. In the UK, the number of the children and young people who cannot access school because of medical reasons is estimated to be more than 10,000 per year (DfES, 2001a). In Japan, the numbers of children who are absent from school for medical reasons for more than 30 days are reported as more than 25,000 in primary school and 21,000 in secondary school (National Institute of Special Education, 2010).

There is significant evidence in past research that many children with chronic or serious illnesses are at risk of psychological and academic problems because of the impact of the illness and the frequent hospital admissions for the treatment (Closs, 2000; Lightfoot, *et al.* 1999; Larcombe, 1995; Mukherjee, *et al.* 2000a, Shiu, 2001). For example, an academic delay accumulated during the hospitalisation period may cause underachievement when they return to school and may lead to low self esteem (Larcombe, 1995 ; Shiu, 2001). Children often have difficulties in relationships with peer and teachers in mainstream school (Larcombe, 1995; Lightfoot, *et al.* 1999; Shiu, 2001; Poursanidou, *et al* 2003; Mukherjee, *et al.* 2000a & 2000b) which sometimes result in school phobia (Madan-Swain *et al.* 2004). Supporting children to minimize these negative impacts of illness and hospitalisation on children is considered to be important. School teachers are required to raise awareness of special health needs and obtaining health related information (Mukherjee, *et al.* 2000) in order to understand the ill children.

In England and Japan, hospital schools and home education provide educational support to maintain continuity of education for children when they are away from school for health reason (DfES, 2001a; Taniguchi, 2009). In both countries, hospital school and home teachers have a role not only to provide academic supports but to support child's social emotional needs and to make a link between the child and school (Taniguchi, 2009 ; Boonen *et al* , 2011; Farrell *et al.* 2003). However there is little research to investigate provisions as a whole from the perspectives of involved people such as children, parents, hospital and mainstream school teachers. An exploration of the education systems and procedures is considered to be important to

improve continuity of education and social and emotional well-being of the children (Bolton, 1997).

The origin of the study was in my experience as a hospital school teacher in Japan. In my own hospital school, the hospital school and the pupil's main school worked together to support the child. When pupils were in hospital, to what extent the school contacted the child to support them and how they support them were depending on the teacher in the school. After pupils return to school, some pupils obtained sufficient support at school, some others had little support. Some pupils entered school smoothly, some others had difficulties. As a teacher, I understood that individual children were different and their circumstances were different. Therefore, there might be no simple reason to explain these differences. Having said that, I still had a question, were there any suggestions to improve education for the child and support the child's well-being during and after hospitalisation?

While I was studying as a master student in England, I had an opportunity to attend the conference for hospital school teachers in England and other European countries¹. I found some similarities and differences in systems in different countries and in participant teachers' concerns. This experience inspired me to do case studies to investigate provisions of education for children with chronic illness in England and Japan.

1.2.4. Focus and research aims

¹ The Hospital Organisation of Pedagogues in Europe, London, England (2006)

This study is a multiple case study of two cases of provision of education for children with medical needs in England and Japan. It is concerned with the educational settings for children who cannot go to mainstream school due to medical reasons when they are in hospital or at home, and their re-entry into mainstream schools after their hospitalisation. It explores how the systems facilitate to respond to their educational needs and what the problems to providing education for children with chronic illness are. I investigate the perceptions of different groups of people (young people who experienced hospitalisation, parents of children with chronic illness, teachers of hospital and mainstream schools) about the child's educational needs and obstacles to respond to their needs.

1.2.3. Aims of the study and research questions

The aims of my study are:

- To explore the experiences and perceptions of 1) young persons who experienced hospitalisation and 2) parents of children with chronic illness about education for children with medical needs in England and Japan.
- To explore the experiences and perceptions of teachers in hospital and mainstream schools about education for children with medical needs.
- To explore possible differences and similarities of those groups of people's perceived barriers to education for children with medical needs in England and Japan.
- To suggest possible areas for improvement to achieve more positive educational experiences for children with medical needs

In order to specify the purposes of my study, I developed three research questions:

1. What are the educational needs of children with medical needs?
2. How do the systems function to respond to the child's needs?
3. What are the barriers to suitable education for children with medical needs?

1.3. Significance and limitations

My study investigates the perspectives of different groups of people: young persons who experienced hospitalisation in childhood, parents of children with medical needs, and hospital and mainstream school teachers. To my knowledge, there is little research which investigates educational settings from the point of views of hospital school and home teachers who take charge of education in hospital admission and recuperation period.

Secondly, my study investigates the educational provision for the children with chronic illness throughout the process from setting in hospital to setting in school. Although there are research articles focusing on setting in hospital (eg. Taniguchi, 2009) and at school (eg. Murkeherjee et al. 2000; Norris, et al. 1999), there is little research to investigate the process as a whole. As the experience in the different settings may impact on the child, I consider that investigation of whole process is important.

Thirdly, my study investigates provision in two countries, England and Japan. There is little research which investigates the educational provision for children with medical condition in Japan. I expect that this case study contributes to the understanding of the current situation in the investigated area.

The study is limited in the following ways:

1. This study is limited in terms of geographic location to the provision of education for children with chronic illness to a small number of schools and PRUs in central England, and schools in Kanto district in Japan.
2. The choice of types of illnesses considered in the study is a limited number of chronic illnesses. I did not select specific types of illness but representative types of participants. Therefore the types of illnesses themselves were not considered to be of central importance in the study. The most important feature was that the illness caused absence from school.

As this is a small scale study with limited numbers of participants, the results of this study may not reflect systems and practice in different schools other than the researched ones, and also may not reflect a variety of different types of illness and medical condition. Therefore it may not be appropriate to generalise the study to other contexts.

1.4. Structure of the thesis

- **Chapter two : Literature reviews**

I reviewed 1) Inclusive education, 2) Children with medical needs and school experience, 3) Policy and practice.

- **Chapter three : Theoretical reviews**

I reviewed literature relevant to two theories, social ecological theory and self-efficacy theory. I also explain the relationships with the theories and this thesis.

- **Chapter four : Research design**

I present the research design of this study. Methodology, participants, data collection methods, analysis methods, ethics are explained.

- **Chapter five: Findings of case study in England**

I present findings of perspectives of 1) people who received education and 2) people who provided education in England.

- **Chapter six: Findings of case study in Japan**

I present findings of perspectives of 1) people who received education and 2) people who provided education in Japan

- **Chapter seven: Analysis and Discussion**

I present data analysis and discussion. 1) System and practice in England and Japan, 2) Teacher's supportive and unsupportive attitudes, and 3) Possible areas to be improved in system and teacher attitudes

- **Chapter eight : Conclusion**

I present conclusion, limitation of the study, and further development of the study.

1.2.7. Definitions of key words

Barriers

Department for Education (2012: p.5) explained barriers as ‘... things that stops disabled people living as other people. For example, the ways that people think and act towards disabled people.’ Pivik et al (2002) defines ‘physical barriers’ as ‘an impediment to full participation to activity. They also defines ‘institutional barrier’ as those reflecting the institutional bureaucracy, which include bureaucratic inflexibility, and belief towards resource availability. ‘Attitudinal barriers’ is defined as inappropriate comments, lack of knowledge, rude behaviour (ibid, pp.98-99).

In this study, *barriers* are defined as:

Impediments which prevent the child to full participation to activity which other peers participate.

Children with medical needs

The DfES (2001a) defines the group covered by the guidelines of ‘education for children and young people with medical needs’ as ‘all those pupils who are unable to attend schools because of medical needs, both those who are physically ill or injured and those with mental health problems (1.1).’ Mental illnesses in this guideline involves anxiety, depression and school phobia. Although pregnant girls receive education in some hospital schools, they are not included in this Access guideline because there is separate guidance available for school age parents (DfES, 2001a).

Closs (2000: pp1-2) categorises types of medical conditions of children as;

- Children with a life threatening illness

- Children with prolonged infective or viral conditions
- Children who are required to undergo prolonged or recurrent surgery or treatment
- Children with genetically determined conditions which cause physical and/or cognitive deterioration and which are currently life-threatening /life shortening
- Children who experience a range of symptoms or needs which arise from impairment, damage or dysfunction of organ or central nerves system
- Children with otherwise more stable impairments who are subject to periods of associated illness
- Children with allergic or other responses to environmental or ingested substances

Based on Cross's lists and the guideline (DfES, 2001a), I define the *children with medical condition* in this study as:

children who have any illness, injuries, health conditions and mental health difficulties or who under go prolonged or recurrent surgery / treatment. They involve children with any sickness or illness including life-threatening, life-shortening illness, chronic/acute illnesses, genetically determined conditions, mental health conditions and children who experience symptoms or needs which arise from their health conditions.

Inclusive education

The UNESCO Salamanca Statement on special educational needs

- Every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning.
- Every child has unique characteristics, interest, abilities and learning needs.
- Education system should be designed and educational programmes implemented to take into account the wide diversity of these characteristics and needs. (UNESCO,1994,p.viii-ix)

On the base of this statement, I develop the definition of inclusive education in this study as :

Education in which children has equal opportunity to achieve and maintain learning and social emotional well-being. Education system is designed and educational programme implemented to take into account the wide diversity of these characteristics and needs that children have.

Suitable education

The Education Act 1996 provides that:

Each local education authority shall make arrangements for the provision of suitable education at school or otherwise than at school for those children of compulsory school age who, by reason of illness, exclusion from school or otherwise, may not for any period receive suitable education unless such arrangements are made for them (Section 19).

It defines suitable education as ‘efficient education’ which is appropriate to ‘the age, ability and aptitude and to any special educational needs the child (or young person)

may have'. Code of practice (DfES, 2001b), which is the guideline of the provision of education for children with special needs describes its own aim as 'enabling pupils with special educational needs (SEN) to reach their full potential, to be included fully in their school communities and make a successful transition to adulthood (1.2.)'. As children with medical needs is considered to have the equal rights to any other children regardless they have special educational needs or not, I apply this prospect to the definition of suitable in this study.

That mean, suitable education in this study is defined as:

efficient education in which children with any age, ability, aptitude and needs are able to reach their full potential, to be included fully in their school communities and make a successful transition to adulthood.

Chapter Two

Literature review

2.1. Introduction

According to Hart (1998:31), the main purposes of conducting a literature review include:

- The construction of a map of the literature.
- A demonstration of familiarity with the subject area.
- Acquisition of a knowledge base from which the previous research can be analysed critically.

In order to serve these purposes, I made four purposes of the literature review for my study:

- To understand relevant concepts of inclusive education
- To identify main findings of studies in regard with impact of illness on children, barriers and facilitators to education
- To understand background of education for children with medical needs in England and Japan
- To consider appropriate research methodology for my study

For these purposes, I review literature regarding as 1) Inclusive education, 2) Children with medical needs and school experiences, 3) Education for children with medical condition in England and Japan

2.2. Inclusive education

The first section is about inclusive education. I reviewed literature on inclusive education in order to understand basic concepts of inclusion. As there are substantial body of literature in this area, it was not feasible for me to review a wide range of literature in this study. Therefore, I focused on discussions of three topics which seem to be important for my study: 1) Special educational needs, 2) Disability models, and 2) Barriers to inclusive education.

2.2.1 Inclusive education and special educational needs

Who inclusive education is for is one of the issues that I am concerned about in terms of concepts of inclusive education. It is often pointed out in literature that the UNESCO Salamanca Statement on special educational needs created a global movement of inclusive education (Mittler,2000). This statement notes:

- Every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning.
- Every child has unique characteristics, interest, abilities and learning needs.
- Education system should be designed and educational programmes implemented to take into account the wide diversity of these characteristics and needs. (UNESCO,1994,p.viii-ix)

This statement notes that wide variety of characteristics and needs should be taken into account in school system. Although this statement may have ideological impact on education internationally, Mitchell (2005:15) notes that different country has different definition about inclusive education. This is because cultural values and beliefs, levels of economic wealth mediate the concept of inclusive education.

Values such as social cohesion, group identity, collectivism, universal welfare, equity and equality, may have impact on meaning of inclusion.

In Japan, the government introduced a reform which is called Special Needs Education (MEXT, 2012). The aim of this reform is described as realising a society to be cohesive and inclusive, in which human rights of people with disabilities are respected and individual educational needs of children with disabilities are met (National Institute of Special Needs Education, 2008). This system is criticized that it simplifies the child's special needs into just disabilities, therefore the system may not pay enough attention to the fact that special needs include a diversity of needs that any children may have (Sanagi, 2011).

In contrast, Code of Practice (DfES, 2001b) , which may be one of an important policy document in terms of education for children with special needs in England, does not specify the child's needs from the perspectives of disability. It states that children have special educational needs if they have 'a significantly greater difficulty in learning than the majority of children of the same age'.

As they are just two examples of policy documents, it is not my intention to say that they reflect ideology about inclusive education of two countries. However, from this simple contrast, a question arose. What is disability? Are children with medical conditions considered to have 'disability' or 'special needs'? How are they supported in the system? Next section discusses disability and children with medical condition.

2.2.2. Models of disability

Llewellyn and Hogan (2000) explained usefulness to consider models that, as children themselves rarely seek help from them, their problems are often defined by other adult people involved with the child. When the adult interpret the information given by others about the child, the use of models may help widen perspectives of situations and aid understanding of the child.

The ‘medical model’ is one of the disability models, which assumes that difficulties that people with disability have are associated only with their physical impairment (Coleridge, 1993). Therefore, overcoming disability is a matter of individual person’s effort (Johnston, 1994). It is argued that, as this model assumes the problems are located within the individual person with a disability, it does not take into account the social problems which exclude disabled people from society (Oliver, 1996).

In contrast, the ‘social model’ defines disability as socially constructed and imposed on people with impairment (Hutchison, 1995). This model put problems on the collective responsibility of society as a whole not on the individual (Llewellyn et al, 2000). It is considered, for example, that difficulties that people with disabilities have are caused by barriers such as prejudice and lack of facilities, which are created by society (Coleridge, 1993; Oliver, 1996).

The ‘transaction’ model assumes disability is a result of interaction of influence of individual persons’ characteristics and the environmental influence (Llewellyn et al.2000). According to Llewellyn et al (2000), this model assumes that people influence each other in both positive and negative ways, therefore, any behaviours do not have a single cause. A child interacts with other people and any environment

surrounding him, which may have an impact on the child's functioning and psychological well-being (ibid: p.161). Therefore, perceived disability by the child may be influenced such interaction. This model may require people who support the child to consider individual children's difficulty from various directions. That is, not only the child's deficit nor environmental factors, but the child's feeling, behaviours and reaction of others to the child may be influential factor of the child's difficulties.

As the needs a result of interaction, individual children may have difficulties in different ways. However Closs (2000) points out that needs of children with medical needs are often overlooked. Although the impact of illness and difficulties cannot be assessed by just medical condition, it may not be well known. Ikari (2001) said, when difficulty are not visible, it is difficult for other people to identify what problem the child has (Ikari et al. 2001), which may cause overlook the child's needs.

Different people may identify the child's need different way, which may depend on what they perceived as difficulties and how they interact with the child. If so, are there any differences in perceived needs by the child and people around them? How may such differences have an impact on the child in real life world?

2.2.3. Barriers to inclusion

Researchers who investigate whether the school meet the child's special needs identified barriers to inclusion.

Pivik et al. (2002) interviewed 15 students with mobility limitations who studied in secondary school and their parents to investigate their perceptions of barriers and

facilitators to inclusive education. They found barriers in physical environment (eg. school building, facilities), intentional attitudinal barriers (eg. bullying, isolation), unintentional attitudinal barriers (eg. lack of knowledge), and physical limitations (eg. lack of time to move to other classroom). Attitudinal barriers reported were mainly issues in peer relationships such as bullying and name calling. Unintentional attitudinal barriers were identified in relationships between teachers. Lack of understanding of the child was considered to cause inappropriate work given and failure to provide support.

Baker and Donnelly (2001) researched environmental influence of children's social experience and found negative and positive influences of environment on the child. In terms of school, school building and facilities, pupils attitudes, school leadership, teachers' professional approach, and school policy are suggested as influential factors on the child.

From teachers' point of views, teacher's own negative attitudes were identified as barriers to inclusion (Wolstenholme, 2010). Wolstenholme (2010) interviewed educational specialist in a range of settings including LA officers and school teachers. They found that teachers' lack of own role to address certain care needs, and also severity of the child's needs cause teachers' negative attitudes towards the child and resulted in inappropriate support to the child.

Regarding a role of teachers, research found that teachers play a crucial role in implementing inclusion (Forlin et al. 2010). Burke and Sutherland (2004) found that

negative attitudes towards inclusion are because of practical concern about how to do rather than ideological reasons. There are research evidence that teacher's self efficacy belief to teach children with difficulty have a positive correlation with their attitudes towards inclusive education (Weisel and Dror, 2006; Savolainen, et al. 2012). Savolainen et al (2012) had a large scale of questionnaires survey with school teachers. As a result of quantitative data analysis based on a self efficacy scale, they concluded that teacher's self efficacy belief was connected to their attitudes toward inclusive practice.

These researches suggest that attitudes of teachers and pupils as well as school facilities and environments are considered to be potential barriers to inclusion in general. Next section reviews literature in order to consider whether there are any specific issues for children with medical needs.

2.3. Children with medical needs and school experience

This section reviews literature on education for children with medical condition in order to understand impact of illness, and barriers and facilitators to education for ill children. In the process of this review, I also considered different methods of data collection and approaches about who were investigated in the studies.

2.3.1. School attendance and impact on the child

Children with chronic illness are absent from school for an average of 16 days a year compared to about 3 days for healthy children (McDougal, et al. 2004). Some chronic illnesses affect children's school attendance more profoundly. For example, Vance

and Eiser (2001) reviews literature on school absence of children with cancer and reported that average absence are from 25 to 80 days, which depends on nature of cancer and treatment. Other examples are 19.5 days a year in average for cystic fibrosis (Wildhagen et al. 1996 in Shaw et al. 2007). The pattern of educational interruption is vary. According to Bolton (1997: 3), who researched one hundred parents of children with various chronic illnesses, the patterns of disruption of education which was found in her study were;

- The single, medium to long period of time out of school that may derive from a relatively uncomplicated accident or a one-off illness
- The repeated interruptions associated with serious chronic illness, which include long and short period of school absences (eg. cancer)
- The short but frequent periods of time out of school (eg. severe asthma)
- The regular short absences for the treatment regimes (eg. renal failure)
- The long periods out of mainstream school

(eg. psychiatric illness, mental health problems)

In addition to hospitalisation, child's health conditions and scheduled clinic visit are also cause of frequent absence (Sexson and Madan-Swain, 1995). Long-term or frequent absences from school may affect children negatively in their development and school life. For example, an academic delay accumulated during the hospitalisation period may cause underachievement when they return to school and may lead to low self esteem (Larcombe, 1995 ; Shiu, 2001). In addition, research suggested that separation from school cause relationship difficulties with peers and teachers in mainstream school (Larcombe, 1995; Lightfoot, *et al.* 1999; Shiu, 2001; Poursanidou, *et al* 2003; Mukherjee, *et al.* 2000) which sometimes resulted in school

phobia (Madan-Swain et al. 2004). Boonen and Petry (2011; 494) noted that prolonged school absence is problematic because education plays a major role in stimulating social development of the child in promoting a sense of normalcy and psychological well-being.

The complexities of patterns of hospitalization and school absence may require children to have appropriate support while they are absent from school in order to prevent negative impact on the child in their school life.

2.3.2. School experiences

Children's school experiences are researched by investigating perceptions of the children themselves, parents and school teachers. Norris and Closs (1999) conducted interviews with children with serious medical condition, parents and school staff in primary and secondary school in order to investigate teacher-child, teacher –parent relationships. They found that teachers' perceptions of the child's medical condition, such as feeling of fears about seriousness of condition, lowered expectation about the child, sometimes negatively affected teacher-child relationships.

Lighthoot, Wright and Sloper (1998) investigated support needs in mainstream school. They conducted interviews with pupils with chronic health condition, parents and teachers in primary and secondary schools. They identified difficulties in dealing with impact of school absence, exclusion from school life, teachers' reactions to the illness, and peer relationships. Larcombe (1995) had interviews with children with different types of medical conditions and their parents, teachers. She concluded that teachers

need to be informed about medical condition, as lack of information was identified as cause of difficulties to support children in school.

While many research focus on only school life after the child return to school, there is little research which investigate the child's experience throughout the process from hospitalization to re-entry to school. Bolton (1997) conducted interviews with one hundred parents and their children who had chronic illness to investigate their educational experience in hospital, at home and at school. She found that process to return to school was particularly difficult for some children. Flexibility of procedure and a good relationships with teachers are required. She also suggests that an exploration of the education systems and procedures which are most effective in promoting child's social and emotional well-being.

Education in hospital and home teaching seem to be under researched area. As one of few research, Wiles (1998) identified a role of hospital school to link with the child and the school, to support the child by close collaboration with medical staff as well as counselling role to the child and families. Taniguchi (2009) also identified similar findings about the role of hospital school as a result of study on hospital schools in Japan.

Farrell and Harris (2003) researched hospital schools in different authorities, and suggested effective practice in the provision of educational services for children and young people with medical needs. Boonen and Petry (2011) researched re-entry to school after a period of homebound instruction for children with illness. They found that homebound practice contributed to build social contact with the child and peers in

school, which improved peers' understanding of the child and resulted in smooth re-entry.

Research suggest that hospital school and home teaching may have impact on children and their school life. However, there is little research which investigate the process of the child's educational provision from the period in hospital and after reentry to school. Also there is little research which investigate the perspectives of teachers in hospital school and home teaching.

2.3.3. Research on specific illness or illness in general

Illness and treatment may have influence on children's life in various ways.

According to Eiser (1993), there may be two perspectives in researching impact of illness on children. One is investigating specific illness and its consequences, which may reflect medical point of views. It assumes that different illness has different treatment and different consequences..

Another perspective is 'no categorical' approach, which stresses similarities of life stress and difficulties that were identified across different conditions (ibid; p.15). This type of research may be more beneficial to bring recommendation for children with illness in general.

As examples of research on a specific illness, there are several questionnaire surveys with children with cancer, which revealed that children with cancer have more school absence than healthy children or those with other chronic illness (eg. Charlton et al, 1991; Vannatta et al. 1998) As an example of study on non specific illness, Lightfoot

et al (1999) had interviews with children with variety of illness to investigate school life for children with illness in general.

On one hand, studies focusing on a specific category of illness are useful to understand a range of impact that cancer may have on children, there is an argument whether it is appropriate to generalise the finding into other illness (Eiser, 1993). It is also questionable what are specific for cancer. Eiser (1993) argues that researching a specific illness is not necessarily clear how far any identified impacts or difficulties are caused by the specific characteristics of the illness, and how far such impacts are considered to be different from those of other illness. She stresses the importance not the 'label' attached to the illness but the extent to which the illness and treatments disrupt the child's ability to maintain everyday activities (ibid. p.15).

My research interest is educational provision for children with chronic illness in general. System and policy are generally not supposed to made for specific illness but for any types of illness and medical condition. It is not my intention to identify whether certain system fits for certain illness or not. It may be appropriate not to specify the types of illness, but investigate illness in general who needs long term or recurrent hospitalisation.

In summary, literature review of this section suggested that illness and hospitalisation often have an impact on the child's school life and social well-being. Although educational support while the child is in hospital and at home is considered to influence their school re-entry and school life, there is little research how educational provision support the child responding to their needs, who may have

various absence patterns and health conditions. Although there may be different needs caused by different illness and medical conditions, are there any common barriers to their education and well-being at school?

2.4. Policy and practice

2.4.1. England

Although education authority were legally permitted to provide educational service for children who were absent on the ground of health, it became a statutory duty in England in 1993 (Closs, 2000). According to Bolton (1997) and Closs (2000), the Education Act 1993 established a statutory duty to provide education to children with medical condition for the first time.

It states:

Each local education authority shall make arrangement for the provision of suitably full-time or part- time education at school or otherwise than at school for those children of compulsory school age who, by reason of illness, exclusion from school or otherwise may not for any period receive suitable education unless such arrangements are made for them (the Education Act1993 :298 (1)).

This recognises educational entitlements of children with illness. The associated guidance to education authority in relation to this was found in DfEE Circular 12/94. It stresses educational continuity, liaison between all parties, and a liaison role for hospital teachers (Bolton,1997). It is pointed out that no national standards of quantity or quality of out-of school education were specified in law or guidance (Closs, 2000).

In real life settings, to what extent children with medical needs are recognized as having special educational needs or not, is one of issues discussed in the literature. For example, Closs (2000: 6) claims that ‘children with illnesses may be less likely to be considered to have special educational needs than children with constant or deteriorating and /or overt cognitive and / or physical impairment’. She refers to the 1993 Education Act which defines special educational needs as ‘difficulty in learning’ or ‘disability’, and says that different interpretations of ‘learning difficulties’ ‘disability’ and ‘difficulties in learning’ may have caused confusion. Children who have medical conditions may have difficulties in learning, but they may not necessarily have a disability or learning difficulties.

There is some evidence in other studies which supports Closs’s claim. Mukeherjee, *et al.* (2000a) report that most of the pupils with medical conditions in mainstream schools in their study were not registered as SEN pupils, which might have caused a lack of individual care. Although it is a controversial issue whether children with medical conditions have special needs or not, the lack of a contact person for them such as a SENCO is considered to be one of the problems to support those children (Lightfoot, *et al.* 1999).

The *Access to Education for Children and Young People with Medical Needs* document (DfES, 2001a) was published as a guideline to education for children with medical needs. Significant issue in this document may be that children with medical needs may have special needs statements. This guidance note:

A medical diagnosis does not necessarily imply that a pupil has a special educational need. However, it is possible that a medical condition may increase the likelihood that a pupil has a significantly greater learning difficulty than the majority of children...If this is the case, then the pupil will have a special educational need within the meaning of the Education Act 1996 and this may require a statutory assessment. (4.5.)

Farrell et al (2003) conducted a project investigating provisions in several LEAs, which aims to identify best practice in the provision of effective service for children with medical needs under this guidance. As one of the findings, they identified difficulties in mainstream ownership such as collaboration between school and hospital school and mainstream school's obligation to support the child.

2.4.2. Japan

Education for children with medical needs

In Japan, special education for children with disabilities has been part of the education system since 1947 when the Constitution of Japan and the School Education Law have secured the rights of education and equal opportunity of education for all children. However, children with illnesses were exempted from school education, because education was considered to impose excessive stress on ill children. It was in 1961 when schools for ill children and in-hospital education were legally made a part of the school education system (Taniguchi, 2009).

Although compulsory education for children with disabilities was established in 1979, many children in hospital remained without education due to a lack of numbers of hospital schools and rigid criteria of entitlement to hospital school,

(Taniguchi, 2009). After 1994, the government promoted education for ill children and changed the regulations of entitlement to hospital school education (MEXT,1994), which resulted in increasing numbers of children who could access education in hospital (Takigawa, 2010;Taniguchi, 2009). Taniguchi (2009) explained that the cause of the delay in the improvement of education for children with medical needs was because people generally made the assumption that education was not a priority for ill children. It is also said that people are not aware of the ill child's needs because their needs are not always recognisable (Tanigucchi, 2009).

Recent reforms of Special Needs Education in Japan

Education for children with special needs in Japan has been sometimes criticised for having segregated children with disability from main stream education (e.g. Miyoshi, 2009). The recent reform which is called Special Needs Education is expected to improve this situation. The government stresses that the reform aims to provide appropriate support to respond to individual needs of children with disabilities rather than educate those children in separate settings (Kawai, 2007). According to Kawai (2007), this reform responds to the Convention on the Rights of Persons with Disabilities. This convention states that inclusive education and reasonable accommodation of the individuals should be promoted (UN, 2006).

According to MEXT (2012), Special Needs Education provides various forms of education for children with disabilities such as schools for special needs education and special classes in regular classes. It aims to enrich education for children with disabilities. The types of disabilities which are supported is expanded to involve Developmental Disabilities such as Learning Difficulties and Attention Deficit

Hyperactivity Disorder (ADHD), which had not been paid attention to in the former system. The reform aims at realising a society that is cohesive and inclusive, in which human rights of people with disabilities are respected and individual educational needs of children with disabilities are met (National Institute of Special Needs Education, 2008). Under the reform, all schools are required to obtain a special needs education coordinator and organise a special educational needs system within school. It is also required to provide individual educational plans in order to respond to diverse needs. Collaboration with specialist agencies in the community is also suggested (MEXT, 2012).

Although this reform aims at inclusive education, there is some criticism that separated education is still remaining. Koyama (2011) pointed out that the numbers of children who study in special units in mainstream school and special schools have been increasing. She said that, on the one hand, this system was effective to identify children's special needs who had not been well supported in mainstream classes, but on the other hand, it promoted separated education by supporting them through separated units in school. She claimed that one of the causes of this was a lack of provision of measures to support children with special needs within regular classes. In order to achieve inclusive education, Koyama (2011) suggests not to rely on special care in special units and special schools, but to involve children with disabilities in regular classes in mainstream school.

A study shows the gap of attitudes between teachers and special needs units teachers. Miyaki *et al* (2010) carried out a study with 34 special support education coordinators. More than half of them pointed out the low level of awareness among teachers about

special support education. Others claimed that the school management team did not pay attention to the support system.

There seem to be two weaknesses of the Special Needs Education system identified by researchers. Firstly, lack of understanding of theory of inclusive education is pointed out. For example, the system simplifies the child's special needs into just disabilities. The system therefore may not pay enough attention to the fact that special needs include a diversity of needs that any children may have (Sanagi, 2011). Moreover, Miyoshi (2009) claims that difficulties which people with disabilities have are considered to be caused by individual deficit. Because of this perception, people may not consider that society itself may have created difficulties which people with disabilities suffer from. It is suggested to consider the interaction of the individual child's condition and environmental factors which may cause a disadvantage for the child (Sanagi, 2011). The second weakness is insufficiency of the system. For example, Sanagi (2008) compared the roles of special educational needs coordinators (SENCO) in England and Special Needs Education coordinators in Japan. He found that the system in Japan is lacking the relevant legal and social background to support the coordinators' work. He pointed out that there seems to be a risk that system and practice which are developed without fully understanding the theoretical framework of inclusive education may not achieve inclusion (Sanagi, 2011).

The literature showed so far, that there seem to be some problems caused by people's low awareness about inclusion and the insufficient system although the Special Needs Education system aims at inclusive education. However there is little research about how this system affects education for children with medical needs. According to

Takeda (2004), more than 80% of children with medical needs are studying in mainstream school. As the system is relatively new, not so much research has been done about how those children are supported under this system and what problems they have.

System and practice

Education for children with health impairment is provided by three types of institutions. According to the leaflet “To understand children with illnesses” (“Byouki no kodomo no rikai notameni”) published by the Association of Headteachers of Schools for children with health impairment (2010) to promote awareness of mainstream school teachers, education for the children with medical needs in Japan are provided by:

- (A) Special schools for children with health impairment or physical disability which have hospital schools, outreach teaching in hospital and home teaching.
- (B) Outreach teaching in a hospital as a part of a designated primary / secondary school which are located close to the hospital. A teacher visits hospital to teach inpatient children when it is required.
- (C) A unit for children with health impairment within a primary / a secondary school. This is a resource room for children with health impairment who are enrolled in regular class may visit few times a week to receive special instruction.

Central hospitals in the region which have regularly considerable numbers of inpatient children usually have this type of hospital school (Takigawa, 2010). These hospital schools which are a part of special schools have relatively large numbers of teachers and have branch sites in several hospitals. Hospitals with a smaller numbers of inpatient children usually have hospital schools of type (B). Education for children who are at home due to medical reasons is provided through home teaching which is organised by special schools of Type (A). Type (C) units look after children who are not hospitalised but are not well enough to attend mainstream teaching. Type (C) units frequently take on students from other schools which do not have such units. Type (C) units have recently increased in number (Takigawa 2010).

Literature reviews that education for children with medical needs in Japan has been included into regular school system later than education for children with other special needs, and researcher hypothesis that lack of attention and misunderstanding may have caused this delay.

Some researchers pointed out that many children in hospital are still left without education. For example, a study found that hospital school plays an important role to support children in hospital by social emotional support and connecting them to the community (Taniguchi, 2009) and they also support child's return to school (Kamibeppu 2011). However, there seem to be a number of problems in the process of returning to school, such as low awareness of the needs of the ill child in the mainstream school (Horibe, 2011). Moreover, a study found that insufficient numbers of hospital schools have prevented access to education for children in hospital (Ikari *et al.* 2002). According to a questionnaires survey (Tochigiken Bengoshi kai, 2009),

in which 120 hospitals responded out of 330 hospitals which have pediatric wards in 7 prefectures including Tokyo, 58 % of them did not have any education for primary school pupils, and 63% did not have education for junior high school students. As the response rate is quite low, this figure may not accurately represent the situation. However, it is likely that not all children in hospitals are able to access education.

2.5. Summary of chapter two

Perceptions of inclusive education are influenced by various factors such as culture and value. As an example, there was a difference in policy documents in England and Japan. Are children with medical conditions considered to have ‘disability’ or ‘special needs’?

How are they supported in the system?

What people identify as child’s disability may influence what they understand the child’s needs are. As a result of contrast of three disability models, I found that child’s needs are considered to be a result of interactions between the child and environment. From this conclusion, question emerged, Are there any differences in perceived needs by the child and people around them? How may such differences have an impact on the child in real life world?

In terms of barriers to inclusion, researches suggest that attitudes of teachers and pupils as well as school facilities and environments are considered to be potential barriers to inclusion in general.

Regarding school experience of children with medical needs, I found that complexities of patterns of hospitalization and school absence may have impact on the child' school life and social development. There may be different needs caused by different illness and medical conditions. However, are there any common barriers to their education and well-being at school?

As a result of review, I develop three research questions:

1. What are the educational needs of children with medical needs?
2. How do the systems function to respond to the child's needs?
3. What are the barriers to suitable education for children with medical needs?

In order to fill a gap of the research in this area, I investigate education for children with medical needs throughout the process of hospital to school. I answer the questions by investigating different perspectives of people.

Chapter Three

Theoretical review

3.1. Introduction

This chapter reviews theories which are relevant to my study. One is social ecological theory and another one is self-efficacy theory. As I explain later, my study applies interpretive paradigm (see 4.3.1.), and therefore, it is not theory oriented. However, I have ideas from these theories to develop my study. I explain how I use these theories in my study.

3.2. Social ecological theory

The social ecological theory assumes the human behaviour and its environment are mutually influenced (Bronfenbrenner, 1979). It assumes that the individual's behaviour and development are influenced by multiple factors including interpersonal, social, cultural and political issues (Kazak, 1989). Bronfenbrenner (1989) also suggests considering a perspective of a time related component. He notes that characteristics of the person are a joint function of those of the person in the given time and the environment of the person up to that time. Therefore, change of the time may need to consider its influence on both environment and the characteristics of the person.

Llewellyn et al. (2000) suggest that this theory is useful for researchers to examine issues such as mainstream school re-entry of the child with special needs. In the process of school re-entry, the existing relationships between the child and

environment alters and creates a dynamic that may have a impact on the child's developmental change. Data obtained before and after a particular life experience or life transition may enable researchers to examine the mutual influences of the school community, education system and the self (ibid.: p.160).

I consider that social ecological system theory helps me to understand dynamic and complex children's needs who go through different stages of inclusion process, such as hospitalisation, re-entry process to mainstream school after discharge, and after entry into mainstream school. When child is in hospital, environment in hospital and the child's condition may interact and may influence the child's need that the child had then. When the child returns to mainstream school, the dynamics of three different issues may have an impact on the child's needs. That is, they may be the impact that the child has had until then in hospital, the child's condition, and environment in school. Therefore, when the child returns to school after hospitalisation, the child's educational needs at school may have been influenced by the experiences and educational support that the child had received in hospital. I consider that the ecological theory is helpful to investigate the child's needs which may have been influenced system and practice of educational provisions in different stages.

In my study, I investigate the ecological system around the ill child in the different stages of process from hospitalisation to return to school. That is, 1) in hospital, 2) in recuperation at home / return process to school, and 3) at school.

As regards the environment in the ecological system, I investigate three levels of system adopting the concepts of ecological theory. The first level is individual

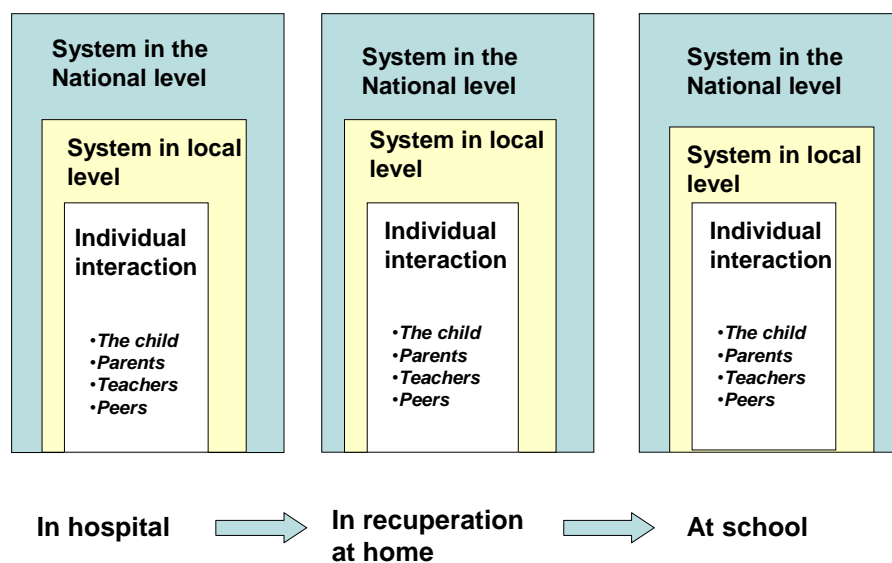
interaction level. Bronfenbrenner (1979) suggests that a child has direct impact from the interaction with in persons around them (eg. the child-the teacher) , and also have an indirect impact from the interaction people around him (eg. parents – the teacher).

Secondly, I investigate local level of practice which may have influence parents and teachers (eg. school policy, local level of support system). Thirdly, I investigate and also national level of system and practice (eg. education system). I consider how these different levels of system and practice may have an impact on the child's education.

I do this by investigating the experiences in each stages of the process that the participants described.

Figure 3.1 shows the ecological system of my study.

Figure 3.1. Ecological system of educational system and practice



3.3. Social efficacy theory

3.3.1. Self efficacy

In my study, impact of interaction between people (eg. the ill child – teacher, parent – teacher) on the child is the important issues that I investigate. In order to consider process of this influence, I chose concept of self efficacy which is in Albert Bandura's self efficacy theory to use supportively. Self efficacy is defined as belief about one's own ability to take an expected action (Bandura, 1997).

According to Bandura (1997:116-117), people's action are initially shaped in thought. When people need to take a certain action, they construe situations and predict the likely outcomes. When they predict positive outcomes, how things go in a good way, people may take action. On the other hand, if they predict negative outcomes, how things go wrong, they may not decide to take action. Bandura (1989:1181) notes that these conceptions of prediction are formed on the basis of influential factors, which are the knowledge gained through observational learning, inferences from exploratory experiences, information conveyed by verbal instruction and pre-existing knowledge. In this process, people's belief about their own ability to judge to what extent they can manage things to result in positive outcomes may influence the decision that they make. If people think that they do not have the ability to manage things, they may not take action in order to avoid failure. However, if they believe that they have the ability to manage things, they may take action to achieve a positive outcome. Bandura calls people's self belief about their own ability self-efficacy.

The simplified concepts of decision making process that I understood from Bandura's theory (1997) is

When a person considers whether she takes an action or not in a certain situation, she first **refers to influential factors** that she has as her own knowledge (which she obtained by observations of others, experiences, instructions, pre-existing knowledge). Secondly, she makes **a prediction of outcomes**. Thirdly, **make decision to take or not take action**. Sufficient knowledge may strengthen her self efficacy, and it may lead her to take action. Insufficient knowledge may weaken her self efficacy and it may lead her not to take action.

I discuss in later chapter about influential factors, which may have an impact on teacher's positive and negative attitudes towards ill children. I considered that data of **'facilitating factors' and 'obstacles' to respond to the needs** were people's perception about something may influence the teachers' action. I also considered that data of **teacher's 'supportive attitudes' and 'unsupportive attitudes'** were action that teacher took.

In my study, the participants often said the words 'aware'. For example, they said 'awareness about child's difficulties' and 'lack of awareness of his own obligation'. Without being aware of the child's difficulties, teacher cannot provide support to deal with it. Similarly, if teacher were not aware of own role and responsibility to support the child, teacher may not be motivated to take an action. Therefore, I consider that **awareness** is something occurred in between the first and the second stage.

Therefore, I developed three categories for my study as below.

- 1) Influential factors
- 2) Teacher's awareness
- 3) Teacher's supportive / unsupportive attitudes

These categories are used in Analysis and Discussion Chapter (see Chapter seven)..

3.3.2. Causation model

In discussions in Chapter seven, I borrow Bandura's causation model in order to develop my own model.

Self-efficacy theory provides a causal structure of human behaviour (Bandura, 1997). It assumes that human agency is determined by interaction of personal, behavioural and environmental factors, and factors also determine each other reciprocally. Bandura developed a model consisting of the following three variables to describe causative factors in human agency, which he called triadic reciprocal causation (see Figure 3.2.).

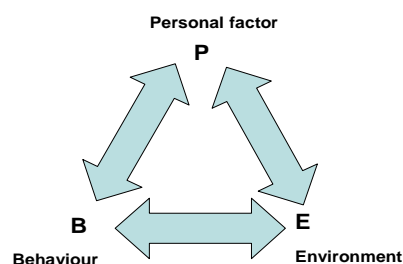


Figure 3.2. Triadic reciprocal causation model (from Bandura, 1997. 5)

Personal factors mean internal personal factors such as cognitive, affective and biological events which affect the person's perceptions and actions. Behaviour signifies the person's performance. Environment means the external factors around the person. All factors interact reciprocally to determine each other. This mechanism functions (1) when people acquire competencies, and (2) when people take any actions in general.

I borrow this model and develop a model for my study (see 7.3.). However, my study is not about self-efficacy. I use this model to consider relationships between teacher's attitudes, teacher's awareness and influential factors (see 7.3.).

3.4. Summary of chapter three

This chapter presents two theories are relevant to my study.

Social ecological theory helps me to investigate the whole systems of provision of education for children with medical needs. I investigate three systems in different stages (in hospital, at home / at school) and in each system I investigate three levels (national level, local level and interpersonal interaction). I examine the existing relationships between the child and environment alters and a dynamic that may have a impact on the child. Self –efficacy theory inspires me to develop categories and a model to examine teachers' attitudes towards the child. They are used to examine the relationships of teacher's attitudes, awareness and influential factors.

Next chapter explains the research design of this study.

Chapter Four

Research Design

4.1. Introduction

According to Cohen et al. (2005), there are two principles to determine the methodology. Firstly, research design is governed by '*fitness for purpose* (ibid, P.73)'. That means, research strategies and methods should be appropriate for the purposes of the research. Secondly, the research design should be *workable* (ibid, P.73). That means, practical research design should be decided considering the balance between what could be done ideally and what would actually work. In this chapter, I explain the methodology of my study applying these principles. Firstly, I explain the origin of the study in order to describe the issues that I was concerned, and identify the purposes of the study. Secondly, I explain the methodology. I consider the reasons why the approaches and theories underpinned my study are appropriate to my study. Thirdly, I demonstrate the overall research design. I then explain context of the study identifying differences between ideal research instruments and reality. Thirdly, I explain details of research methods and selection of participants. Fourthly I discuss the ethical issues. Finally, I explain the methods of data analyses, and consider the limitation of the study.

4.2. Aims and research questions

The aims of my study are:

- To explore the experiences and perceptions of 1) young persons who experienced hospitalisation and 2) parents of children with chronic illness about education for children with medical needs in England and Japan.

- To explore the experiences and perceptions of teachers in hospital and mainstream schools about education for children with medical needs.
- To explore possible differences and similarities of those groups of people's perceived barriers to education for children with medical needs in England and Japan.
- To suggest possible areas for improvement to achieve more positive educational experiences for children with medical needs

In order to specify the purposes of my study, I developed three research questions:

4. What are the educational needs of children with medical needs?
5. How do the systems function to respond to the child's needs?
6. What are the barriers to suitable education for children with medical needs?

The first question was to identify the participants' perceptions of educational needs of ill children. It investigates their perceptions about the impact of the child's medical condition, hospitalisation, and any other environmental factors that they would mention on the child's education when they were in hospital, in the recuperation period at home and after they go back to mainstream school.

The second question was to consider the participants' perceptions about factors which facilitate education for children with medical needs. It investigates 1) how the participants understand the systems and policies of education for children with medical needs, 2) their perceptions of their own role and the roles of others, 3) what the parents / the child did to receive educational support in hospital and mainstream

school, 4) what hospital and mainstream school teachers did to provide educational support, 5) any other factors that they would mention which result in positive educational experiences for children with medical needs.

The third question is to identify the participants' perception of difficulties which they considered a cause of negative outcomes in child's education. It investigates what the perceived obstacles were and why they understood them as problems.

4.3. Methodology

4.3.1. Research paradigms

According to Cohen (2005), educational research is taking two different perspectives of social reality. One is the traditional objective approach of positivism and the other is the subjective approach which is referred to as anti-positivism or the interpretive paradigm.

Positivism assumes that the social world is an objective reality which is external to individuals. It assumes that human beings respond mechanically to their condition and environment, and therefore, the researchers' role is to observe the phenomena objectively to analyse the cause and effect like relationships and regularities between selected factors (Cohen, 2005:5-7). They are concerned with searching for universal laws which explain and govern the reality which is being observed (Burrell and Morgan, 1979).

Positivism is often criticised that social world is not fully explainable as a mechanism. Habermas (1972) argues that scientific explanation in positivism seems to ignore important aspects of human society such as values and beliefs. It is not concerned with people's intentions and individualism (Cohen, 2005).

While positivism seeks the objective one reality in which law-like statements can be generalised, the interpretive paradigm aims to understand and describe multiple realities (Pring, 2000). It assumes that social reality is the result of individual people's subjective consciousness; therefore it can only be understood through investigating the views of individuals who are involved in the phenomena, within their natural settings (Cohen, 2005). Within the Interpretive Paradigm people's subjective interpretation and understanding of actions is considered to be knowledge. Knowledge is also considered to be subjectively formed during the research process, therefore, research is assumed to be a product of the values of researchers and cannot be separated from the researchers' subjective views (Mertens, 1997).

The Interpretive Paradigm assumes that people are not passive and mechanically react to environment but that they act intentionally and actively make decisions about their activities (Blumer, 1969). It denies the existence of cause and effect like universal laws in the social world which positivism seeks. Instead, the social world is considered to be formed by interactions of people's behaviours, and assumes that people understand and interpret the meaning of the phenomena and their experiences from their point of view (Usher, 1996). In view of these assumptions, the interpretive

approach seeks to explain how the phenomena are understood and interpreted by those who are involved in them (Pring, 2000).

4.3.2. The paradigm adopted in my study

In my study, I adopted the interpretive paradigm. This is because the interpretive approach has some distinguishing features which I regarded as appropriate for my study for following reasons. Situations of children with chronic illness are often changed depending on their condition and treatment that they have, such as staying in hospital or at home, having ill condition or recovering and going back to school. In the process of these changes, many different people are involved in the child's education. These people may have individually different views about the child's education. The interpretive approach is appropriate to investigate situations which are changing rather than fixed, and which involves multiple interpretations of and perspectives on single events and situations (Cohen, 2005).

According to Beck (1979), the purpose of social science is to understand social reality as different people see it and to demonstrate how their views shape the action which they take within that reality. Adopting this point of view, my study investigates perceptions and experiences of different people involved in education for children with illness in order to demonstrate how they interpret their experiences and how their views have an impact on the children's education.

According to Usher (1996) and Pring (2000), researchers need to be aware that phenomena may be observed subjectively by the research participants and the

researcher in the process of research. In order to reduce the subjectivity which interferes with the interpretation, Usher (1996) suggests that being aware of the researcher's own pre-understandings of phenomena is important. In my study, I investigate practice in hospital schools and other educational institutions. As I myself was a hospital school teacher, I avoid any risk to support for hospital school. I include any negative issues about hospital schools in order to investigate the data objectively as much as possible.

4.4. Research design

4.4.1. Approach

4.4.1.1. Qualitative study

My research is a qualitative study, using interpretive method approach attempting to make sense of the concept of education for children with medical needs while they were in hospital, at home and after they go back to mainstream school. I decided to use qualitative data in my study because the phenomena that I was looking at were a natural setting and I wanted to investigate it from perspectives of people who were involved. Qualitative data was considered to be appropriate to collect rich data of people's experience and perceptions to understand the phenomena of education for children with medical needs as a whole from people's point of views.

4.4.1.2. Case study

This study is a multiple case study which involves two cases of provision of education for children with medical needs in England and Japan.

Yin (1981) defines the case study as an empirical inquiry that:

- investigates a contemporary phenomenon within its real-life context; when
- the boundaries between phenomenon and context are not clearly evident; and in which
- multiple sources of evidence are used.

This study investigates the phenomena of education for children with medical needs from the point of view of different groups of people involved in order to identify the barriers to education for this group of children. As the investigated phenomena involve various people, such as child, parents, teachers and peers, I considered it appropriate to collect data from different sources to investigate the process as a whole. Moreover, the issue that this study aims to identify, that is what people consider as barriers to prevent education for children with medical needs, may be different for different people, according to their roles and various influential factors. It seems to be complex to identify how such perceptions interact and construct a whole. As mentioned above, Yin (1981) suggests that the case study is appropriate to investigate phenomena in which the phenomenon and context are not clearly separated. Evidence from multiple relevant sources may help to understand complex phenomena. The case study approach is considered to be suitable to investigate the topic of this study, which involves complex interactions of people, through data from various points of view.

I chose multiple case study approach because I expected that contrasting different cases

may help me to understand case of Japan more objectively and clearly. I have only two cases because I consider it would be appropriate to make my study simple and

clear. I chose England as a case to contrast with a case of Japan, because both countries are similarly developed democratic countries, and they have the national insurance system and the compulsory education system until 16 years old, which may be related to the topic that I investigate. A practical reason for this choice was that I had an opportunity to study in a university in England, therefore I expected that it would be convenient to find appropriate participants to my study through the network of the university staff.

4.5. Selection of participants

This section presents the selection of samples. Firstly, I explain theoretical framework for the selection of participants. Then I present the process of selection, followed by the list of participants.

4.5.1. Theoretical framework for sampling process

I adopted interpretive paradigm in my study in order to investigate education for the ill children from different perspectives of people who are involved. Educational settings of children with medical condition may be changed depending on where they are, namely, in hospital, at home, or at school (DfES, 2001a). In the process of these changes, many different people are considered to be involved in the child's education. I expected that perspectives of such different people who are involved in the child's education would be useful to explore the real world of phenomena, education for children with medical needs.

In order to investigate the phenomena systematically, I used the concepts of social ecological theory (see 3.2.). This is because this theory may help me to understand dynamic and complex needs of children who go through different stages of process such as 1) hospitalisation, 2) re-entry process to mainstream school after the child's discharge from hospital and 3) after they go back to school. Bronfenbrenner (1979) suggested considering a perspective of a time related component in investigation, as environmental change around the child may have an impact on the child. I consider that educational settings in these three stages are important to investigate to understand the child's education as a whole.

Having understood these concepts, I decided types of people to involve in my study as:

- 1) Persons who received education
- 2) Persons who provide education in three different stages

In terms of the first group, I select either persons who experienced hospitalisation in childhood or parents of children with medical needs in each country. Regarding the second group, I select teachers in different settings in each country. In order to focus the investigation on education and to make the study simple, I did not involve the other possible persons around the child, such as medical staff and peers at school.

In terms of persons who provide education, I selected people who may take charge of education in three stages of the child's process; in hospital, at home, and school. From a Literature suggests the educational settings in these stages are generally hospital school, home teaching and main schools (DfES, 2001a: NISE, 2010) Therefore I

selected teachers in 1) hospital schools and home teaching, and 2) teachers in mainstream schools as samples.

4.5.2. The process of selection of participants

4.5.2.1. England

Hospital school and home teaching teachers

I initially made a choice to restrict my search to the West Midlands region in England. This selection was made for practical reasons, that is, for reasons of feasibility to conduct the interviews, as the university where study was located was in the same area. I searched the websites of all 33 local councils in the region to find hospital schools. I looked at the information about education for children with medical needs and the list of schools. Five councils presented information of alternative education for ‘children with medical needs’ or ‘children in hospital’. One of them was a special school and the other four were Pupil Referral Units (PRUs). I sent request letters to five schools (see Appendix 1). One special school and one PRU accepted to participate in the research.

The second stage of the selection of special school and PRUs was to use a list of hospitals in the network of Children’s hospitals specialised in child cancer, which is called Children’s Cancer and Leukaemia Group (CCLG). I knew about this network at the seminar for teachers about child cancer. According to CCLG (2007), specialist medical treatments of child cancer and leukaemia are provided in the 20 hospitals in the UK, among which thirteen hospitals are in England. That is, any children in England who need such treatment would stay in one of the hospital in the list. Child

cancer is one of the illnesses which are often discussed in the context of having an impact on the child's school life (eg. Vance and Eiser, 2000). I hoped that hospitals in the list would provide useful insight into finding out how children with cancer are supported in their educational needs in hospital. In order to find hospital schools in the listed hospitals, I used the websites of all 13 hospitals and general search engines, using key words such as 'hospital school in X (name of the city where the hospital is located)' 'hospital and home teaching service in X', 'special school for children with medical needs in X', 'PRU for children with medical needs in X', 'Hospital and outreach educational service in X'.

These key words were developed through the following considerations. According to the website of a special school in the West Midlands, which provided hospital school education, the school was described as 'specialised in children with medical needs', which seemed to be different from other special schools for children with physical difficulties. Similarly, one of city councils described the PRU, which provided hospital school and home teaching, as 'PRU for children with medical needs' or 'specialist unit for medical needs'. They were differently classified from another type of PRU for children with behaviour problems. Such information about names and categories was useful to develop key words to search other hospital schools in other regions.

As a result, I found three special schools and four PRUs which provided hospital school education within the hospitals in the list. Out of the three special schools and four PRUs, one was the special school in the West Midlands that I had already

contacted. I sent request letters to the remaining two special schools and four PRUs. One PRU accepted to take part in the research.

A third method of sampling was employed in order to expand the scope of data sources. I made use of the opportunity to discuss my research interest with a number of special schools and PRUs from outside the West Midlands. This opportunity was presented to me by taking part in number of seminars and conferences where I made contact with the representatives of these schools. Out of these, two special schools in and one PRU gave me the opportunity for unofficial visits. Only the PRU agreed to take part in the research officially.

In each of the special schools and PRUs which agreed to participate, the head teacher or the head of department selected the teachers to be interviewed. Three teachers in the special school, one head teacher and three teachers in one of PRUs, and four teachers in other PRUs were interviewed.

Mainstream school and local authority

In the case of the mainstream schools, I expected to be able to access mainstream schools which hospital schools and units had worked with. However, hospital schools were reluctant to disclose mainstream schools because of confidentiality issues in connection with the pupils. Instead of this, I accessed two mainstream schools, one primary and one secondary school, through the assistance of colleagues at university. Although they were opportunistic samples, they were good examples of local schools which provided education for children from multi cultural backgrounds who had various needs. The secondary school that I visited had experience of working with one

of the researched hospital schools to support a pupil in the hospital. The schools selected the participants. One teacher and SENCO participated the study. A head teacher of the primary school also participated.

In addition to teachers, the educational consultant service for parents of children with special needs which belongs to a local authority was selected to be interviewed. The reason for this selection was that it was a typical service which any local authorities in England have, but that there was no similar service in Japan. Therefore, it was considered to be important to have data from this service to understand the system in England.

The possible weakness of the selections of samples in this group of people who provide education is that the limited numbers of samples may not reflect a variety of schools. That is, all sample sites of hospital schools, PRUs and mainstream schools were in urban areas which may not reflect the perspectives of schools in rural areas. Smaller sized hospitals than the selected hospitals may have different systems for children, and hospitals which have specialities of certain medical conditions may provide different support for children in the hospital. Therefore, the limited numbers of hospitals in this study cannot reflect such varieties.

Persons who were in hospital at school age

The data of experiences of children with medical needs were collected by interviews with young people who were in hospital at school age. There are two reasons for this selection. Firstly, it is likely to be difficult to do research on children in hospital. As it is pointed out by some researchers who carried out research with children with

medical needs, it is a complicated and time-consuming process to receive ethical approval from the NHS and the relevant ethical committees to carry out research in hospitals (Alderson 1995; Miller, 2000). For example, Stalker *et al.* (2004) who interviewed children with medical needs reports that the process of obtaining ethical approval and access to children was complicated and time-consuming. As a result, the delay affected the following research. As a researcher from outside the UK, it seemed even more difficult for me to deal with this problem under the unfamiliar system. Secondly, as the literature shows, researchers often point out that many children with medical needs are staying at home or in mainstream school, rather than in hospital (Farrell *et al.* 2003; Ofsted 2003). Even if I had been able to recruit the interviewees through hospital or hospital school, it might have been difficult to access those who had been discharged.

The interview participants within the group of people who received education for children with medical needs were university students and staff who had experiences of hospitalisation and illness in their childhood. They were recruited as voluntary interviewees through posters that I distributed in various public spaces on campus including libraries, restaurants and shops for one term. The reason for this selection was that there might be some interviewees from various backgrounds. As a result, one member of staff and two students who responded were recruited as research participants.

A possible weakness of this selection method was that there might be students and staff on campus who may not have seen the posters and therefore were not involved in the interviews. The sample also did not involve people with different educational back

grounds other than university backgrounds. These limitations were taken into consideration in dealing with the data, especially in recognising that generalisations were not possible.

4.5.2.2. Japan

Hospital school and home teaching teachers

In searching special schools which provide education in hospital and home teaching in Japan, I used the list of special schools for children with medical needs which were published by the association of head teachers of those schools (Association of Head Teachers of Schools for children with health impairment, 2010). In addition to special schools, I searched units in which designated mainstream primary or secondary schools provided outreach teaching in hospital. For this purpose, I used a list of the participant schools of one of the regional seminars for hospital school teachers that I had attended in the past. I selected schools from one of the prefectures in Kanto district. Three special schools and two main stream schools which provided education in hospitals in the prefecture were sent request letters (see Appendix 2). One hospital school accepted to participate in the research. The head teacher selected the teachers to participate in the study. A head teacher and two hospital teachers were selected as participants.

A possible weakness of this sampling method is that only one special school was selected, therefore, the study could not involve any data about other special schools and units in hospitals.

Persons who experienced hospitalisation in childhood and parents

Accessing children with medical needs who received education in hospital and home teaching was difficult in Japan as well as in England. The school that I accessed allow me to have interview with teachers but was reluctant to involve the pupils and their parents into research. Instead of accessing this group of people through schools, I accessed two charitable organisations which support families of ill children, one was for chronic illnesses and the other one was concerned with children with cancer. However both of them replied that they would not participate in any research for degree purposes.

Because of conducting research from a distance, that is, from the UK, getting access to appropriate sites and participants was particularly difficult. The online forum presented a feasible and accessible source of data. A discussion about this selection of method is present later (see 4.5.3.3.). One of the reasons was that the participants in the forums involved different groups of people, such as parents, teachers of children with illnesses and people who had childhood illnesses, who might provide rich data for the study.

I used one of the widely used online social network systems (SNS) in Japan. Anyone who is over 18 years old and who can read and write in Japanese is able to register the SNS. This SNS does not have any social, political, or religious ideologies.

In order to select participants, I accessed online forums for families of ill children and people who support children with illnesses. I selected this SNS specifically because the purpose of each community and eligibility of members were clearly explained by

the organisers, and the memberships were also assessed by the named organiser. This system was helpful to identify suitable communities to access for my study purpose.

I firstly selected the communities within the SNS according to the context of the communities by using the search engine in the SNS. Key words were children with illness, children with difficult illness, children with cancer/ kidney trouble/ heart trouble/ asthma/ mental health, family of children with illness. This produced a result of 83 possible communities in all. Secondly, I selected 23 communities out of the 83 according to the criteria as follows:

- Communities which aim to share information about social issues to support families and children with illness
- Communities which are concerned with children with illness who are in Japan

Thirdly, I selected 5 communities out of these 23, which I, as a researcher, was eligible to be a member of. I did not select the communities for ‘patient’, ‘family of patient’ and ‘medical practitioners’.

Finally, I examined the topics in the forums of the selected five communities, and found two communities which had school related topics. I selected three topics from these two communities which were relevant to my study. The topics were ‘problems about education’, ‘general school issues’, and ‘school when the child is under treatment’.

I sent a request mail to the organiser of the SNS and the organisers of the forums that I selected asking for consent of using the forums as selecting research participants (see Appendix4). I introduced my self, position, and explained purpose of mu research.

I explained what data I needed, that is, posted comments on the forum and any further information by asking questions through email. In the mail, I explained how I would maintain confidentiality, anonymity, and privacy of the participants. For example, I do not disclose any individual name, handle name, name of place as well as other private information. Then I asked if to contact participants for this purpose is against the SNS and the community policy.

After I obtained consents from them, I sent request mails to the all participants, who participated in the discussions of the topic that I selected. In the mail (see Appendix 5) I introduced my self (name, position, contact address) and explained purpose of the research. I explained about voluntary participation, withdrawal, my obligation to maintain confidentiality and so on. I asked them if they are interested in participation send me back the consent form by mail function of the community. I offer three level of participation. 1) agree with using some comments that he / she selected, 2) agree with using all comments that he/she sent, 3) agree with further questions by email. (see Appendix 5.and 4.5.3.). Three people who experienced hospitalisation in childhood, eight parents and three teachers participated. Three of them chose 2), and other chose 2) and 3).

Ethical issues in using online forums are discussed later in the section of ethical considerations in online research (see 4.5.3). Validity and reliability of using internet as research data are discussed later (see 4.7).

A possible weakness of this sampling method is that samples may not involve people who could not access the internet, as the literature about limits of internet research confirms (eg. Krants and Dalal, 2000. in Whitehead 2007:784). Moreover, the size of the sample was limited. Therefore the study may not reflect experiences and views which reflect a variety of medical conditions. Validity and reliability of data collected from the internet are also needed to be considered. This is discussed below in the validity and reliability section (see 4.7.).

4.5.3. List of the participants

The list of the participants of this study is presented in the table 4.1. In England, twelve teachers in special schools and PRUs, three teachers in mainstream schools, three consultants in a local authority were involved as a category of people who provide education. In Japan, three teachers in a special school, and three teachers in mainstream schools were involved in this category.

Table 4.1. Participants of the study

Categories	Groups and individuals involved		England	Japan
People who provide education	Special schools and PRUs	Headteacher	1	1
		Hospital teacher	6	2
		Home teacher	5	0
	Mainstream school	teacher	2	2
		Health teacher	0	1
		SENCO	1	0
	Local authority	Consultants	3	

People who receive education	Parents of children with medical needs	0	8
	Young people who were in hospital at school age	3	3
	Total	21	17

Health teacher in the list is a qualified teacher who takes charge of health care and health education in Japan (see 6.2.1.) As the list shows, the numbers of participants in two cases were unbalanced. Although they are not ideally balanced, variety of participants covers range of two targeted groups, which I explained in theoretical framework for selection of participants (see 4.5.1.). That is 1) persons who received education and 2) persons who provided education. As regards teachers, participants involved teachers in different settings. Therefore, I consider data is useful to examine in this study.

4.3. Data collection methods

4.3.1 Face to face interviews

I used face to face interview as one of the data collection methods for my study in Japan and England. I explain the reasons for selecting these methods and how I used it in my study.

I used face to face interviews with the two groups of people (provider and receivers of education). One of the advantages of the face to face interview is that it is useful to collect descriptive data through oral questionnaires. Drever (1995: 8) describes this point as follows, ‘the interview can provide depth of explanation within a particular context, while questionnaires paint a broad though possible superficial picture’.

Another advantage is to avoid low respondent rates which might occur in postal questionnaires (Robson, 2002; Martens, 1998). Face to face interview has also beneficial as observing the respondent's body language and their contextual surroundings may also provide data (Martens, 1998). I selected this method because the respondents may describe the detail of cases in conversation style rather than writing it on the paper. I expect that an interview enable me to ask questions flexibly rather than fixed questionnaires.

According to Yin (2003; p.90), the open-ended question is considered to be an appropriate strategy to ask "key respondents about the facts of a matter as well as their opinions about the events". Thomas (1998; p.129) describes this type of questions as 'loose question strategy' or 'Broad questions approach', which aims to reveal variable ways of respondents' interpretation through general questions. The aims of the interviews in my research were to collect data of people's perceptions about what the child's needs are, how the system facilitates to respond to their needs, what the met and unmet needs were and why, from individual people's points of view. Considering these aims and the diversity of samples, it seemed important to ask questions which did not restrict the respondents' replies. Therefore open-ended questions were developed to be used in all the semi-structured interviews in my study.

4.3.2. Online research

This section firstly reviews how the online research method has been used in previous research, and explains the reasons and purposes of this method in my study. It then explains how I used online research in Japan. Ethical considerations in online research are discussed later (see 4.5.).

In the literature, the internet has been used as a research tool to do research with people who have health conditions and disabilities. Research is often done by online questionnaire surveys via e-mail or web page delivery (eg. Meho, 2001; Berger *et al.* 2009) and observation of the internet communities of relevant people (eg. Klemm *et al.* 1998; Brownlow *et al.* 2002). According to Brownlow and O'Dell (2002) and Mann and Stewart (2000), the benefits of using internet as a research tool is that it offers possibilities for researching groups of people who are hard to research in traditional methodologies. Brownlow and O'Dell (2002) observed the online communities of people with autism and explained a reason to use this method is that the use of the internet by autistic people was increasing as a forum for self-advocacy and a way of meeting other members of the autistic community (e.g. Blume 1997), which enabled researchers to hear voices of people in naturally occurring discourse in online forums. Similarly, communities for patients of certain medical conditions are considered to be rich resources of qualitative data for health researchers to understand the experiences and views of people and patients (Eysenbach *et al.*, 2001). Another example is Rodgers and Chen (2006), who researched an internet community of women with breast cancer by observing postings to the bulletin board.

I used online communities because I considered it would help me to hear voice of different groups of people. As the purpose of the study is to consider perceptions of different groups of people who are involved in education of ill children, I expected that participants involving a variety of stakeholders would enable me to investigate opinions from different perspectives in naturally occurring interaction among them.

I selected the community following the ethical requirement (see 4.5.3.). I used online communities for families and people who support children with medical needs in Japan in order to understand the participants' views and experiences related to education for ill children. Previous research found that patients and their families are likely to use internet communities to seek information and interaction with peers (Klemm 1998; Rodgers *et al.* 2005; Suzuki *et al.* 2003). After I obtained consent from the participants of the forums (see 4.5.3.), I sent email to ask them questions. Qualitative data of their experiences and opinions were collected. Details of process and ethical consideration is presented later (see 4.5.3.).

4.4. Development of interview schedule

4.4.1. Semi-structured interview

According to Robson (2002: pp270), there are three types of style of interview: Fully structured interview, semi-structured interview, and unstructured interview. Fully structured interview has questions with fixed wording in a pre-set order. Semi-structure interview has predetermined questions but the order and wording of questions can be modified based on the interviewer's perception of what seems most appropriate. Unstructured interview lets the conversation develop within the area of interest and concern.

In my study I use semi-structured interviews because this seem to be appropriate to collect rich descriptive data of participants' experience and opinions which covers certain topics that I investigate. As my study investigate the participants' personal experience and opinions, I consider that it is important to ask questions flexibly in the

interviews in order to let the participants talk what is important for them to talk. Flexibility in order and wording may be also important to establish rapport.

4.4.2. Interview schedules

Interview schedules are developed based on the research questions. I mainly use open-ended questions. The advantage of this type of questions is that it lets participant answer flexibly and allows the interviewee to widen or go in depth of what are talked (Cohen, et al. 2000). I consider this flexibility is important in my study, because it may allow participants to talk about the topic according to their interpretation and priority, and also allows me to collect appropriate data for my study by asking following questions.

As an example, some extracts from the interview schedule for young people who experienced hospitalisation in childhood are shown below (see Appendix 3)

- 2-1 Could you please tell me your experience about education when you were in hospital?
- 2-2 What was your main concern when you were in hospital?
- 2-3 What was helpful / unhelpful for you to reduce your worries?
- 2-4 What do you think the reason for it?

First question is asking the participants' experience of education while they were in hospital. I did not narrow the topic, for example, whether there was hospital school or not.

I expected them to explain anything significant for them in order to expand the interview from what they talk. The second question is made to answer the research question about the child's needs. The third one is asking how the systems /practice

worked and what they think as useful and useful support. The fourth one is asking to answer the third question, obstacles to respond to their needs.

Interviews schedules for all groups of people can be seen in appendix (see Appendix 3).

4.5. Ethical considerations

4.5.1. Ethical considerations

The study applied for ethical approval from the Ethics Committee in the school of education of the University of Birmingham in 2007. In this section, I explain how this study adheres to the ‘code of practice for ethics’ of University of Birmingham (2013) and the ethical guidelines by the British Educational Research Association (BERA, 2011). I do this by addressing nine suggestions by BERA (2011) and other issues in the code of practice of University of Birmingham (2013).

Voluntary informed consent

BERA (2011) required researchers to ensure all participants in the research understood the process. It especially notes:

Social networking and other on-line activities...presents challenges for consideration of consent issues and the participants must be clearly informed that their participation and interactions are being monitored and analysed for research (BERA, 2011: 11)

In order to fulfil this, I obtained consent from the interview participants and the online forum participants. I explain the process of gaining consent for the face to face

interviews. The process of gaining consent from the participants of the online forums is followed.

Firstly, request letters to participate in the research were sent to the head teachers of the schools and their approval was received either by post or by emails. Secondly, the individual teacher's consent was obtained orally prior to the interviews. I did not obtain written consent because the ethical guidelines, which I applied at that time, did not specify the form of consent that was needed. Consent was obtained addressing the ethics guideline as follows. I developed an interview check list (see Appendix 4) according to the BERA guidelines (2004). The interviews were conducted following this check list, and I made sure that the participants understood the process and agreed to their participation. I explained their voluntary informed consent (BERA, 2004: 10, 11, 13), their right to withdraw (ibid, 15) and how privacy and anonymity would be protected (ibid, 25-28). All the interview participants were asked for their consent after this process, and consent was obtained orally. Permission to audio record was also obtained prior to the interviews.

In terms of participants of the online forums, I followed BERA (2011), and the guidelines by Association of Internet Researchers (AoIR, 2012) and The Code of Practice of Ethics (University of Birmingham, 2013). I followed the guidelines and relevant research books throughout the research, that is, in the process of selected the community, obtained consent and data analysis and presentation (See 4.5.3.).

In the section of ethics on online research of my study, I explain how each topic related to my study. In the section (see 4.5.3.), I surmised the process, and what I

used as data. I explained how I protect the confidentiality in the presentation of the findings (see 4.5.3.).

Openness and disclosure

Researchers must therefore avoid deception or subterfuge unless their research design specifically requires it ... (ibid, 14)

I disclosed my self as a researcher to any participants of this study. For example, when I sent the request letter to schools, I explained myself, my position and contact address as well as information about research. When I contacted the organisers and the forum participants, I sent mails through the community system, in which I explained my self, my position.

Right to withdraw

I explained the ethical issues, including the participants;' voluntary participation and right to withdraw to the interview participants before I started interviews. In terms of participants in the online forums, I also explained the same issues in the mail when I contacted them.

Children ,vulnerable young people and vulnerable adults

BERA (2011:20) notes that researcher needs to avoid distress or discomfort in the research process and to reduce the sense of intrusion and to put them at ease. The group of young people in this study are all in their 20s; therefore, children under the age of 18 were not involved in this study. However, the young people and adults who

were involved were considered to be vulnerable as they were patients or members of families of patients. I considered their vulnerability seriously, and avoided distress or discomfort in the interviews. For example, I selected the place for the interviews. I used the private rooms in the library on campus or in schools in order to avoid any risk of distress. I prevented their stress and threat of disclosing sensitive topics in public. I selected a quiet and bright room to make them feel at ease.

Incentives

BERA(2011) suggests to avoid any incentives to encourage participants. I did not provide any incentives to the participants.

BERA(2011) also note,

Researchers must take steps to minimise the effects of designs that advantage or are perceived to advantage one group of participants over others.

In order to avoid any risk of incentives, I involved any positive and negative data for any groups of participants.

Detriment arising from participation in research

I avoided any detriment arising from participation in research. For example, I did not disclose any private information that I obtained from the participants. I also avoided any negative impact of requesting online forum participants to participate to my study. This is discussed later (see 4.5.3.)

Privacy

In the process of the research, confidentiality and anonymity of all the participants were protected as follows. The data was kept confidential in a lockable cabinet and

PC which required password. The data were used only for the research purpose. I understand that sensitive topics were treated as confidential issues as ESRC (2003) also suggested. I considered that all data about individual children and adults such as name of illness and place of hospital /school were anonymous, I made fields notes without identifiable information of individual persons, and saved any record of private information, such as contact details, separately from the field notes. therefore, in order not to disclose the identity of individual persons.

Disclosure

BERA(2011:29) note,

if the behaviour is likely to be harmful to the participants or the others, the researchers must also consider disclosure.

In my study, it was unlikely to identify any harmful behaviour. But I understood my responsibility of this disclosure, and I understood where to report in case I identified any concerns. That is, I understood who was the responsible and appropriate person to report, such as school teacher in the school that I visited for my study.

From the Code of Practice (UoB,2013) I write here which were not mentioned so far.

Research Data

Researchers are required to keep clear and accurate records which must be in durable and auditable (UoB,2013). Audio recorded interview data and transcripts, record of analysis, any corrected documents and record were kept.

Ethical review

My study had ethical assessment and approval from university before I started data collection in 2007.

Misconduct, Mismanagement of data

Code of practice (UoB,2013) notes

fabrication, including the creation of false data or other aspects of research including research documentation such as regulatory or internal approvals or participant consent

I did not have any misconduct in my study. There is no fabrication and creation. All relevant data and record are kept to approve this. In order to avoid any mismanagement of data, any data were recorded.

Plagiarism , Misrepresentation

I presented reference of any thought and ideas from other publication.

Mismanagement of data

I avoided mismanagement of data by keeping confidentiality of participants.

4.5.2. Ethical considerations in research on sensitive topics

Researching on experiences related to health issues is considered to be a sensitive area which requires special consideration in conducting the research from the researcher.

Lee (1993: p.4) defines sensitive research as ‘research which potentially poses a substantial threat to those who are or have been involved in it’. If there are any risks that researchers or participants feel threatened in the process or as a result of the research, such research is considered to be sensitive. Disclosure of private experiences

in interviews, for example, might be threatening for the interviewees. However, it should be taken into account that the level of stress is different depending on the individual person. Careful consideration of privacy, confidentiality and 'a non-condemnatory attitude' of researchers are important to build trust with research participants (Lee, 1993: p.98). The issues of sensitivity affects all stages of the research process in a variety of forms, therefore researchers should consider any potential risks in methodological, ethical, technical, political and legal issues throughout the research process (Lee, 1993).

Brannen (1988) in Lee (1993: p.102) suggests contingencies in interview research on sensitive topics. Firstly, he suggests that the researcher should bear in mind that the interviewees will very likely talk about sensitive or confidential information when trust has been established between the researcher and the interviewee. If the researcher reveals their definition of the topic in the early stage of the interview, it might restrict the interviewee's own definition, which might result in 'depersonalizing' the respondents (Lee, 1993:p.103). In order to prevent this, it is suggested to present the topic gradually in the process of the interview (Lee, 1993). Brannen (1988, in Lee 1993: p.102) also suggests that the complexity of sensitive topics and the interviewee's emotions should be taken into account. As sensitive topics are likely to contain complexity and emotionality, it is difficult to investigate them by simple questions or pre-coded categories. Therefore the researcher needs to take into account the interviewee's interpretations about the topic in the process of interviewing (Brannen, 1988 in Lee, 1993; p.104).

In terms of emotional distress, the interviewees sometimes expressed their feelings when they described painful experiences, for example, dislike of people who had showed offensive attitudes towards them. I just responded to express my empathy with their feeling. It seemed to be appropriate to encourage them to continue talking without disturbing their thoughts.

Brannen (1998) also suggests that the interviewing conditions needs to be considered. He stresses that an interview dealing with sensitive topics should be a 'one-off' interview so that the interviewee and interviewer would not meet again afterwards. Braunnen said this is essential to ensure trust (Lee, 1993: p.112). In contrast, some other researchers argue that interviewing with the same person more than once is necessary to deal with sensitive topics. For example, Laslett and Rapport (1975) in Lee (1993: p.113) suggest that different types of data would be collected in the first and second interview. While the first interview provides superficial information, the second one provides more complete data.

I agree with Laslett and Rapport's suggestion from my experience. When I had the opportunity to carry out interviews with the same interviewee twice, both of the interviewees and the interviewer were more relaxed in the second session and more detailed data were collected than in the first session. However, I also understand the merit of one-off interview from my experience of one of my interviews. I carried out an interview with a hospital teacher, who asked me to have a lesson with her students about Japan in her school sometime later. In the interview, she was reluctant to describe her students' medical conditions to me. She said "I cannot tell details now,

because you will see them” She was worrying about any risk that private information might be disclosed to students through me.

Finally, Brannen (1998) stresses that the disclosure of private information from published material must be prevented.

4.5.3. Ethical considerations in on-line research

Researchers often discuss the ethical considerations with regard to online discussion groups in the literature (e.g. The Association of Internet Researchers 2002; Bromseth, 2002; Eysenbach and Till, 2001; Hewson *et al.* 2003; King, 1996; Mann and Stewart, 2000; Markham, 2004). As an example, Eysenbach and Till (2001: 1103-05) clarify seven ethical considerations in qualitative research on the internet as follows:

- ***Intrusiveness***-Discuss to what degree the research conducted is intrusive
- ***Vulnerability***- Discuss how vulnerable the community is.
- ***Perceived privacy***- Discuss the level of perceived privacy of the community.
- ***Potential harm***- Discuss whether the intrusion of the researcher or publication of results has the potential to harm individuals or the community.
- ***Informed consent***- Discuss whether informed consent is required or can be waived.
- ***Confidentiality***
- ***Intellectual property rights***

In this section, I explain the methodological choices I made by referring to the ethical issues mentioned by Eysenbach and Till (2001) and relevant discussions in literature.

4.5.3.1. Intrusiveness and vulnerability

Although data can be collected from online forums without direct interaction between researchers and participants of online communities, it is stressed that researchers need to take the level of intrusiveness and potential harm of researching communities and individual participants into consideration (Eysenbach and Till, 2001). Some internet communities, especially for vulnerable people, are supposed to be involving only people who are vulnerable in the context of their community. Therefore, members are unlikely to expect that a researcher is involved and that the community members are researched. It is reported that the researchers are sometimes perceived as ‘intruders’ and may damage the community (Eysenbach and Till, 2001).

If my appearance is considered as intrusiveness by community members, it would be harmful for the community. In order to avoid this, I carefully selected the community, which are open to anyone including a researcher. I did this following the guidance. This is explained later (see 4.5.3.).

4.5.3.2. Perceived privacy and informed consent

Although it is technically possible to observe online communities without contacting the participants to avoid any influence of research on the community, conducting research without consent of participants is a controversial issue. Even though an

online forum is accessible in public, it is stressed that the ‘perceived privacy’ that the group of participants may have needs to be considered seriously (King 1996:119-129). That is, if the participants consider the forum private, researchers need to obtain permissions from the participants to observe their forums. Brownlow and Lindsay (2002) also note that a group could be private in the sense that only group members or those with related issues are the intended audience, not researchers. Therefore obtaining consent is considered to be important.

The two online communities that I used in my study in Japan were accessible to read within the Social Network System (SNS) (see the details of the researched SNS in 4.5.2.2. and 4.5.3.). The registration of members to these communities was also open to anyone in the SNS who was concerned with ill children. Therefore I registered with these two communities as a researcher and wrote my self introduction as a researcher in the members’ self introduction page within the communities which any members could read. I also explained my self as a researcher in the request mails. I also posted to other topics of the same community as a member; therefore, the members understood that I, a researcher, joined in the community as a member.

Although these facts may indicate that these communities may be considered as public and a researcher is accepted as a member of the community, it may not mean that a researcher is allowed to use the online community for research purposes without any permission of the members. There are two reasons for this. Firstly, a member is expected to contribute to the community by sharing information and views with others, however, using the community for research purposes may not be considered as a direct contribution to the community unless the community has such

purposes specifically. Therefore, as the second reason, other participants may not expect that their discussions in the online forums were observed for research purposes. For these reasons, I decided to obtain consent from the participants to the online communities in Japan that I observed. The process of obtaining consent was described previously (see 4.5.2.2.). I obtained the consent from the SNS organisers, the form organisers, After that I sent request mails to all participants of the relevant topics that I selected (see 4.5.3.). Request mails and a consent form are shown in the appendix (Appendix 5).

4.5.3.3. Potential harm

It is required for a researcher who uses online communities for research purposes to consider any potential harm or risk for the individuals, for online communities and for researchers (AoIR, 2012). In my study, potential harm for the community was that informing the community members about using their forums for research purposes may cause damage for the community if it is not appropriate for the aims of the community. Sharf (1999) suggests that the researcher should consider whether or not the purposes of the research are in conflict with or harmful to the purposes of the group, and whether the research will benefit the groups in some way.

My study investigates people's views and experiences regarding children's educational needs and barriers to education, and reflects their views in an academic study. The aim of the study is to contribute to long term improvements in education for children with medical needs. The selected two communities described their aims as to promote supportive environments for children with illnesses, to reduce prejudice about illnesses, to raise awareness of ill children among the people in society. For

these aims, these communities involved any people who were concerned with ill children such as families of ill children and various specialists. It was unlikely that my appearance as a researcher was harmful to these two communities.

In order to obtain consents from the participants, I followed the process that Brownlow and Lindsay (2002) applied in their research. I made initial contact with the organisers of each community (see Appendix 5), introduced the research project, explained how ethical issues would be secured and asked for the organiser's permissions to use the online communities for my study. After I obtained their permissions, I sent emails to the individual participants to people who posted to the topics that I selected (see 4.5.3.) and asked their consent to use their posted opinions as data for my study (see Appendix 5). I explained that the aim of the study was to reflect the views of families of ill children and people who supported ill children in an academic study which aimed to contribute to the long term improvement of education for children with medical needs.

I used comments of the participants, whose consent I obtained, as data, and I did not use others in my study. I also sent the emails to the participants to my study to ask further questions to support the opinions that they sent.

Another potential risk to the community and the individual may be in the publication of the study. This is discussed next.

4.5.3.4. Confidentiality and intellectual property rights

Regarding confidentiality, Eysenbach and Till (2001) emphasise the importance of avoiding the risk of ‘violating privacy’ in the process of reporting. Because of powerful internet search engines, using the exact words that a participant used in the conversation might reveal the original message, including individuals’ name and email addresses. In order to avoid this problem, it is important to consider whether the material is referred to by direct quote, or whether it should be paraphrased (Association of Internet researcher, 2002). In order to secure anonymity, Milligan (2005) suggests to remove or change all identifying elements from the message header, the name / pseudonym of sender of the posting, and the name of the community. It is also suggested to remove demographic data, and references to places, people and events in the text. I followed these recommendations in my study. I removed any identifying information and avoided direct quotes from the online forums in the presentation of the study.

4.6. Methods of data analysis

The interview transcripts, posted opinions of the online forums and their emails were printed out and read thoroughly. The data were firstly analysed through descriptive coding by highlighting passages. Secondly, codes were grouped according to settings, that is, **in hospital, in recuperation at home, at school, no specific setting**. Thirdly, codes in each group of setting were grouped in order to develop categories. Concepts of grouping were based on the research questions. Concepts were **needs, facilitators to respond to needs, obstacles to respond to needs, positive relationships, negative relationships, system and practice**. As a result, codes were divided into sixteen categories (see table 4.2.).

Table 4.2. Data analysis : categories

Categories					
educational provision	medical needs	academic needs	social emotional needs	positive issue in relationships	system and practice
facilitators to access provision	facilitators to medical needs	facilitators to academic needs	Facilitators to social emotional needs	negative issues in relationships	
obstacles to access provision	obstacles to medical needs	obstacles to academic needs	obstacles to social emotional needs	obstacles in relationships	

The sixteen categories were grouped according to common themes. As a result, six themes were developed. (see table. 4.3.)

Table 4.3. Data analysis: Themes

Themes					
continuity of education	medical needs and support	academic needs and support	social emotional needs and support	interpersonal relationships	system and practice

Table 4.3. shows an example of themes. Categories and codes of academic needs and support, which is based on data of young people who experienced hospitalisation in childhood in England. All codes can be seen in appendix (see Appendix 6).

Table 4.4. An example of a theme, categories and codes

Themes	Categories	Codes
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Academic needs and support	In hospital	Academic needs	overcome delay of study / preparation for examinations
		Facilitating factors in responding to academic needs	teaching style / individual support
		Obstacles to respond to academic needs	Impact of health condition / impact of admission patterns / limits of environment (time, facilities) / teachers' specialism / lack of collaboration with school
	In convalescence at home	Academic needs	Overcome academic delay / Preparation for examinations
		Facilitating factors in responding to academic needs	learning in small groups
		Obstacles to respond to academic needs	Limits of environment (time, facilities) /teacher's specialism / lack of collaboration with school
	At school	Academic needs	Overcome academic delay/ preparation for examinations/ Sitting examinations
		Facilitating factors in responding to academic needs	Teacher's attitudes Teacher's support (additional lessons, work sheets), pupil's initiative
		Obstacles to respond to academic needs	Teacher's attitudes (lack of awareness of needs) / low expectations

Similarities and differences were compared within each group of people, across groups (see Chapter 5 and 6) and across cases (Chapter 7).

4.7. Reliability, validity, and generalisation

4.7.1. Validity and Reliability

As regards validity and reliability in interview methods specifically, Gull *et al.* (2007) suggest 1) to collect evidence of the respondents' opinions, and 2) to determine whether the respondents express similar opinions on other measures of the same construct (Gull *et al.*, 2007:229). I used these suggestions to assure validity and reliability not only for the interview data but also in the online forums data as follows.

According to Frankel (1999) and Wasukul (1996), it is a threat to internet research that the internet user may mislead others about their identities when they participate in the internet research. In my study, I investigated opinions on online communities sent by community member, whose consent I obtained. I also sent emails to them for further questions. These communities were not for commercial purposes nor for promoting any specific ideologies but for sharing information and opinions among members. Therefore, it was hard to consider that members who voluntarily participated in these communities may have used false identities or wrote false experiences purposefully, as there seemed to be no benefit for them to do so. However, in order to assure the validity of what the participants wrote in the online forum, I looked at whether the self reported profiles of people whose consent I had obtained were consistent with other opinions that the same person posted into other topics. I also sent the participants an email to ask about any ambiguities in what they wrote into the online forums. For example, I sent an email to one of members who wrote about the administration process of entering a hospital school. I sent an email to this

participant to ask further information about the hospital school. I then compared the reply that I received with the hospital school policies.

In addition to the strategies that I have mentioned, I employed some other strategies that were suggested in Robson (2005:174) in order to reduce the threat to validity and reliability in this study. These were *triangulation*, *member checking*, and *audit trail*.

Triangulation is the use of multiple sources to enhance the rigour of the research (Robson, 2005). In my study, I used *data triangulation*, which involved more than one method of data collection, and methodological triangulation, which involved qualitative and quantitative data (ibid; 174). For example, in order to identify how the system is organised within a special school, data were collected not only from hospital school staff, but also from other staff such as home teachers of the same sites. I conducted interviews with different groups of people, collected data from relevant documents and online research.

Member checking is returning to respondents and presenting to them materials that the researchers made (ibid: 175). In my study, I asked the participants if they want to ensure the accuracy of the transcript. One participant requested. I sent the interview transcripts to her, and she sent me back. She approved the accuracy of the transcripts.

Audit trail is to keep a full record of the activities while carrying out the study. I kept a record of the raw data such as interview transcripts, field notes, research journals and details of data analysis to refer to any relevant records to ensure the accuracy.

4.7.2. Generalisation

According to Robson (2002), generalisability is the extent to which the findings are generally applicable in situations different from the study (Robson, 2002). This study aimed to identify possible barriers to education for children with medical needs by exploring views and experiences of different groups of people who were involved in education for children with medical needs. As this was a small scale study, as such it cannot be generalisable. For example, this study certainly doesn't reflect education affected by various medical conditions in different settings. As my study is a case study of two cases in limited areas, it aims to understand the situation in the cases as an example. Whether the findings are applicable in other cases or not may be needed further research.

4.8. Limitation of the study

Because of small scale of study, collected data may not reflect perspectives of other people who were not involved in this study. For example, this study could not cover diverse medical conditions that children have. Sample sites of school were selected in certain urban areas in both England and Japan, the study may not reflect issues in any other different areas including rural areas. Moreover, as the study was concerned about education, it involved mainly educational stakeholders but no other experts such as medical staff was involved. In terms of internet research, study did not reflect perspectives of people who do not access internet and who did not participate in the communities which were used in the study. These possible limitations needed to be considered in discussion and generalisation of the study.

4.9. Summary of chapter four

Adopting interpretive approach, this study investigates education for children with medical needs from perspectives of different groups of people. It aims to explore educational provision by perceptions and experiences of stakeholders, people who receive education and people who provide education. I do this in a case study of two cases in England and Japan. Case study approach aims to explore possible differences and similarities of those groups of people's perceived barriers to education for children with medical needs in England and Japan.

Research questions were 1) What are the educational needs of children with medical needs?

2) How do the systems function to respond to the child's needs? and 3) What are the barriers to suitable education for children with medical needs?

Participants are young people who were in hospital in childhood, parents of children with medical needs, teachers in hospital and main schools. Main data collection method is face to face interview; however, online research is also used. Participants are selected from the selected online forums in Japan.

Qualitative data collected by interviews and online research are thematically analysed in order to identify participants' perceptions about barriers to education for children with medical needs. I explained how my study was applied within the ethical guidelines.

Next chapter presents the findings of case in England.

Chapter Five Findings of Case study of provision in England

Chapter 5 and 6 present the data and the analysis to answer the research questions:

1. What are the educational needs of children with chronic illness as perceived by the participating groups of people the study (young person who experienced hospitalisation in childhood / parents of children with chronic illness / teachers in hospital and main schools)?
2. How ill children were supported in system and practice to respond to their needs in different stages in the process between hospitalisation and re-entry to mainstream school?
3. What are the barriers to education for children with medical needs as perceived by the participating groups of people in the study?

The chapters contain interview data and online research data in England and Japan, the perception of stakeholders regarding child's needs, systems of education for children with medical needs and barriers to it. Chapter 5 presents the results of the study in England. Firstly, I present the findings of perspectives of people who received education (Young people who had hospitalisation in childhood). Secondly, I present findings of perspectives of people who provide education (hospital and home teachers / mainstream teachers / local authority). In Chapter 6, I present data and analysis of data in Japan.

I present findings according to six themes; continuity of education, medical needs, academic needs, social emotional needs, interpersonal relationships, system and practice. The tables of codes in context of the themes were demonstrated in each section of theme. All the tables of whole codes of this study can be seen in Appendix 6 . .

5.1. Perspectives of persons who experienced hospitalisation in childhood

5.1.1. Participants of the interviews

Data of perception of pupils with chronic illness were collected by interviews with young persons who experienced hospitalisation in childhood. There were three participants for the interviews of this group in England in my study (see Table5.1.). As explained in previous chapter (see 4.5.2.1.), the participants were two university students and one young university staff who responded to my poster advertisement for voluntary participants to my study at the university where I was studying. Each interview was conducted on campus individually for about an hour. As the findings describe details of three participants' experiences, I use pseudonyms for them, Ben, Judy, and Emma. Ben is experienced hospitalisation in primary school age, Judy was in secondary, and Emma was in both. Their patterns of hospitalisation were either a long term admission or frequent admissions. Ben did not receive alternative educational provision, Judy studied at hospital school, and Emma received education from both hospital school and a teaching centre of PRU.

Table 5.1. Participants of interviews: Young people who experienced hospitalisation in childhood in England study

Data No. (Pseudonym)	Gender	Year when hospitalised	Pattern of hospitalisation	Alternative provision
EY1 (Ben)	male	Year 5 and 6	Recurrent admissions	None
EY2 (Judy)	female	Year11	Long term	Hospital school, PRU
EY3 (Emma)	female	Year 6 to 12	Recurrent admissions	Hospital school, PRU

These participants described their experience in different urban areas in England in late 1990s.

Although the data may not reflect the present situation, I consider that these interview data are useful in my study for three reasons. Firstly, they provided rich data about details of experience at school and in hospital from the pupils' point of view. Secondly, as grown-up young adults, they looked back their childhood experience and explained causes or consequences of certain events from their perspectives. I consider that such data were useful to examine how people interpreted the meaning of experience and events which they were involved.

Thirdly, the Education Act 1993 has already been in force at the days which the participants talked about in the interviews. This Act established a statutory duty for Local authority to provide 'full time or part time education at school or otherwise than at school for those children of compulsory school age who, by reason of illness...' (Department for Education, 1993:19). The governmental guideline for education for children with medical needs (DfES, 2001), which was valid when other interviews in my study were conducted, was also referred to the Act 1993 as its statutory framework (ibid, p.5). Therefore, I consider that the interview with this young people provided useful data about their experiences and interpretation of interaction with

people in hospital and at school, which occurred in the same legal framework as other groups of people in my study. In data analysis and discussion, I took the time difference of data into consideration when it was appropriate.

5.1.2. Continuity of education

The theme of continuity of education examines how the continuity of education was delivered while children were in hospital, while they were at home in recuperation period, and in the process of returning to school (see Table 5.2.).

All the three participants mentioned in the interviews that they had an offer of support from hospital school when they stayed in hospital. Judy and Emma understood that it was statutory to provide hospital education for children in the ward. However, the decision of whether they received education in hospital school or not were mainly affected by the child's condition, the child's needs, patterns of admission and to how extent they could receive support from their main schools. In case the child needed academic and mental emotional support, and also, the child had stable condition while they were in admission, they received education from the hospital school (Judy, Emma).

However, in case the child's condition was too severe to receive education whenever he had short and recurrent admissions, he did not have education from the hospital school (Ben). In his case, he had enough support from main school whenever he was discharged from hospital, which also caused of his decision not to receive education in hospital.

Received educational support in recuperation period and in the process to return to school were individually different. Ben, who had recurrent admissions when he was in primary school, kept contact with main school throughout the process and received provision within school such as allowing flexible attendance at school. Emma, who had recurrent admissions in primary and secondary school, also kept going to school as much as possible in between admissions. She also received support within school such as flexible timetable and attendance, which she accepted helpful for her to keep school life.

Table 5.2. Continuity of education; Young people who had hospitalisation in childhood in England study

Themes		Categories	Codes
Continuity of education	In hospital	Provisions that the child received	Hospital school / support from school
		Reason for receiving education in hospital school	Statutory support / Needs of academic support / Needs of mental support / Needs of social support / Lack of support from school
		Reason for not receiving education in hospital school	health condition / support provided from school
		Obstacles to access hospital school	None
	In recuperation at home	Provision that the child received	Teaching centre /support from school
		Reason for receiving home teaching	Need of academic support, Lack of support from school health condition
		Reason for not receiving home teaching	Support from school
		Obstacles to access home teaching	System / lack of communication
	Return	Provision of returning	Dual registration to

	process to school	to school	alternative and main school / provision within a school / private tuition / interagency meeting / school visit by medical staff
		Facilitating factor in providing smooth return process	system, Communication among stakeholders
		Obstacles in return process	lack of communication

In case of having a long term admission and recuperation period at home, Judy received alternative provision of individual lesson at teaching centre. When she returned to school, she received education from both of teaching centre and school. However, she found difficulties in relationship in peers and teachers at school in this process, which resulted in her changing school afterward. Issues in interpersonal relationship are analysed later (see 5.1.5.).

As preparation for return to school, Ben mentioned that he had collaboration between school and hospital such as meeting and school visit by nurse, which he thought was helpful to promote teachers' and pupils' understanding about his condition.

Data found that continuity of education was maintained for all three participants. However, received provisions and perceptions about them were individually different. The environmental issues such as provided support from school, communication among school, hospital, local authority were identified as influential to their education as well as the individual factors such as health condition, pattern of admission and perceived needs.

5.1.3. Health conditions and medical care related needs

The theme of medical conditions related needs examined the child's health condition which caused difficulties at school and medical care related needs that the child experienced in school setting, while the child was in recuperation period, in return process to school and after they went back to school. The facilitating factor and obstacles to respond to their needs were also examined (see Table 5.3).

Table 5.3. Medical condition related needs :Young people who experienced hospitalisation (England)

Themes		Categories	Codes
Medical needs and support	In recuperation at home/return to school / at home	Child's needs due to health condition	Limit of strength and tiredness / unstable conditions /change of conditions / appearance change / Individuality of condition
		Medical care related needs	Place and time for medical care / teacher's awareness of needs / protecting privacy
		Facilitating factors in responding to health condition and medical care needs	Flexibility (timetable, use of facility, rules) / understanding of needs and condition / sensitivity / communication
		Obstacles to responding to health conditions and medical care needs	Inflexibility (timetable, rules) / lack of understanding of needs and condition / lack of sensitivity / lack of communication

All three participants mentioned that limit of strength and severe tiredness caused difficulties at school when they were not fully recovered or after they had treatment.

They commonly mentioned that flexible adaptation of timetable was helpful when they could not attend school whole day. Flexibility in rule (eg. leaving the lesson earlier to move to another classroom) and in usage of facilities (eg. putting a chair in the playground to take a rest in lunch time) were also considered to be useful to reduce the child's difficulties.

Receiving medical care or medication at school was considered as a sensitive issue, as different children have different views about how to do it. Ben openly had medical care such as taking blood tests at school by a nurse, which promoted other children's understanding about his condition. In contrast, Judy thought the medication as a private issue. She was annoyed about other people interfering with it. She needed a secure place and time allowance so that she could take the medication without letting other students know about it.

In order to provide appropriate support to respond to children's needs, all three participants mentioned that teachers needed to understand the child condition and medical care needs. Ben, who had positive experiences of receiving well support in his primary school, considered the reason for supportive atmosphere was that all teachers knew about all children as it was a small scale of primary school, therefore, his condition and needs were well understood by teachers. He also mentioned that the school, the hospital and his home were located closely, which may have caused good communication in teachers, medical staff and his parents.

As an obstacle to responding child's needs, negative experiences of lack of teachers' understanding the child's health condition were found in the interviews. Emma and Judy claimed that child's chronic condition, which was often changed, unstable and unpredictable, were not always understood well by teachers. For example, Emma experienced that a teacher accused her in class that she could not explain when her chronic illness would be better, although the doctors did not have clear provision about her rare illness and no explanation was given to her at that time. She said;

She [teacher] was basically asking me, "when you are coming back to school properly? When is this condition going to end? When are you going to get better? What are the doctors doing about it? And I said, "I don't know. I just don't know. They haven't said what they are doing about it." And then she said, "Look! You are a young woman now, nearly fifteen years old. Don't you think it is your responsibility to find out what's going on? Start taking your responsibility if you want your own health"I just felt like having been attacked from all angles. You are completely powerless, especially at that age.
(Emma)

She claimed that, as a patient and a student, she was vulnerable in the power relationship between her and medical doctors or teachers. Both of her doctors and this teacher didn't communicate with her well, which she pointed out that a cause of misunderstanding in this case. It also seems that this teacher did not take into account the complexity that certain illness might have and assumed that it was her fault not to know the provision of her treatment. She said;

Treating the child as an individual and there are no hard and fast rules.
The sick child A is different from sick child B and sick child C. And they are not always 'sick', you know, there are well periods in between. Yeah, it's complex. (Emma)

All three participants said that teachers needed accurate medical information so that they could understand the ill child. Judy added that teachers could explain to children in easy way to understand. However, participants also mentioned that medical information should be treated sensitively. Judy suggested that *‘it is important to consider how to explain the illness to other people. Ask the child ‘what would you like to do?’ Someone doesn’t want to let anyone know about their illness, someone does.’*

4.1.4. Academic needs

The theme of academic needs examines what needs the child had in terms of studying, and how their needs were met or unmet in hospital, in recuperation period at home, and after they went back to school (see table 5.4.).

Table 5.4. Academic needs: Young people who experienced hospitalisation (England)

Themes		Categories	Codes
Academic needs and support	In hospital	Academic needs	overcome delay of study / preparation for examinations
		Facilitating factors in responding to academic needs	teaching style / individual support
		Obstacles to respond to academic needs	Impact of health condition / impact of admission patterns / limits of environment (time, facilities) / teachers' specialism / lack of collaboration with school
	In convalescence at home	Academic needs	Overcome academic delay / Preparation for examinations
		Facilitating factors in responding to academic needs	learning in small groups

		Obstacles to respond to academic needs	Limits of environment (time, facilities) /teacher's specialism / lack of collaboration with school
	At school	Academic needs	Overcome academic delay/ preparation for examinations/ Sitting examinations
		Facilitating factors in responding to academic needs	Teacher's attitudes Teacher's support (additional lessons, work sheets), pupil's initiative
		Obstacles to respond to academic needs	Teacher's attitudes (lack of awareness of needs) / low expectations

Academic needs in hospital and in recuperation at home

Ben said that he did not have academic concerns, other two who were in secondary school had concerns about academic issues, which were mainly how to catch up with delay and to prepare for examinations. They received education in hospital school.

As a facilitating factor to respond to needs in hospital education, Emma and Judy pointed out that the small group or individual study was helpful. They studied what hospital school provided and both of them did not receive any support from their home school such as worksheets to study in hospital. Judy said that such support from the school would have been helpful especially for a pupil with a long term admission.

Emma pointed out that limited lesson hours in hospitals restrict the quantity of lessons. Moreover, she claimed that there were not enough resource and numbers of subject teachers to help academic education.

The interviewees who had recurrent admission mentioned that the admission pattern and impact of treatment might limit the quality and quantity of academic study in hospitals. For example, Ben received chemotherapy in hospital which severely affected his conditions during his stay. He did not have any education in hospital for this reason. Emma, who was hospitalised only when her condition was devastatingly bad, said that she also had difficulty to study under unstable conditions (EY3).

Judy had educational support at a teaching centre in PRU after a long term admission. Although she accepted the small group of teaching was helpful for her to study focusing on her academic needs, she concerned with not having received any support from school in this period as well as in hospital.

Academic needs in mainstream school

Participants experienced difficulty in study at school differently. Ben said that he did not have significant academic problems when he went back to primary school.

However, Judy and Emma experienced problems of catching up the missed lessons in the secondary school. Although both of them mentioned that some teachers provided different forms of supplemental teaching such as individual lessons and extra worksheets which were helpful, some other teachers did not take into account their absence and consequent problems of delay, and provided no support. In order to receive support, Emma experienced that asking teachers for help was effective to get support rather than waiting for teachers' attention and offer.

An obstacle to academic needs was found in terms of sitting examinations in secondary school. Judy claimed that her academic ability was underestimated by her school after her long absence, and she was not given the equal opportunity to take exams as other students had. She said, while most of her peers took nine subjects in GCSEs exams, she was allowed to take only six subjects because the headteacher restricted it. According to her, the reason for this restriction was that if she fails, it may affect the reputation of the school.

She said:

I was mad when I heard it, and my parents were also mad about it. I felt as if it was the end of the world. (Judy)

As the schools tend to stress the importance of GCSEs and most students put high value on achieving good marks and qualifications at that stage of the lives, the impact of GCSE related issues seem to be huge on any students including those with medical conditions.

In contrary, when school was supportive about sitting examination regardless the long absence, the participant had more positive impression about school. Emma mentioned about her experience;

It would have been a lot easier for them [school] to say, 'Well, no, sorry, we can't cater for this kind of child.' Because there was a risk that somebody like me would pull down the league table. But [they didn't say it like that and] they cared for each girl just as a human being, which was great. (Emma)

Emma said that her school dealt with her difficulties flexibly and most of the teachers were supportive. Because various factors may be different between these two cases, it is not appropriate to compare the different attitudes of the two schools. However,

what is noteworthy is that both of the interviewees considered school's attitude towards them in connection with school's reputation. That means that either in the girls' own thinking or because someone had suggested this to them the school's reputation and their own illness were somehow connected. The fact that these two words appeared somehow connected had an impact on their trust in the institutions. While one felt as if the school had denied her future, the other one felt like the school had respected her dignity.

5.1.5. Social emotional needs and interpersonal relationship

The young people acknowledged in the interviews that their illnesses and hospitalisation affected their social relationships and feelings at school in their childhood. This section presents findings in themes of social and emotional needs and interpersonal relationships to examine the social difficulties and emotional issues that children with medical needs reported to have had.

Social emotional needs

This section presents findings of what social and emotional problems the young people who participated in the interviews reported to have had during and after hospitalisation in their childhood. Their social and emotional conditions, facilitating factors to respond to needs, and obstacles in responding needs were examined in two different stages of (1) hospital and recuperation period, and (2) at school.

Table 4.5. shows the codes within the context of social emotional needs which I developed from the interview data.

Table 5.5. Social emotional needs: Young people who experienced hospitalisation (England)

Themes		Categories	Codes
Social emotional needs and support	In hospital and convalescence at home	Child's social emotional conditions	Anxiety about future , fear of death, stress, loneliness, anxiety about communication with peers, identity as a child
		Facilitating factors in responding to child's social emotional conditions	Communication with peers/ support from staff in hospital / support from family / counselling / distractive activities
		Obstacles to responding to child's social emotional conditions	lack of communication with peers
	At school	Child's social emotional conditions	Difficulties in peer relationship / difficulties in relationship with teachers
		Facilitating factors in responding to child's social emotional conditions	Communication with peers, communication with teachers , peer's attitudes , teacher's attitude, Understanding of illness
		Obstacles to responding to child's social emotional conditions	Teacher's lack of understanding of illness , peer's lack of understanding of illness , lack of information

Ben and Emma said in the interviews that they had anxiety about future and fear of death due to seriousness of the illness that they had. Ben said, *'I was worried if I would be able to finish before I go to secondary school...and I also wondered if I would survive the treatments whether I come out to the outside.'* (Ben)

Judy who had childhood cancer said that children with such a life threatening illness often felt isolation. She said, *‘They feel isolation. It is important to have friend who understand their feeling, who can talk to, who are in similar situation. I did not have one at that time.’*

As supportive issues for them to deal with their feelings, participants mentioned about ‘support from family’(Ben, Emma) and ‘positive attitudes of family’ (Ben) as well as support from medical staff including counselling . Two participants who received education from hospital schools said that having a visit of hospital teachers was helpful to have a distraction from illness.

While Judy said that she did not have any contact from school nor friends when she was in hospital for a long term admission, other two who had recurrent admissions kept communicating with peers when they went back home between admissions. Ben said his efforts to keep communication with school were useful to make supportive environment in school:

When I was out of hospital, I was obviously still ill but not as bad. So I tried to go to school as much as possible. I think if you have communication with your school, and then your classmates and teachers understand what’s going on, what you are going through, what problems you might have, what problems you are likely to cause. I think that’s important. (Ben)

Emma, who kept contact with school and had close friends at school, said positive peer relationship make the ill child feel like a normal child rather than an ill patient.

I was very lucky to have a group of friends. I think for the kids, for lots of teenagers who just desperately want to be normal, then it [having friends] might be more than an issue’ (Emma)

As a difficulty after going back to school, Judy pointed out accepting differences in her appearance and physical mobility before and after the illness. Peer's attitudes towards such differences also affected her peer relationships.

When children get sick suddenly, it is hard for them to accept the differences and changes in themselves before and after the illness. Friends know how I was before. For example, I liked sports very much, but after I got illness, I could not do sports. They asked me why. They also asked me about my appearance in nasty way. (Judy).

As positive experience, Judy said that her friends accepted her as she was without asking her uncomfortable questions about her illness, and therefore, she could openly say what support she needed and what she didn't want others to do. She considered that such attitudes made positive relationships.

Teacher's lack of understanding also mentioned in the interviews. Emma and Judy mentioned in the interviews that, while some teachers understood their difficulties at school caused of their health condition or absence and provided support, some others did not provide appropriate support. Whether teachers understood the ill child and supported them well or not was important to affect child's school life and their feeling.

4.1.5.2. Interpersonal relationship with peers

This section presents the findings of perceptions about interpersonal relationship with peers during and after hospitalisation that the young people who had hospitalisation in childhood had. I examined their positive and negative experiences and their perceived obstacles in relationships.

Table 5.6. shows the codes within the context of interpersonal relationships with peers which I developed from the interview data.

Table 5.6. Interpersonal relationship with peers: Young people who experienced hospitalisation (England)

Themes		Categories	Codes
Interpersonal relationships	The pupil and peers	Positive issues	Communication / feeling of normality / feeling of belonging / understanding of condition
		Negative issues	Rumour / name calling / treated differently
		Obstacles in relationship	Lack of communication / negative image about illness / lack of understanding about illness

Communication with peers was one of the issues which were often talked in the interviews. Ben had positive experiences in peer relationships saying, ‘It [having illness] affected my social life only in a good way. Because I became close with a lot of my friends, they helped me through it.’ He considered that this was because he had kept contact with school, have improved other people’s understanding about the child and their relationships. He said

When I was out of hospital, I was obviously still ill but not as bad. So I tried to go to school as much as possible. I think if you have communication with your school, and then your classmates and teachers understand what’s going on, what you are going through, what problems you might have, what problems you are likely to cause. I think that’s important. (Ben)

Another issue which were often talked about in positive experience in peer relationship was attitudes of peers. Two participants said that being treated the same

as other children in peer relationship was important to make them feel normal as a child. For example, one participant said:

They would be there when I came out of hospital, and they just accepted that I spent a lot of time there...that was helpful to be able to go into school and have contact with my friends, and to have, you know, some sort of resemblance of normality. Because I think that was one of the really difficult things about having a chronic illness as a teenager, you are not normal.
(Emma)

She said that because of her illness there were many things that she could not do, which other peers could do; therefore, it was especially important for her to do something ‘normal’ when her condition was stable.

Judy also stressed that feeling ‘normal’ was important for them to maintain their identity as teenagers. She described positive impressions about friends in college in the interview, ‘They didn’t make me feel different’, and ‘they gave me equal opportunities’ Friends’ attitudes which were equal in their relationship, regardless of whether they had a illness or not, was important for her to make her feel comfortable in the relationships.

Contrary to that, the negative experiences were referred to as, for example, Judy said “[I was] *treated differently*.”

I wanted normality. I wanted to be treated the same as everyone else, not as an ill person. But they [her school friends] treated me differently. They said things in an insensitive way, in a negative way. (Judy)

The two participants experienced that rumours about them were spread among peers while they were absent from secondary school. Judy also experienced friends' asking 'nasty' questions about them. Such difficulties in human relationships at school often had a strong impact on children. Judy decided to go to different school because of these negative experiences.

Interpersonal relationship with teachers

This section presents the findings of perceptions about interpersonal relationship with teachers during and after hospitalisation that the young people who had hospitalisation in childhood talked in the interviews. I examined their positive and negative experiences and their perceived obstacles in relationships.

Table 4.7. shows the codes within the context of interpersonal relationships with teachers which I developed from the interview data.

Table 5.7. Interpersonal relationship with teachers: Young people who experienced hospitalisation (England)

Themes		Categories	Codes
Interpersonal relationships	The pupil and teachers	Positive issues	Equality / teacher's supportive attitude / understanding of illness and needs/ flexibility
		Negative issues	Teacher's unsupportive attitudes / inequality / low expectancies
		Obstacles in relationship	lack of understanding of illness and needs / lack of communication

As far as relationships with teachers are concerned, Judy and Emma suggested in the interviews that teachers should treat them equally to other children.

I just think, you know, first and foremost children with medical needs are children, and you know, they happen to have a medical condition. But they're children first...Don't overlook the human being because of their condition.
(Emma)

However, as a fact, they said that had difficulties in school which were caused by their physical conditions. Such difficulties prevented them from doing things in the same way as others did. When teachers showed understanding for the children's wish to be treated equally, and supported them to overcome difficulties which prevented their learning for example, they felt like the 'teacher understood me'. Such experiences were talked about as positive memories in school. For example, Judy said:

My German teacher said in the class, 'Don't worry even you don't understand the lesson now, because you missed lessons while you were in hospital', and he taught me later. He didn't expect me to miss things and gave me adequate teaching. He was sensitive to me and understood me. (Judy)

Contrary to that, Emma talked her experience in which a teacher told her off in class because she could not answer the question although she explained that it was the first lesson after her long absence. She said, *"I did really feel like she [teacher] has given up on me. She didn't care"* This teacher did not take into account her difficulties, which made her feel like being ignored.

In the case mentioned earlier (see 4.1.3.), a headteacher of Judy's school did not consider how to support a ill child's disadvantage in taking exams caused by her

absence. Although he acknowledged her academic delay, he restricted the number of her subjects instead of listening to her wish about this issue and supporting her in catching up with her studies. It resulted in, from her point of view, her equality being infringed.

When the participants talked about the negative experiences, especially in the relationship with teachers, they often expressed themselves emotionally, sometimes with abusive words. It is surprising that they remembered the details of the situation and the words what they heard although it happened to them long ago. It may show that such negative experiences between teachers have had a strong impact on the children.

Other issues in interpersonal relationships

This section presents issues in interpersonal relationships other than between the ill child and peers / teachers. The participants talked about relationships between *parents-child, parents-teacher, teachers in hospital and school, and teacher – teacher within school* in the interviews. I examined positive and negative issues, and obstacles in each relationship from the perspectives of the persons who experienced hospitalisation in childhood. Table 4.8. shows the codes in the context of other issues in interpersonal relationships which I developed out of the interview data.

As this study was focusing on school issues of ill children, I did not ask about family issues specifically in interviews. However, participants sometimes mentioned about impact of parents on their school experience. Ben said parents' positive attitudes

Table 5.8. Other issues in interpersonal relationships: Young people who experienced hospitalisation (England)

Themes		Categories	Codes
Interpersonal relationships	The pupil and parents	Positive issues	support child's positive attitudes
		Negative issues	N/A
	Parents and teachers	Positive issues	communication / parent's network / parent's experience
		Negative issues	Teacher's unsupportive attitudes
		Obstacles in relationship	Lack of communication
	Teachers within main school	Positive issues	Sharing information / collaboration among teachers
		Negative issues	Difficulties in sharing information / difficulties in collaboration
		Obstacles in relationship	Lack of communication among teachers / lack of awareness of child's need

were helpful for him to overcome difficulties caused of his illness. The particularly noteworthy issues talked in the interviews were the participants' perception about the factors to promote good communication with teachers and peers. Two participants mentioned that their mother played an important role in liaison between the child and school. Ben said his mother had been working as a parent committee member; therefore, she had a lot of contact with school and other parents. Emma said her mother used to be a school teacher, so she knew whom she should contact and how, in case she needed any support. In these cases previous knowledge was useful for the mothers to communicate with school. Negative issues in related with the pupil-parents

and parent –school relationship, and obstacles in relationship were not mentioned in the interviews.

As regards teachers’ relationship within school, Ben said teachers seemed to exchange information well because teachers of different year also understand his condition and needs well. He said that this was because the school was a small scale of primary school, *‘it means everyone knows someone, so they care’*.

5.1.6. System and practice

There were few comments about issues in system and practice in the interviews of this group. In terms of continuity of education, Judy experienced boundary of local authority. According to her, it was not the local authority of the pupil’s school to have responsibility to provide home teaching, but the local authority of the pupil’s residential area. However, she said, lack of understanding of the system of both authorities caused delay of providing her home teaching. (see table 4.7.)

Table 4.7. System and practice: Young persons who experienced hospitalisation in childhood (England)

Themes		Categories	Codes
system and practice	Return process to school	Issues in support provided	Lack of collabor authorities

5.2. Perspectives of people who provide education

This section presents the findings of the data analysis of the perspectives about education for children with medical needs of people who provide education in

hospital schools, home teaching, teaching centre, main school and local authority. Findings are analysed and presented according to six themes (**continuity of education, medical needs, academic needs, social emotional needs, interpersonal relationships, and system and practice**). I present the participants' perceptions about each theme and examine similarities and differences among them. Relevant sections of the governmental guidelines of education for children with medical needs (DfES, 2001a) are referred to in order to contrast how policy is interpreted in practice.

5.2.1. Participants

The participants of the interviews with people who provide education were teachers of four different schools and consultants of a local authority (see Table 4.1). One of the schools was a hospital school which belonged to a special school (Site A). A head teacher and three teachers were interviewed. One of other schools was a PRU which provided education in a teaching centre and home teaching (Site B). A head teacher and four teachers were interviewed in Site B. Another PRU provided education in hospital schools and a teaching centre (Site C). Three teachers in this PRU were interviewed. Two main schools were also involved in my study. Site E was a secondary school, in which a teacher and a SENCO participated in the interview, and Site F was a primary school. Three consultants of a parent partnership service which belonged to a local authority took part in the interview.

Table 5.9. Participants of teachers and staff of local authority in England study

Site	School type	Participant's position	Gender	Data No
Site A	Special school (Hospital school, teaching centre, home teaching)	Head teacher	female	ET 1
		Teacher	female	ET 2
		Teacher	female	ET 3

		Teacher	female	ET 4
Site B	PRU (Teaching centre and home teaching)	Head teacher	female	ET 5
		Teacher	female	ET 6
		Teacher	female	ET 7
		Teacher	male	ET 8
		Teacher	female	ET 9
Site C	PRU (Hospital school and teaching centre)	Head teacher	female	ET10
		Teacher	female	ET11
		Teacher	female	ET12
Site D	Secondary school	Teacher	male	ET13
		SENCO	female	ET14
Site E	Primary school	Head teacher	female	ET15
Ste F	Local authority (Parent partnership service)	Consultant	male	ET16
		Consultant	female	ET17
		Consultant	female	ET18

5.2.2. Continuity of education

The child's movement between institutions

Children with chronic illnesses often move between institutions because of their conditions and treatments. In this study, there were four patterns of children's movements that the teachers explained in the interviews (see table 4.2.). Pattern type1 was as follows. According to the head teachers of the two hospital schools (ET1, ET10), children in hospital, who need one short or long term hospitalisation for chronic illness or injury, usually go back to school after they leave hospital. Type 2: some children, who need a period of being at home before they return to school, receive one to one tuition at home or have a period of being taught in a small group of students in the teaching centre. Type3: There were also children who need recurrent hospital administrations. They tended to move between hospital school and main school repeatedly . Type4: Another type was identified by the head teacher (ET5) of the PRU (Site B). Some children in her PRU were at home for health reasons but did not have hospital admission. They were able to receive education in home teaching or

teaching centre of the PRU by a referral from a school or CAHMS. They would go to main school after they left the alternative education.

Table 5.10. Types of children's movement between institutions

Type 1. Hospital school(s) → School
Type 2. Hospital school(s) → Home teaching or/and Teaching centre → School
Type 3. Hospital school(s) ↔ School
Type 4. Home teaching or/and Teaching centre → School

This section examines how continuity of education is maintained among different institutions. Table 4.3. presents the codes which appeared in data analyses of this themes.

Table 5.11. Continuity of education: Persons who provided education (England)

Themes		Categories	Codes
Continuity of education	In hospital	Provisions that the child received	Hospital school (long term, recurrent, outpatient) / support from school
		Facilitating factor to access hospital school	regulations / system / communication
		Obstacles to access hospital school	System / lack of awareness
	In recuperation at home	Provision that the child received	Home teaching /teaching centre /support from school
		Facilitating factor to access home teaching/teaching centre	regulations / system / communication
		Obstacles to access home teaching	System /regulation / lack of communication /lack of information
	Return process to school	Provision of returning to school	Dual registration to alternative and main school
		Facilitating factor in return process to school	Interagency meeting school visit by hospital staff /gradual return process
		Obstacles in return process	lack of communication

Access to hospital school

The government guideline (DfES,2001) mentions that educational needs of children with medical conditions may be overlooked while they are away from school because their absence is considered as being ‘authorised’ (DfES, 2001a; 3.13). In order to prevent prolonged absence from education because of medical reason, the guideline provides the standard timescale of when alternative education should be arranged as follows:

LEAs must have arrangement to ensure that a pupil with medical needs who is away from school for any period has access to education. If a pupil is away from school for more than 15 working days, education, in whatever form, should begin immediately [as] the pupil is absent from school (DfES, 2001:3.2.).

15 days means the ‘total time of predicted absence from school’ which includes periods of hospitalisation and recuperation after discharge (ibid, 3.2) and it does not necessarily mean to be continuous throughout the 15 days.

The Access guideline (DfES, 2001a) also provides,

Education should be available on the day of admission in recurrent illness cases, for example where a child is having dialysis. In other cases the judgement about when education should begin will need to take account of the length of stay and medical condition. (3.14)

Pupil who are admitted to hospital on a recurrent basis experience particular educational disruption. These pupils should have access to education from day one (4.7.).

In three sites of hospital schools (Site A, B C), head teachers (ET1, ET5, ET10) and teachers (ET3, ET11) mentioned about this guideline (DfES, 2001a) as these policies were reflected in school policies and regulations of their hospital schools. The following list summarises the priorities according to which the researched hospital schools and home teaching centres provide education. Teachers referred to these in the interviews (ET1, ET5) and can also be found in the leaflet of the PRU (Site C).

- Children with an illness or diagnosis indicating a hospitalisation or time at home after discharge of more than 15 working days
- Children with recurrent admissions
- Children with SEN statement
- Children who are taking public examination

Teachers often mentioned that recurrent admissions have increased recently in particular (ET1, ET2, and ET10). A teacher in hospital school (ET10) referred to the school statistics which showed that 678 pupils out of 1440 admissions in total were in hospital school due to recurrent admissions in 2009. Certain illness such as Cystic fibrosis required children to have frequent admissions like 15 times a year at the most (ET10), and children with cancer tended to have recurrent short term admissions rather than long term admissions (ET2).

In order to provide education in hospital as soon as the child enters hospital, early identification of the child's educational needs in hospital is considered to be important (ET3, ET4, ET6, ET10). Communication with medical staff, such as having the daily

consultations with medical staff in the units, are commonly used methods for hospital school teachers to identify such children in hospital (ET2, ET3. ET10).

In hospitals where outreach teaching is arranged only when a school aged child is staying, it is considered to be important to inform parents about education in hospital so that parents are able to contact hospital school (ET11). For this purpose, leaflets of educational services in the hospitals and relevant medical and social services such as CHAMS are available to raise awareness of parents who visit there (ET11).

Outpatient children also received education. Children who were discharged from hospital and had treatment as outpatients, who were not well enough to go to local school, were able to study in the hospital school (ET3). Children who underwent kidney dialysis as outpatients were also able to receive education in the hospital (ET3). They spent half a day in the hospital three times a week, which was an enormous disruption to their education; therefore, those children were also involved in hospital education although they were not inpatients (ET3).

Access to home teaching and teaching centres

According to the Access guideline (DfES, 2001a), education for children with medical needs at home is provided in two different ways depending on the duration of being at home. Firstly, for children whose absence is expected to last less than 15 days, it is the school's responsibility to make an arrangement. It says, 'arrangements should be made in liaison with the child's parents to provide the child with homework as soon as they can cope with it' (ibid, 3.10). Secondly, if the absence is expected to last more than 15 days due to chronic conditions, alternative arrangement should be made. The guideline says 'The LEA should ensure that the child is provided with

education as soon as they are able to benefit from it' If the child has recurrent absence due to medical condition, he/she is entitled to the latter type of education. (DfES, 2001a:3.10).

Home teaching is the arrangement for children who are away from school long term. In the interviews, teachers mentioned that there were two types of children who were taught through home teaching. One was those children who had medical proof that they needed to stay at home for more than 3 weeks after they were discharged (ET3, ET10). The other type of children in home teaching was those who were not able to attend school due to psychiatric or emotional problems (ET4, ET7, ET8, ET12). They were accepted to home teaching only when they had referrals from designated persons such as CAMHS, educational social workers, clinical psychologists, or the SEN assessment service (ET5, ET6, ET11).

While teachers (ET1, ET10) said that children who were in recuperation at home after hospitalisation and who obtained medical approval were able to start home teaching smoothly, home teachers often said in the interviews that children who could not go to school for mental health problems often had difficulties to access home teaching for three reasons (ET6, ET11).

Firstly, there may have been a lack of information to parents about the educational support for children with mental health (ET6, ET11). Parents often did not know that children who cannot attend school for mental health difficulties are entitled to receive alternative education and that school has to arrange it (ET6, ET11). Parents who

contacted their services were suggested to talk to school and request a referral from school (ET6).

Secondly, in the regulations of the PRU, home teaching was not available for the child until they had received a medical diagnosis as a proof of an educational need which often resulted in a delay of providing education (ET11). A similar opinion that emerged from the interview was that the prolonged time for the clinical assessment may have disrupted continuity of education (ET5, ET7, ET8,).

Thirdly, financial issues were also pointed out in the interviews as one of the potential barriers to access certain types of education for children with medical needs (ET6, ET11). One teacher of PRU (ET11) said that '*we are not school but a service*' which is provided by LEAs. The LEA charges the school where the child is on role for the services, because the school has received funding for the children including funds for the days that he/she is away from school for medical reasons (DfES, 2001a:8.8). This teacher said that this charging system might cause a barrier, saying;

...school has to pay for them to come to us, and they don't like that very much, because we are quite expensive. We don't set the fees or anything, but the amounts of money that the school gets for the child from the government do not cover the amount that our LEA charges. So they guess about that. So sometimes they try to keep them at home, they send out work, they don't refer them to us either (ET11).

A teacher in another PRU also said, '*some schools called us to ask about the cost and didn't call back again. We were worried that there might be pupils in the school who needed referral*' (ET6)

Return process to school

The Access guideline (DfES, 2001a:6.3.) describes the process as follows;

For some, reintegration is likely to be a gradual process over a period of time. Initially some children and young people will benefit from flexible arrangements which may include attending school part-time while retaining some other support... (6.3.)

A gradual process was often used for children who lacked the physical strength or confidence to spend the whole day / week at school. Both researched PRUs (Site B and C) and the special school (Site A) in this study provided an integration period. During this time, the child received education some hours in a week at a teaching centre or home teaching, and also attended some lessons at main school (ET5, ET7, ET11). Pupils were encouraged to increase the time that they attended lessons at school. Site C used a gradual return system which they called 'sliding scale'. In the reintegration period, their service reduced the teaching time at the site gradually as the student increased the time to go to school (ET11). A teacher explained this system:

The more time the child can spend in school, the more we will cut back on five hours. For example...then the child is well enough and could access school for three hours per week, and we cut our time by one and half hours. Then when the child could go to school ten hours per a week, then we close the case.

Through deciding on goals in the time of attending school, it was expected to prevent prolonged absence from school and to motivate pupils to make efforts to return to school (ET11). In other two sites, the time scale was not so strict, but pupils often had gradual integration. As an example of returning after long term absence from school, it was difficult for her to go into the new school, gradual integration was arranged in the interdisciplinary meeting for her. Her home teacher took her to school for short

sessions, twice a week for a while. The teacher also talked to teachers about the difficulties that the children who had leukaemia might have. She also had a talk to the peers in the school about her. She gradually increased the time to spend in the school (ET7).

A teacher (ET7) described this gradual process as an important opportunity for the child, as it enabled her to build confidence to return to school by developing relationship with peers and teachers. Such gradual return was addressed in liaison with main school to make supportive environment in the school by raising awareness about child's difficulties among teachers and peers (ET7, ET6). For example, a medical staff or hospital teacher visited school to talk with teachers and peers in school when it was needed (ET 10). A teacher said that it was essential to establish good communication between school and alternative school in the gradual return process (ET7).

5.2.3. Medical needs

This section presents findings of data analysis of the perceptions about medical needs of group of people who provides education. Table 4.6. shows categories and codes appeared in this theme

Table 5.11. Medical needs: People who provide education (England)

Themes		Categories	Codes
Medical needs and support	In hospital	Child's needs due to health condition	Condition and impact of medication (Limit of physical function / limit of strength / impact of treatment / unstable conditions) , change of conditions

		Facilitating factors in responding to health condition and medical care needs	understanding individual condition and needs/ Collaboration with medical staff (meeting, sharing information), education plan that corresponds with treatment provision, flexibility (timetable, lesson plan)/ team teaching, sensitivity
		Obstacles to responding to health conditions and medical care needs	Limited staff availability
	In convalescence at home / at school	Child's needs due to health condition	Condition and impact of medication
		Medical care related needs	Place and time for medical care
		Facilitating factors in responding to health condition and medical care needs	Flexibility (timetable, use of facility, rules) / understanding of needs and condition / individual educational plan / communication
		Obstacles to responding to health conditions and medical care needs	system (SEN statement, information sharing) / teacher's lack of understanding of needs and support / lack of communication

Responding to medical needs in alternative education

Teachers mentioned in the interviews that understanding child's medical condition and needs were essential to teach children with health problems (eg. ET1, ET2, ET3, ET5, ET10). Teachers understood the child's condition and impact of medication in liaison with medical staff, which was useful to identify needs and to provide appropriate lessons (ET3).

The importance of identifying individuality in children's needs was commonly mentioned in the interviews by teachers in hospital school (EY3), PRUs (ET5, ET6) and mainstream teachers (EY14, EY15). It was especially stressed not to label children by their medical condition (ET3, ET5). A hospital teacher said (ET3), 'All

children are different. Different back ground, family problems, different age, different time to come here. The child's condition is varying although the name of disease is the same as others.'

The importance of understanding medical condition and impact of it on individual child was often mentioned in the interviews (ET2, ET3, ET5, ET6, ET7, ET9). Teachers in hospital and home teaching shared information with medical staff and any relevant specialists regularly to understand children's condition and needs (ET, ET10, ET11). A teacher (ET6) said, 'Medical information is not useful as it is, because there is lots of jargon. We have to collect more practical information for us, for example, how this symptom affects this particular student's life, daily life, and school [life].' In order to understand the needs, information were collected through various sources who worked with the child such as family, school, medical and social welfare staff, as well as the child themselves in hospital school and PRU and mainstream school ((ET, ET6, ET12, ET14). In order to respond variety of children's medical needs, flexibility in teaching (eg. lesson plan, teaching material, teaching style) was considered to be useful un hospital schools and teaching centres (ET3, ET6).

Respond to medical and health related needs in mainstream school

According to a consultant of parent partnership service in a local authority whom I interviewed (E16), the range of medical conditions that children had was increasing. Therefore schools were required to respond to diverse educational needs caused from various medical conditions. For example, many children with developmental delay in mainstream schools needed support of personal care skills such as feeding themselves.

However, a consultant (ET16) said that school facilities, teachers' knowledge and skills in many mainstream schools were not well enough yet in this area.

As an obstacle which the same consultants group identified in the interview was that children with medical needs were not always accepted to have a SEN statement unless they had learning difficulty or other physically or sensory difficulties (ET16, ET17, ET18). They explained a reason for this is that one of criteria is having learning difficulty, which often prevents the child with medical condition to obtain SEN statement (ET16).

SENCO in a secondary school whom I interviewed also mentioned that students with medical condition in their school, who did not have learning difficulty, did not have SEN statement. However, the Guidance and Support Unit (GSU) has the responsibility of supporting children with medical needs regardless having statement or not (ET14). Their roles were varied including assessing the needs, liaising with the GSU and the subject teachers, supporting children in the classroom and the unit, and working in partnership with outside agencies. If any special educational needs were identified, Individual Education Plan (IEP) was created regardless of having SEN provision or not. IEP which she showed in the interview included special arrangement and support, such as reduction of lesson time. Pupils who need medical care are also provided appropriate support in liaison with school nurse (ET14).

When I visited this school (SiteD), three students who had different medical conditions (heart problem, cystic fibrosis and broken leg) received support for their medical care from school nurse as well as other support from teaching assistants at

school (ET17). Whenever any student stayed in the local hospital, SENCO had a role to contact the hospital school (ET17).

Difficulties in sharing information of child’s medical needs among teachers within school were also mentioned in the interviews with teachers in a secondary school (EY13, EY14). This is reported later (see 5.2.6.).

5.2.4. Academic needs

This section presents findings about perceptions about academic needs of group of people who provides education. Table 5.12. shows themes, categories and codes in this theme

Table 5.12. Academic needs: People who provided education (England)

Themes		Categories	Codes
Academic needs and support	In hospital	Academic needs	overcome delay of study / preparation for examinations / sitting examinations
		Facilitating factors in responding to academic needs	curriculum, support from school, record of study / teaching style/ collaboration with main school / reasonable adjustment in examination
		Obstacles to respond to academic needs	Impact of health condition / limits of environment (time, facilities) / teachers' specialism / lack of collaboration with school
	In convalescence at home	Academic needs	Overcome academic delay / Preparation for examinations / Sitting examinations
		Facilitating factors in responding to academic needs	learning in small groups / individual support
		Obstacles to respond to academic needs	Limits of environment (time) /teacher's specialism / lack of collaboration with school
	At school	Academic needs	Overcome academic delay / preparation for examinations / Sitting examinations
		Facilitating factors in responding to academic needs	Teacher's attitudes (awareness of needs) / Teacher's support (additional lessons, work sheets)
		Obstacles to respond to academic needs	Teacher's lack of awareness / difficulty in sharing information

Curriculum in alternative education

The Access guideline (DfES, 2001a: 1.8.) says,

Hospital schools are not under a legal obligation to offer the National Curriculum.

This is applied to hospital schools because

Educational law reflects the special nature and variable circumstances of hospital schools by providing, in some areas of legislation, more flexible arrangements than those applying to other special schools (1.8).

On the one hand, the nature of circumstances of hospital school is taken into account to reduce the obligation to provide curriculum; on the other hand, it is also

encouraged to protect the rights of children with medical needs to have equal educational opportunities as other children have.

Pupils with medical needs should have access to the full National Curriculum wherever possible. As a minimum, pupils with medical needs are entitled to a broad and balanced curriculum complementary and comparable to that in school (8.8).

These issues were reflected in the school policy of a hospital school. A school policy document of Site A in this study notified that ‘a broad and balanced curriculum within the framework and strategies of the National Curriculum’ and ‘a personalised approach’ to respond to the individual needs, taking account of health and medical needs, are provided.

According to the school policy documents about curriculum (Site A,B,C), these sites provided various opportunities to learn at hospital and teaching centres throughout curriculums including Physical Education and arts as well as other subjects. Children were taught either the curriculum that the hospital school offered or home school provided materials (ET1, ET3, ET5). The decisions about the priorities and balance between the two were made by negotiation between the child and the teachers (ET3). However, it was often mentioned in the interviews that main schools did not always send teaching materials for the child in hospital (ET3, ET10, ET11). This is examined later .

Children’s academic needs and practice in alternative education

Teachers often mentioned that to catch up delay of studying and to prepare for examinations were considered to be main issues in academic needs (eg. ET1, ET5, ET10). Teachers made an individual educational plan (IEP) with the child and the parent, in which academic issues such as short term aim and subjects to study were involved (ET3). Hospital schools, teaching centres and home teaching provides individual lesson or lessons in a small numbers of pupils, which enable teachers to teach individually and flexibly considering child's condition (ET1,ET5).

Keeping precise record of the individual child's studying was also considered to be important as evidence of students' academic achievements especially when they returned to local schools (ET2, ET3, ET6, ET10). Hospital schools developed its own forms of children's administration and academic issues which suited different types of long term, short term and frequent admissions (ET3, ET10). Individual student's records of attendance, contents of lesson that he/ she received and the achievement were precisely kept everyday in order to send all records to the school where they were on roll, as well as to share the information for team teaching within the hospital school/ PRU (ET3).

For pupils who needed to sit examinations, hospital schools and PRUs were accepted as an official exam centre for national examinations (ET3, ET8, ET11). Special arrangements could be made under the statutory regulation. If pupils took exams after they left hospital, hospital school would ensure that the school and the exam boards were aware of any medical problems and needs to prevent any disadvantages (ET3).

As an obstacle to provide sufficient academic support, PRU teachers talked about difficulties to teach all subjects by limited number of teachers regardless of their specialism (ET6, ET10). Limited allocated time was also mentioned as issues which may have an impact on the subject selection, especially in home teaching (ET10, ET11). Home teaching provided 5 hours lesson per week, which was designated as minimum in the Access guideline (DfES, 2001a). Although subjects taught were decided by negotiation between most of the students and teachers, it was likely that Key stage 4 students were taught mainly core subjects to facilitate them obtaining GCSE qualifications to make use of limited time of home teaching (ET3, ET11). As many students in this PRU had experienced low self-esteem and withdrawal (ET5), obtaining qualifications was considered to be important to widen their opportunities to return to social life and gain their self esteem (ET5, ET11).

Children's academic needs and support in mainstream school

A SENCO (ET14) mentioned in the interview that the individual educational plan was made for students who needed academic support to overcome delay of study due to absence for medical reason. Students were able to study in guidance and support unit or class room with an assistant teacher (ET14). Teachers were also informed to provide study supply for those pupils (ET14). In order to inform teachers about such child's needs, there was an internal database about individual students, which all the teachers of this school were able to access.

According to teachers of this school (ET13, ET14), the individual student's data, an attendance report was accessible as well as the academic record. Therefore any

teacher were able to access the information about who was absent and for how long. The IEP was also shown if the child had one.

Taking an example of this data base which was shown in the interview, a year 10 student who has frequently absent due to her chronic illness, attended 68% of school days last year. She did not have any statement but had an IEP. According to her IEP, she would have '*Teaching Assistant accompany*' and '*monitoring of progress by subject teachers*'. The IEP also mentioned that '*Teacher gives catch up work*'. If any teachers were aware of her frequent absence, or, Teaching Assistants requested teachers to access her IEP, they would be able to acknowledge what they should do to support her. It was not certain from this database to what extent the required support had been provided, however, her academic record of the past two years showed that she received grades from only two subject teachers. Other teachers commented that the assessments are not available due to her lack of attendance.

As the academic results might be affected by various factors, it may not be appropriate to consider whether her academic achievement reflected the support that she received. However, the fact that she has not had enough academic records in the past two years, although she attended 68%, made me question whether she has had the support that she needed.

Regarding the information sharing, this data base seems to be a good system to inform all the teachers about the students' needs. The database was just a part of a information sharing system and interaction between teachers and the Guidance and Support unit monitored whether the students were supported or not. However, to

what extent the teacher took into account the required support seemed to be depend on the individual teacher's decision.

5.2.5. Social emotional needs

This section presents findings of perception about social emotional needs of group of people who provides education. Table 5.13 shows themes, categories and codes in this theme

Table 5.13. Social emotional needs: The people who provide education (England)

Themes		Categories	Codes
Social emotional needs and support	In hospital	Child's social emotional conditions	Anxiety about future, fear of death, stress, loneliness, anxiety about communication with peers (8)
		Facilitating factors in responding to child's social emotional conditions	collaboration with family and hospital (2) / collaboration with school (5) / Understanding of individual needs (5)
		Obstacles to responding to child's social emotional conditions	lack of communication with peers and school teachers (4) inappropriate facilities in hospital (1)
	In convalescence at home	Child's social emotional conditions	Anxiety about future (3) Low self esteem (5)
		Facilitating factors in responding to child's social emotional conditions	Communication with children / staff in teaching centre (4) communication with peers / school teachers (3), counselling (1) social skills training (4) progress in study (1)
		Obstacles to responding to child's social emotional conditions	Lack of communication with peers/school teachers (1)
	At school	Child's social emotional conditions	Difficulties in peer relationship / difficulties in relationship with teachers / low self esteem / withdrawal from school
		Facilitating factors in responding to child's social emotional conditions	Communication between the child and other pupils, teachers / teacher's awareness of the child's social emotional conditions / inclusive school ethos

		Obstacles to responding to child's social emotional conditions	Lack of communication between the child and other pupils, teachers / teacher's lack of awareness of the child's social emotional conditions
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Social and emotional needs in alternative education

Teachers often mentioned in the interviews that children with health conditions had difficulties in relation to social emotional issues (eg. ET1, ET2, ET4, ET5, ET7). In hospital, children were often under stress caused of various reasons such as seriousness of illness (ET3), impact of treatment (ET2, ET3), anxiety about cure and future (ET3), anxiety about family and school issues (ET3, ET10). In order to support children who had such needs, teachers collaborated with parents and other specialists in hospital to identify needs and to provide appropriate lessons and activities which may suite the child's condition and emotional needs (ET1, ET3).

In case the child had a long term admission, maintaining social relationship of the child was also considered (ET2). For example, in the oncology ward for young children who tend to have long term admission, a teacher made news letters about the lessons with the children to send to their schools, which enabled them to maintain social relationships with their peers (ET2).

In teaching centres where pupils often had mental health difficulties, social and emotional aspects of children's need were considered to be crucial (ET 4, ET5, ET12). Teachers especially identified pupil's lack of self confidence was the issue to be considered. For example, a head teacher of PRU (ET5) said;

So first thing what we have to do is to try to build their confidence, make sure they can achieve. And then they would begin to believe that they can actually

settle out to work again, because they missed a lot of schooling, and the think they cannot achieve anything. And when they begin to feel comfortable with themselves, they begin to be happy here, trust us, our staff. Maybe we can get back in whole business of education and make progress which is what most of them doing. That's very important.

She stressed in the interview that a good child-teacher relationship was vital for leaning to happen. Especially for children who had mental health difficulties, past negative experiences often prevent them from having communication with other people.

So when they are first coming, its' a long time before they begin to understand that they can trust people here, and that people are actually interested in the individuals. Once they begin to do that, then maybe relationships build, and they get on with school work, because school work was not very important to them when they had got far more important things to worry about. (ET5)

At the teaching centre of PRU (Site C), there were varieties of programmes to enhance the pupils' social development (ET5, ET6). When they were able to do something that they couldn't do before, they were likely to gain confidence. Throughout the activities in which they worked with adults and other pupils, they also learned how to interact with people (ET5). Such social skill training was involved in the curriculum which was considered to be essential for children in this school.

The pupils also had individual or group counselling to learn how to cope with difficulties. If children had had difficulties in school such as bullying, it was unlikely that they went back to the same school, because the school was the same difficult place for them. In such cases, children often went to another school. The teachers said it took a few years for some children to gain confidence to go back to school.

A teacher in this PRU mentioned that teachers needed to have sensitivity and flexibility to identify the child's needs, because the cause of problem often could not be clearly seen and the children themselves might not acknowledge what the real problem was and what their needs were (ET8). The same teacher referred to a case of a pupil who had difficulty to study at a teaching centre;

...you [a pupil] may go back home and say “no, not go in there again”, so [we] stop the process over again, and say, “we know what’s wrong with it, what didn’t you like, what and how did you feel uncomfortable,” and you talked them through. And it may be something simpler, “what I don’t like was eating in front of the people,” and then you can make an arrangement ... (ET8)

He said that child's needs were often found in the process of communication between teachers. Another teacher in different PRU also mentioned about similar process. She and said one-to one based or a small group of teaching were suitable settings to allow such a process and to identify needs (ET11).

Social emotional issues in main schools

A hospital teacher (ET3)(ET10) and PRU teacher (ET6) said that when a pupils return to school, they asked the school to decide a named person in the school whom the pupil could contact whenever they had any difficulties, including social and emotional issues.

Teachers in main schools also mentioned in interviews that pupils' social emotional development was important issues that teachers needed to pay attention to (ET16, ET17, ET18). When pupils had any mental health issues, teachers in both primary

and secondary school had a system to work with CHAMS, so that they could provide appropriate support for the pupil (ET14, ET15). In primary school, a head teacher (ET15) said that a form teacher and assistant teachers in a class room observed individual children's behaviour and their peer relationships to identify any needs of support, especially when there was a child who might have difficulties. In secondary researched in this study, a teacher (ET13) said that the pastoral care team had a responsibility to look after well being of the students. When students had difficulties in social and emotional issues, they could contact the team through a form or a subject teacher.

5.2.6. Interpersonal relationship

This section presents findings of perceptions about interpersonal relationship of group of people who provides education. Table 5.14. shows themes, categories and codes in this theme.

Table 5.14. Perceptions of people who provide education (England) : Interpersonal relationships

Themes		Categories	Codes
Interpersonal relationships	Parents and teachers (hospital school, home teaching, school)	Positive issues	Communication, understanding of role, teacher's understanding of illness and needs, teacher's supportive attitudes, parents' positive attitude, mediatory role
		Negative issues	parents' unsupportive attitude, teacher's unsupportive attitude
		Obstacles in relationship	Lack of communication
	Teachers in hospital and main schools	Positive issues	Collaboration in teaching, awareness of role, sharing information
		Negative issues	Lack of collaboration, negative impact on child (feeling of isolation)
		Obstacles in relationship	Lack of communication, lack of awareness of role, teacher's workload

	Interdisciplinary relationships	Positive issues	Communication, Collaboration in providing support, facilitating meeting
		Negative issues	Difficulty in communication
	Teachers within main school	Positive issues	Sharing information, collaboration among teachers
		Negative issues	difficulties in collaboration, lack of awareness of needs
		Obstacles in relationship	Difficulties in sharing information among teachers, lack of awareness of child's needs, lack of awareness of regulations, workload, unsupportive system within school

Relationships between parents and teachers

Interpersonal relationships between parents and teachers were often mentioned in the interviews which may have impact on child's education. A home teaching teacher said that parent's understanding and cooperation were considered to be important to promote educational environment for children (ET11). In order to promote parent's understanding, all hospital school, home teaching researched in this study had regular review meetings with parents which provided opportunities for parents, teachers, and relevant specialists to communicate each other and promoted collaboration among them (ET1, ET5, ET10).

However, teachers experienced that partnership with parents was not always available because some parents did not appear to the regular review meeting of their children. (ET3, ET8, ET12). Although there may be various reasons for this problem, two teachers mentioned their experience that parents' health conditions or views to education sometimes might have affected their attitude towards their child's education (ET8, ET12). For example, in a case in which parents themselves had little education and did not have good impressions about school, which seemed to have affected their reluctance to contact their children's school (ET12). In such case, teachers promoted

partnership with parents by understanding parents and working in liaison with other agents such as social work (ET12).

In contrary, when parents found difficulties in communicating with schools, Parent Partnership Service (PPS) in local authority plays a mediatory role between parents and school if the parents need it. According to the consultants of this service whom I interviewed (ET16, ET17, ET18), they supported parents in mainly three ways. Firstly, they helped parents to communicate with schools, local authorities and other statutory agencies, when parents needed any support. Secondly, they provided information and advice to parents such as parent's role, rights, and responsibility relevant to their child's education. Thirdly they linked parents to appropriate services by providing information about various services and voluntary organisations. The member of PPS said in the interview that 'getting them [parents] in touch with the right organisation or people who can support them is important. It would enable them to receive appropriate support' (ET18).

. Partnership with main school and alternative education

According to the Access guidelines (DfES,2001), the main school has a 'vital role' to ensure that children are able to receive educational support while they are away from school, because children are on roll at the school even when they receive education from the hospital school, the home teaching service and the teaching centre. (DfES,2001a).

The schools are obliged

- To have a policy and a named person responsible for dealing with the pupils who are unable to attend school because of medical needs.
- To supply the appropriate information about a pupil's capabilities, educational progress, and programmes of work.
- To be active in the monitoring of progress and in the reintegration into school, liaising with other agencies
- To ensure the pupil is kept informed about school social events, are able to participate in activities such as homework club and study support.
- To encourage and facilitate liaison with peers. (DfES, 2001a : 1.17.)

Teachers in alternative education mentioned in the interviews that, while some schools had enough communication with hospital school and home teaching when the pupil received support from them, not so many schools did this communication (ET3, ET6, ET10). Schools did not always send worksheets for the pupil to study, although such support was considered to be helpful for the pupils to feel like they had a contact with school (ET3, ET10). A hospital teacher said that lack of communication often made the child feel isolation (ET10). She stressed the responsibility of school to keep contact and said, 'One of the big problems is that the school may forget about them. We have to keep reminding school that this child is on your roll, you are getting money for this child from the government. So this child is still in your responsibility.' (ET10)

Whether work was provided by mainstream school or not was considered to have an impact on teaching especially in a small scale hospital school and home teaching (ET11). Where there were only two teachers, it was difficult to teach all specialist

subjects (ET12). A hospital teacher explained her role in sharing study work with main school and said, ‘ the school teacher’s role is to deliver study work for children and the hospital teacher’s role is to modify it and deliver it at an appropriate pace for the child considering her condition and allocated time in hospital’ (ET12).

In order to promote active communication and support from school, a PRU (Site C) exchanged the agreement with the school when the child started hospital education or home teaching (see Appendix 7). It aimed to enable the school to understand its role, which confirmed the school’s responsibilities for the pupil such as supplying work, attending review meetings, contacting the child, and sharing information with the services (ET10).

Although the agreement exchanged with school, a teacher in this site said that it was still difficult to obtain support from teachers. In a case, a child, who was receiving home teaching while she is absent from school for a long term due to medical conditions, had a difficulty to receive homework from school. The parent said school had not delivered any work for the child although she requested it many times. The home teacher monitored it and found that no work had been delivered to the child from school. The home teacher called the school and asked why the work wasn’t delivered. The school found that it was difficult to get work from teachers for the pupils whom they have never met for a long time (ET11)

The home teacher in this case said, ‘I’m not criticising the teachers, because their time is very limited. The teachers are to be expected to provide home work for a child who they never see. It’s quite tricky to manage. In secondary schools especially, to liaise

with all the other teachers and organise work for such a child are not always done well' (ET11).

A SENCO of a secondary school who was interviewed said that it was difficult to collect study material from many teachers in reality (ET14). She also said that teachers might not know the school teachers' obligation to supply materials which were mentioned in the guideline (DfES,2001a). It was because such obligations were not identified in their SEN school policy (ET14). Teachers' low awareness about their obligation supporting children with medical needs was identified in the interview with a teacher in her school. A subject teacher of the same school mentioned in the interview that he did not know about school's obligation written in the guideline (DfES, 2001a) and that it was not common to supply work for children who were absent for medical reasons unless it was especially required (ET13). This teacher suggested that this may be due to workload issues as teachers already have to deal with any different issues everyday in school.

Interdisciplinary work

The Access Guideline (2001a) mentions;

Effective collaboration and a flexible approach between LEAs, schools and other agencies, in particular the NHS, are crucial to the provision of continuity of high quality educational provision for children and young people with medical needs and successful reintegration into school. (5.1)

According to a PRU teacher (ET10), the members who were likely to be involved in the collaboration were:

- Medical staff (eg. medical practitioners, nurses, therapists)
- Social worker
- Connexions
- CAMHS (eg. clinical psychologist, educational psychologist, psychiatrists, psychiatrist nurse etc)
- Mainstream school
- Alternative education (hospital school, home teaching, teaching centre)

The partnership with the specialists worked throughout the period of the referral, review meeting, liaison and follow up after liaison in order to identify needs and provide appropriate support (ET10).

The Access guideline (2001a) does not particularly mention who would facilitate the partnership. According to hospital teachers interviewed (ET3, ET11), it tended to be a hospital teacher who had the leading role of collaboration for a child who was educated on their sites. In one of the researched site (Site C), as an example, the main role of the facilitator was to organise the review meeting of the case every six weeks, monitoring it and inviting the right persons (eg. educational psychologist) to the meeting in right timing when they were needed (ET11). For example, an educational psychologist was not necessary at the moment, but it might be a few months later they need to talk with her. She said, ‘we try to be very mindful of how expensive people’s time is. And we only invite those people who, we will feel, can help and support at the moment in time. So it’s about flexibility (ET11)’ In order to decide about the appropriate persons, she considered that a facilitator needed to understand the child’s

condition and prospects to some extent, as well as good knowledge about the role of each specialist and the communication system to contact them at the right time (ET11).

According to head teachers in hospital school and PRU (ET1, ET5, ET10), when a pupil went back to school from the alternative educational provision at any of the sites in this study, an individual re-entry plan was made in liaison with:

- Named person from a school (eg. Inclusion coordinator)
- Hospital / Home teacher
- Relevant professionals (eg. CAHMS, specialist nurse)
- Parent

The meeting and networking is often facilitated by the hospital/ home teachers.

Timetable, communication system among the members, any concerned issue were discussed and agreed. (Site A, C)(ET1, ET10)

When a student was discharged from a hospital, especially for a long term patients' admission, hospital school teachers were involved in multi-agency case meetings with the full range of medical staff who treated the child and social workers to agree on a discharge plan. (Site C)(ET10).

5.2.7. System and practice

This section presents findings of perceptions of problems in system and practice.

Impact of hospital admissions over authority boundaries, teacher development and education for post-16 are examined.

Impact of hospital admissions over authority boundaries

Teachers in a hospital school mentioned in the interview that there was an impact of hospital admissions over authority boundaries on education in hospital (ET10, ET12). According to them, their hospital (Site C) had children from many different authorities, because children who needed specialist care in their hospitals came to the hospital from a wide range of areas. The statistic of Site C in the annual report of 2009, which the head teacher (ET10) showed me, indicated that 468 children from other local authorities were taught in the hospital teaching service, which was more than half of the total amount of children taught in this hospital. Teachers said that education for those children is affected by local authority boundaries in following two ways. Firstly, it was difficult to liaise with home teaching in those children's cases after they left hospital. As home teaching was financially supported by the local authority, the children outside the council were not able to receive home teaching. If a child from another council required home teaching after discharge, it was the mainstream school's responsibility to refer him/her to the local home teaching centre. It was likely that the liaison process became more complicated than if it happened within the same authority.

A head teacher (ET5) similarly pointed out that the level of service was different from authority to authority. For example, not all councils had teaching centre and enough staff, therefore, children who lived in such area had much limited support compared

with children in other area. 'It's unfair system, it just depends on where you live what you get'(ET5).

Secondly, the problem with children from other councils arose in budget related issue.

The Access guideline (2001a) mentions recoupment as follows:

The inter-authority recoupment regulations require the payment of recoupment in respect of the cost of providing education for persons under the age of 19 in hospital from another authority. The amount of recoupment should be agreed between authorities...to aid the subsequent education of the pupil, that adequate information is provided to the pupil's LEA (5.11).

In order to claim the payment, teachers are required to do time consuming paper work.

A teacher explains the complexity of this problem like this:

We sent a bill to X city for the children we work with, and the hospital school in X city send to our city a bill for our children who are in the hospital in their city. So the money is going back and to. (ET10)

Similar opinion was heard in another hospital school. A teacher (ET4) said that, although children were able to receive treatments from any hospitals under the present medical system if they needed special treatments and were referred to, it was argued that the education system for those children was not designed to fit the medical system (ET4). This enforces teachers' excessive administrative work and consequently it affected teaching in hospitals(ET4).

Teacher development

The teachers acknowledged in the interviews that they had expertise in teaching children with medical needs (ET2, ET3, ET5, ET10). The teachers of hospital school and home teaching service obtained general qualifications as secondary and primary teachers and there was no additional teaching qualification specified for the education of children with medical needs (ET10). They had training about various medical and mental conditions and teaching skills (ET5, ET10). Teachers in teaching centres had training to deal with mental health difficulties and emotional needs (ET1, ET4, ET5).

While teachers accepted the importance of training (ET4), some teachers commented that they learned more from colleague teachers and from their own experience (ET3, ET6). One of the hospital teachers said that it was not about training, but experience that they learned how to respond to the variety of complex needs that children had and how to work in partnership with various specialists (ET3). Another teacher (ET6) said support and advice from other teachers were helpful to learn how to deal with any difficulties in teaching the children with different types of medical needs. Teachers in three sites tended to have long term experience in the same hospital school and home teaching service. Therefore, a teacher stressed that gained experience and developed networks throughout the time were useful in teaching (ET3).

A head teacher of one of the hospitals and home teaching units (ET10) said her concern in the interview, that due to financial reasons, more full time teachers who had experience were replaced with part time teachers. As experience and expertise of teachers were considered to be important, how to maintain the quality of education in her service was a serious issue to be dealt with (ET10).

Post-16

While the researched special school provided education for children over 16 years old (ET1), PRUs offered education to this age range of children (ET5,ET10). A head teacher of PRU (ET10) said that it was common for them to teach children over 16 years old in the ward although it was an unofficial service (ET10). They acknowledged that there was need of education for them in hospital. Similarly, teachers of teaching centres also said that the support after 16 years old was necessary (ET5)(ET7). These teachers were concerned that children with medical conditions who were over 16 seem to be overlooked in the education system.

5.3. Summary of chapter five

This chapter presents provision of education for children with chronic illness in a case of England through perceptions of people who received education (young people who experienced hospitalisation in childhood) and people who provided education (teachers of hospital, mainstream schools, local authority).

Continuity of education in hospital and in recuperation at home was maintained by hospital schools, home teaching, teaching centre and main schools, which were managed by either special school or PRU. Children were on role of main school while they study at alternative education.

The guidelines (DfES,2001a) clarified the role of key agents, such as school, hospital school and LEA. However, obligations of school to support ill children, who are

absent from school, was not well known to school teachers, and therefore, the child's needs to receive support from school do not always met.

Regional differences of system and school financial were an concern which might have been an obstacle to provide support for children in some cases.

Participants commonly stressed that individual child's needs should be identified. Teachers need to understand the child's condition, difficulties and illness, and deal with them sensitively with appropriate support.

Academic delay was serious concerns especially for secondary school pupils. Teachers' support to catch up delay was considered to be important at school.

Participants in different groups commonly identified the importance to support the child's social emotional needs. In addition to anxiety and loneliness caused by illness and hospitalisation, social relationships between peers and teachers might have greatly influenced the child's emotional well-being. To be treated the same as other peers and to maintain the child's identity as a child is considered to be important. Negative attitudes towards the child were serious concerns for the ill child.

While participants commonly accepted that there were many supportive schools and teachers, whether the child had appropriate support or not was considered to depend on individual school and teacher.

Chapter Six

Findings of Case Study of Provision in Japan

6.1. Introduction

Chapter 6 presents the results of the case study of provision in Japan. Firstly, I present the findings of the analysis of the perspectives of people who received education (young persons who experienced hospitalisation in childhood, parents of children with chronic illness). Secondly, I present the findings relating to the perspectives of people who provided education (hospital and home teachers and mainstream teachers). Each section presents the findings according to the six themes, which are ‘continuity of education’, ‘health condition and medical care related needs’, ‘academic needs’, ‘social emotional needs’, ‘interpersonal relationships’, and ‘system and practice’.

6.2. Perspectives of persons who receive education

Participants within the category of persons who received education in Japan were young persons who experienced hospitalisation in childhood and parents of children with medical needs. The data used for analysis consisted of opinions that the participants posted into the online forums and emails that the individual participants sent to me as a reply to my questions.

6.2.1. Participants

Three young persons participated who had hospitalisation in childhood, and eight parents of children with chronic illness also participated. Two of the young persons experienced hospitalisation in secondary school, and one in primary school (see table 6.1.).

Table 6.1. Participants : young persons who experienced hospitalisation in childhood (Japan)

Gender	Type of illness	Year when hospitalised	Pattern of hospitalisation	Alternative provision	Data no
male	Internal illness	Year 7	long term	Hospital school	JY1
female	cancer	Year 8 to 9	recurrent admissions	no provision	JY2
female	cancer	Year 4 to 5	recurrent admissions	Hospital school	JY3

Out of the eight participants in the group of parents, five parents had children who were in primary school when they were in hospital, two parents had children who were in secondary school, and one parent had a child which was first in primary school and then moved on to secondary school while she was in hospital (see table 6.2.).

Table 6.2. Participants: Parents of children with chronic illness (Japan)

Participant	Type of child's illness	Year of child when hospitalised	Pattern of admission	Child's alternative provision	Data No
Mother	brain tumour	Year 2	long term	hospital school	JP1
Mother	leukaemia	Year 2	long term	hospital school	JP2
Mother	cancer	Year 3 to 4	long term	hospital school	JP3
Mother	cancer	Year 5	Long term and recurrent admissions	hospital school	JP4
Mother	cancer	Year 6	long term and recurrent admissions	no provision	JP5
Father	leukaemia	Year 7 to 8	long term and recurrent admissions	hospital school	JP6
Mother	cancer	Year 8	long term and recurrent	hospital school	JP7

			admissions		
Mother	internal illness	Year 6 to 9	long term and recurrent admissions	hospital school and home teaching	JP8

6.2.2. Continuity of education

The theme of ‘continuity of education’ describes the participants’ experience of the educational support they received, facilitating factors, and their perceived obstacles in hospital, in recuperation and in the process of returning to school (see table 6.3.)

In terms of education in hospital, ten out of the twelve participants said that they accessed hospital school. Five of them mentioned that they accessed hospital schools to reduce the delay in their studies, and eight of them said that they received support to deal with the child’s stress and anxiety in hospital. There were three participants who could not access hospital school. The main reason for it was that there was no hospital school where they stayed (JY2, JY3). One participant (JY3), who stayed in several different hospitals, said not all hospitals had a hospital school.

There was a case in which continuity of education was not maintained because of lack of awareness of school teachers. One parent (JP5) said, when her child had a diagnosis, the head teacher of her child’s school said ‘don worry about study, curing the illness is important’ and school provided no support and no information of hospital school to her during her stay in hospital. As a result, her child left without education for three months.

The same parent talked about the problem of regulation as well. She learned from a medical social worker that there was a hospital school in which teachers of a special school for children with medical needs visit only when a school age child stays in the ward. However, she decided not to use this support because of a problem of the regulation to enter this hospital school. She understood that children needed to move their school enrolments from main school to hospital school, but her daughter did not want to do this. She said that changing school would make her daughter feel like being completely separated from school (JP5). Although she remained enrolled in main school during hospitalisation, her school did not provide educational support. As a result, she left without education while she was in a long term admission in hospital (JP5).

In terms of recuperation period at home, one participant's child continued to receive support from hospital school before going back to school (JP1), and another one used home teaching (JY8). Others said that the child stayed at home and went to school when the children's conditions allowed to (JY1, JP2, JP3, JP5, JP6, JP7). While some participants said that school was supportive in this period (JY1, JY3, JP1), a parent claimed that school offered little support for the child while she could not go to school after recurrent admissions for medical treatment (JP5).

In another case, when the child left school, two parents mentioned that there were interagency meetings between medical staff, hospital and school teachers (JP1, JP2), but there was no such meeting for one other participant (JP3). Two parents claimed that systems were different in different hospitals (JP3, JP4). Four participants said that hospital school had contact with school (JY1, JP4, JP6, JP7).

Table 6.3. Continuity of education: Persons who received education (Japan)

Themes		Categories	Codes
Continuity of education	In hospital	Provisions that the child received	Hospital school / support from school
		Reason for receiving education in hospital school	Academic support / mental support / social support
		Reason for not receiving education in hospital school	No hospital school provided / health condition / support provided from school / to prevent separation from main school
		Facilitating factor to access hospital school	regulations / system / communication
		Obstacles to access hospital school	System / regulations / fear of separation from main school/ lack of awareness of educational support
	In recuperation at home	Provision that the child received	Home teaching / support from school / no provision
		Reason for receiving home teaching	Academic support / mental support / social support
		Reason for not receiving home teaching	No service provided / lack of information
		Facilitating factor to access hospital school	regulations / system / communication
		Obstacles to access home teaching	System / regulations / lack of communication/lack of information
	Return process to school	Provision of returning to school	provision within a school
		Facilitating factor in return process to school	Interagency meeting / school visit by hospital staff / information to share with teachers, peers/gradual return process
		Obstacles in return process	regulations / system / different system in different hospital, school

6.2.3. Health condition and medical care related needs

This section presents the findings related to the theme of ‘health condition and medical care related needs’ in recuperation at home and at school (see table 6.4.).

It seems common among the participants that children received cancer treatment as recurrent admissions or outpatients rather than in long term admission. Five parents said that their children were receiving treatment as outpatients with minimum hospital admissions (JP2, JP3, JP4, JP5, JP6). When the children went to school between treatments, the parents were especially concerned that, because the children were under treatment, their conditions required schools to give them some consideration and support.

The flexible adaption of the child’s timetable and of the school rules was often mentioned as supportive for children when they had lack of strength (JY1, JY2, JP1, JP2), and when they had needs such as wearing a hat in school in case they had hair loss (JY2, JP4, JP6, JP7). However, parents thought that limited facilities and numbers of staff may have caused a lack of flexibility in some schools. For example, parents were often concerned with how to deal with fatigue and how to prevent catching viral infections in school. As the children’s physical strength was likely to be weakened by treatment, children often needed extra rest at school. But school could not always provide an appropriate place to rest (JP1, JP4, JP6). Some parents considered that the medical room, where there were many children who were not well, was not safe enough for the children whose immune systems were weaker than other children’s (JP1, JP4). One child sometimes stayed in the library with a librarian (JP1), but not all schools were able to provide an appropriate place or staff to supervise the child (JP4).

Parents often mentioned that children's conditions and their needs often changed especially when the child was under treatment, but that teachers did not always show an understanding about such changes (JP1, JP2, JP3, JP4, JP6, JP7).

Parents were also concerned about teachers' lack of sensitivity when they dealt with the child's medical needs. For example, a parent claimed that her child was shocked when the teacher told the class about her medical needs without consulting with the child or parents in advance (JP2).

Some parents mentioned that teachers' misunderstanding about illnesses may have caused overprotection or inappropriate support for the child (JP4, JP5). In one example, a parent said that the head teacher refused to take the child who was under cancer treatment on a school trip, although there was an approval of joining the trip from the medical doctor. The head teacher explained to her that the reason for his decision was that school would not provide medical care and extra support for her during the trip, (JP5).

Table 6.4. Health condition and medical care related needs: Persons who received education (Japan)

Themes		Categories	Codes
Medical needs and support	In convalescence at home / at school	Child's needs due to health condition	limit of physical function / limit of strength / tiredness / unstable conditions/change of conditions/appearance change
		Medical care related needs	Place and time for medical care / teacher's awareness of needs / protecting privacy
		Facilitating factors in responding to health condition and medical care needs	Flexibility (timetable, rule, facility) / understanding of needs and condition/ sensitivity / communication

		Obstacles to responding to health conditions and medical care needs	Inflexibility (use of facilities, rules) / lack of understanding of needs, condition, illness / lack of sensitivity / overprotection / lack of communication
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As a facilitating factor to respond to the child's medical needs, participants often mentioned good communication with teachers. One parent said, '*Whenever my child's condition changed, and she needed any support and care, I passed on a note to school, so that any teachers who teach my child can see it*' (JP3). Another one said, '*I think it is important to give enough information to teachers, so that they understand what support my child needs and why*' (JP2). Parents also recommended involving medical doctors in communication with school. '*I asked the doctor to contact school directly. A message from the specialist was much more persuasive than those from parents*' (JP8).

6.2.4. Academic needs

This section presents findings relating to the theme of 'academic needs'. I examined the participants' perceptions of ill children's academic needs, facilitating factors to respond to the needs, and obstacles to the needs in three different stages, in hospital, in recuperation at home, and at school (see table 6.5).

Table 6.5 . Academic needs: Persons who received education (Japan)

Themes		Categories	Codes
Academic needs and support	In hospital	Academic needs	overcome delay of study / preparation for examinations
		Facilitating factors in responding to academic needs	teaching style / individual support / collaboration with main school

		Obstacles to respond to academic needs	Impact of health condition / impact of admission patterns / limits of environment (time, facilities) / teachers' specialism / curriculum/lack of collaboration with school
	In recuperation at home	Academic needs	Overcome academic delay / Preparation for examinations / Sitting examinations
		Facilitating factors in responding to academic needs	learning in small groups / individual support
		Obstacles to respond to academic needs	Limits of environment (time, facilities) lack of collaboration with school
	At school	Academic needs	Overcome academic delay / preparation for examinations / Sitting examinations
		Facilitating factors in responding to academic needs	Teacher's attitudes (awareness of needs), Teacher's support (additional lessons, parent's support to children
		Obstacles to respond to academic needs	Teacher's attitudes / lack of awareness of needs

Year 9 is the last year of compulsory education in Japan, and therefore, pupils have to obtain a place in a senior high school in the end of Year 9 to continue their education, which is usually decided by their academic records and entrance exam results. Three participants of this study who experienced hospitalisation when they were in junior high school wrote that they were concerned about their academic record and exam preparation. For example, one of them wrote:

[After I left hospital in the middle of Year 9,] I received neither rehabilitation nor mental care in order to focus on catching up studying and prepare for the exams. I tried to do the same as others did, pretending as if I had no illness, which was very hard. (JY2)

One of them (JY3) had a positive experience in hospital school. As she said ‘ *The hospital school teachers contacted my school to know what other pupils were studying then, which was helpful. One to one lessons in hospital school were very good for*

me '. However, a limited access to studying was pointed out by another participant (JY1). He said that doctors restricted his study time in hospital due to his health condition. He had lessons only three times a week to study English and Maths. This participant said that when the condition was severe, studying was not a priority in hospital. In his case, it was important to receive support after he went back to school. All of these participants (JY1, JY2, JY3) said that they received support such as supplementary lessons in school after they went back.

As regards support for primary school children in hospital, a parent said '*It was helpful that teachers understood the child's condition and teach the child individually*' (JP8). However, a parent (JP1) claimed that not all teachers in hospital had the specialism to teach ill children. Her child received outreach teaching in hospital, where teachers in local primary and secondary school visited to teach ill children. This mother said, not all teachers provided appropriate support for ill children, and some of them did not understand the child's condition. She said that it was because some teachers might not have been specialised in teaching ill children (JP1).

In terms of children at school, a parent of a child who went to primary school between recurrent admissions talked about the importance of academic support to improve the child's well being. She said,

One day my daughter said to me, 'I cannot follow the lessons at school. As I cannot understand the lesson, something else always distracts me, such as...I feel like my wig is heavy. I feel like I have a headache. And then I go to the

medical room.’ She was spending more time in the medical room than in her classroom.

When this parent consulted with the school about this, the headteacher said that school could hardly provide extra support and that parents should support a child which could not follow the normal teaching approach (JP5).

Two participants made suggestions to other parents how to support ill children who are suffering from anxiety about their studies. One of them (JP3) said ‘ *What parents can do is to enable the child not to compare herself academically with others, and to know that she will overcome study delay later*’. Another parent (JP2) said ‘ *I often talked with my child and decided together what she could do and could not do. I wrote to her teacher what she could and what she couldn’t do too. It was useful to reduce her anxiety about school.*’

6.2.5. Social emotional needs

This section presents the findings related to the theme of ‘social emotional needs’. I examined perceptions about children’s social emotional needs, facilitating factors to respond to the needs, and obstacles to the needs that the participants experienced in hospital, during recuperation, and at school (see table 6.6.).

Table 6.6 . Social emotional needs: Persons who received education (Japan)

Themes		Categories	Codes
Social emotional needs and	In hospital and convalescence at home	Child's social emotional conditions	Anxiety about future / fear of death / stress / loneliness/ anxiety about communication with peers

support		Facilitating factors in responding to child's social emotional conditions	Communication with peers / staff in hospital / counselling / distractions
		Obstacles to responding to child's social emotional conditions	lack of communication with peers
	At school	Child's social emotional conditions	Difficulties in peer relationship / difficulties in relationship with teachers
		Facilitating factors in responding to child's social emotional conditions	Communication with peers / communication with teachers/ teacher's supportive attitude/ head teacher's leadership
		Obstacles to responding to child's social emotional conditions	Teacher's lack of understanding of illness / peer's lack of understanding of illness / lack of communication

The participants often mentioned the importance to understand the child's social emotional needs. Two of the young persons who participated in this study said that life in hospital was stressful and that they needed support to deal with anxiety and stress (JY1, JY2). One of them said, *'I experienced terrible loneliness because I had little communication with people outside the hospital. I felt like I was locked in a special place where I was completely separated from my daily life'* (JY1). He said that distractive activities to reduce stress and support the continuation of the child's daily life would have been helpful.

Communication with peers was often mentioned by the participants as an important issue which might have an impact on children. A parent said that communication with peers was helpful for her child to have resilience (JP1). She said that her child kept going to school between recurrent admissions. Whenever she went to school, peers and teachers were supportive and treated her as a peer in the class, which encouraged the child to complete the treatment. Another parent said that a hospital school teacher

liaised with the child and the school, which was helpful to improve communication among them (JP7).

Contrary to this, I also found a negative experience of communication. A parent whose child did not receive any contact while he was in hospital said;

When my child was absent from school just for a few days because of a cold, the teacher used to contact us. But after I had informed the teacher that my son would stay in hospital for a while due to his illness, there were neither visits nor phone calls from the teacher. It seemed that he [the teacher] thought my son was not belonging to the school anymore because my son could not go to school. As I had expected that any teachers would communicate with ill children to cheer them up, I was so shocked with his attitudes. (JP7)

Other parents were also concerned with communication. They said that it was important for the child to know that there was a place to go back to where the child belonged to (JP3, JP4). A parent said,

I believe that school aged children need to have a place to go back to. They need to have a communication with people there while they are away from school. Without communication, they may feel separated from their friends and feel like they are left alone. (JP3)

In addition to peers in school, a parent (JP7) said that communicating with peers in hospital was also important for the child. According to this parent, her son made friends with a boy who had the same illness and they seemed to have a kind of sense of solidarity with each other because they shared a similar experience. Her son's attitude became more positive than before he met this friend.

To what extent the child understands their own illness was considered to be another issue which might have an impact on the child's well being (JP1, JP2, JP3). In order

to reduce the child's fear of treatment and anxiety of future, participants mentioned that children's understanding of their illness was important. They said it might make the child's attitudes towards their future more positive (JP1, JP3).

However there were different opinions about this issue. Two participants (JP1, JP4) reported that there were cases where parents did not inform their child about their illness especially when it was a serious illness such as cancer. As people often had a negative or wrong image about cancer, for example 'cancer is a fatal illness', some parents did not tell the diagnosis to the child in order to prevent a negative impact on the child (JP4). A parent (JP3) who criticised such attitudes of concealing the truth from the child said;

It is possible to hide an internal illness from other people, but it may have lots of bad effects later. I believe that it is my role as a parent to tell the truth of the illness to my son and enable him to explain his own illness so that he can go into society by himself. I want him to accept himself as he is, to like himself including his illness and impairment (JP3).

Other parents supported her opinions, and suggested to explain the illness to the child in a suitable way so that they could understand (JP1, JP2).

Participants often talked about relationships with peers and with teachers at school. As a positive example, a young person (JP1) who returned to secondary school after a long term absence said that the form teacher was supportive to involve him in the class. This enabled him to make friends and to gain a positive attitude towards school life. Contrary to this, another parent said, her child who entered primary school after a long term absence, could not make friends in class and became reluctant to go to school (JP2). Similarly, a parent of a secondary pupil said that her child had

difficulties in making friends after a long term absence, and he withdrew from communicating with peers (JP6).

6.2.6. Interpersonal relationships

This section presents the findings related to the theme of ‘interpersonal relationships’. I examined the participants’ perceptions about positive and negative experiences, and perceived obstacles in relationships between the child and peers, and the child and teachers (see table 6.7.) and in other relationships (see table 6.8.)

Table 6.7. Interpersonal relationships 1: Persons who received education (Japan)

Themes		Categories	Codes
Interpersonal relationships	The pupil and peers	Positive issues	Communication / feeling of normality / feeling of belonging / understanding of condition
		Negative issues	name calling / being treated differently
		Obstacles in relationship	Lack of communication / negative image about illness / lack of understanding about illness
	The pupil and teachers	Positive issues	Teacher's supportive attitude, understanding of illness and needs, flexibility, teacher's experience, head teacher's leadership
		Negative issues	Teacher's unsupportive attitudes , inappropriate support
		Obstacles in relationship	lack of understanding of illness and needs / lack of sensitivity/ lack of communication / lack of experience

As mentioned previously, having communication with peers and having a sense of belonging to a group were often mentioned as positive experiences (JY1, JY3, JP1, JP3, JP8). A parent whose child had difficulties in making friends said, teachers needed to be aware of the impact of hospitalisation on the child’s social development. This parent said, because of the seriousness of the illness, the teacher was concerned

with the child's medical needs such as fatigue, but provided little support to promote peer relationships. She said that there was a lack of understanding about the child's needs, and that it was important for the child to have a circle of friends regardless of her condition (JP2).

As negative experience, participants often said that the child was treated differently from other children. According to a parent (JP5), her child who had cancer could not join a school trip as the head teacher said the school could not provide extra support for those who could not follow the group behaviour (see above section 6.2.5). She said, *'my child looked so shocked and whispered, "am I different from others?"'*

Lack of sensitivity was also mentioned as a negative experience. Two parents reported about experiencing that teachers carelessly talked about the illness without ensuring whether the ill child wanted them to talk about it to the other children or not (JP2, JP4). Even though the teacher thinks that it is for the ill child's sake, the child and parents may not have the same opinion. Another parent said that talking about the child's condition should be treated with caution, because vague information about the child's condition may cause misunderstanding among the children in the class (JP1).

Other examples of lack of sensitivity were also mentioned as negative experiences in interpersonal relationships. Two parents said that peers and teachers were not sensitive enough to the ill children's condition (JP2, JP4). One of them said peers in school laughed at the child whose appearance was different due to side effects of treatment (JP2). They also said that teachers' prejudices towards illness or condition

might cause them to choose a wrong approach to the child's needs. For example, parents criticised teachers' negative comments about their child's wig like "Let's not tell other pupils about the wig, because they will be shocked" (JP4) and "If other children do not notice that she is wearing a wig, it is not necessary to reveal it." (JP2). These parents claimed that the teachers themselves had a negative image about wearing a wig.

Participants said that prejudice and lack of understanding about cancer was a matter which was often seen in society (JP3, JP4). They mentioned that people sometimes said 'leukaemia is infectious', 'cancer is not curable' and 'cancer is hereditary'. She also claimed that the mass media in Japan have made stories about such diseases into tragedies, and that there still seem to be negative images about these diseases in society (JP3).

In order to promote a positive attitude towards ill children, this parent said that providing appropriate information about illness to peers and teachers was important to prevent spreading rumours, the child's being asked questions from peers, and inappropriate support of teachers. She said, '*once children know and understand about illness, they usually become more supportive than adults expect*' (JP3).

However, another parent (JP6) had a different opinion. He said telling the name of the illness should have been treated with more caution, as his teen age daughter seemed to feel a distance between herself and her friends because other people worried about her too much, which seemed to have affected her negatively.

Parents said that whether the child could receive sufficient support or not might depend on the individual teacher's decision and also on the headteacher's leadership (JP1, JP4). In addition, the teacher's past experience such as teaching similar cases of a child with disease or having an experience of being ill themselves were also considered to be factors which might contribute to teacher's positive attitudes towards the ill child . While parents whose children had good relationships at school, said the teacher had '*experience of teaching a child with cancer before*'(JP3) and '*the teacher herself had had a cancer*'(JP1), another parent (JP5), whose teacher showed unsupportive attitudes, said '*the head teacher did not have experience, as she often said "your child is the first case of a child with cancer in this school".*'

Table 6.8. Interpersonal relationships 2 : Persons who received education

Themes		Categories	Codes
Interpersonal relationships	The pupil and parents	Positive issues	support child's positive attitudes
		Negative issues	Not telling diagnosis to the child
	Parents and teachers	Positive issues	communication, mediatory role, parent's network, parent's initiative
		Negative issues	Teacher's unsupportive attitudes
		Obstacles in relationship	Lack of communication, lack of information
	Teachers within main school	Positive issues	Sharing information, collaboration among teachers, head teacher's leadership
		Negative issues	Difficulties in sharing information, difficulties in collaboration
		Obstacles in relationship	Lack of communication among teachers, lack of awareness of child's need

In terms of relationships with the child, parents explained their role in improving the child's education is to support the child's positive attitude (JP3). As possible obstacles to it, negative attitudes to tell the truth of illness to the child were pointed out (JP2, JP4).

As regards relationships between parents and school teachers, some parents suggested to contact a specialist who played a mediatory role, which was considered to be helpful to improve communication between the school and the parents. Examples of such persons were a SENCO who belonged to a local authority (JP1) and a hospital school teacher (JP7). A parent said, *'The suggestions of the coordinator were useful. When a coordinator joined in our meeting, the deputy head talked more positively than before'* (JP1). However, when I asked other participants about SENCO, six parents out of eight did not know about it or how to contact them.

As another facilitating factor, parents also suggested that active approaches from parents were effective to promote positive relationships with teachers. A parent (JP2) said:

Lack of understanding about the illness among teachers often hurts me. But I think it is because teachers do not know about the illness. Therefore what I can do is just to keep talking with them so that they can understand my child's illness and difficulties. (JP2)

Another parent (JP1) said:

I would suggest approaching teachers from the parents' side rather than just expecting them to offer support to you. In my case, I wrote letters to the headteacher three times, in which I explained my son's feelings. I think the letters were effective to let him understand my son.

Similarly, other parents also suggested making notes to hand in to teachers. Examples of such communication were to let the teachers know what the parents want the peers to understand about the child's illness (JP1, JP3), with whom in school the information should be shared (JP3, JP4), and what support the child needs when and why (JP1).

As obstacles to relationships, lack of information and lack of communication were pointed out (JP4, JP5, JP8). A participant claimed that it was difficult to obtain enough information about hospital school from the main school. Some parents suggested that parents' networking in hospital and online was helpful for them to share information (JP3, JP4, JP5).

Parents also mentioned possible difficulties among teachers to share information within school (JP1, JP2, JP4). On one hand, parents said that teachers needed to understand child's conditions (JP1, JP2, JP4), on the other hand, a parent said that there was a risk that inaccurate information might result in teachers' misunderstanding (JP1). In order to prevent such a risk, parents suggested to clarify the parent's opinions about what information should be open to all and which should be shared only among certain teachers, and to discuss about it with school (JP1, JP3).

6.2.7. System and practice

This section presents the main findings relating to the theme of ‘system and practice’ (see table 6.9).

The issues that the participants were often concerned with were the regulations of entering hospital school. The regulations required the parents to move the child’s school enrolment from main school to hospital school. A parent (JP5) in this study pointed out that this system caused the child’s fear of separation from school. She suggested that the regulations should be flexible so that any children in hospital could receive education from hospital school without changing school enrolment.

There were different systems in different hospitals which may have affected the provision of education in hospital. In some hospitals, interagency work involving medical staff and school was established to support the child when they return to school (JP1). However, in some other hospitals there were no such systems (JP3, JP5).

Table 6.9. System and practice : Persons who received education (Japan)

Themes		Categories	Codes
System and practice	hospital school and home teaching	Regulations of receiving alternative education	entry process, access information,
		Issues in support provided	Differences in different councils , lack of awareness
		Issues in teachers' expertise	Teacher's training
	Return process to school	Issues in support provided	Different system in different councils
	School	Issues in collaboration with alternative education	Role of people involved,
		Issues in collaboration within school	Information sharing

Another example of different systems was that, in some hospitals, outreach teaching was provided by nearby schools only when a school age child in hospital requested it. A parent in such hospital could not access appropriate information about educational support that they could have received; as a result the child was left without education while she was in hospital (JP5).

There were several cases that parents mentioned about lack of awareness of the school about educational needs of ill children and the school's role to support them while children could not attend school in hospital. For example, participants experienced that schools did not have any contact with children while they were in hospital (JY1, JP4, JP5, JP7), although they considered that such communication was important to respond to child's social and emotional needs (JY1, JP5, JP7).

6.3. Perspective of people who provide education

This section demonstrates the findings of analysis of perspectives of people who provided education. The group of people were hospital school teachers and primary school teachers. Data were collected face to face interviews and emails. Each interview took about an hour. I present the findings according to six themes, which are 'continuity of education', 'health condition and medical care related needs', 'academic needs', 'social emotional needs', 'interpersonal relationships', and 'system and practice'.

6.3.1. Participants

The participants of people who provided education in Japan involved teachers of two types of schools. A head teacher and two teachers participated from a special school

for children with medical needs, which had several hospital schools within a city as branch schools. Three other teachers participated from different primary schools (see table 6.10). All schools were located in urban area in the Kanto district.

One of the primary school teachers (JT6) is a *Yogo* teacher in Japanese. *Yogo* teacher is ‘a qualified teacher who takes charge of *Yogo*’ (Education Act 28:7), that means, they support children’s development through health care and health education in school (Japanese Association of Yogo Teacher Education, 2003). According to this participant (JT6), a *Yogo* teacher is a qualified teacher who is trained for children’s health care at school, and who is usually involved in school management and school activities as a responsible person of health education. According to Suzuki (2002), there is no equivalent word in English to signify this position. Therefore, in this study, I use ‘health teacher’ instead of *Yogo* teacher for convenience.

Table 6.10. Participants of people who provided education (Japan)

School type	Participant's position	Gender	Data No
Special school (Hospital school and home teaching, teaching centre)	Head teacher	female	JT1
	Teacher	female	JT2
	Teacher	female	JT3
Primary school	Teacher	female	JT4
Primary school	Teacher	female	JT5
Primary school	Health teacher	female	JT6

6.3.2. Continuity of education

This section presents findings of continuity of education, which involves perceptions of teachers about educational provision, facilitating factors and obstacles when children are in hospital, at home and in the process to return to school. (see table 6.10).

In terms of education in hospital, a head teacher of hospital school (JT1) said that continuity of education was maintained by providing education to children regardless of the length of their admission. Children with short term recurrent admission were also able to receive education on the day they enter the hospital as long as they were registered to the hospital school (JT2).

In order to identify children who need educational support in hospital, hospital teachers worked in liaison with medical staff, main school where the child was on role, and the child's parent (JP2). In recuperation period, in which the child could not return to school after they left hospital, they were able to receive home teaching or study at the teaching centre (JT1, JT2). There was no regulation about timescale to provide home teaching, as the provision was made on the base of the child's health conditions which was approved by the medical doctor (JT2).

Hospital teachers said that the present system of collaboration with medical staff and local school were useful to identify children who need to access hospital school (JT3).

As an obstacle to continuity of education, teachers mainly mentioned three issues. They were system in school enrolment (JT3, JT6), different regulation about educational support in different councils (JY2) and lack of information about education for ill children (JT5, JT6).

Firstly, according to teachers interviewed (JP2 JP3), there is a regulation that children need to move school enrolment from their main school to hospital school, but parents and children sometimes felt it stressful. A hospital teacher (JP3) said, 'The word

“*tenko*” (moving school enrolment from one to another), which we use to explain administration process to entre hospital school, sometimes gives the child and parents an impression that the child leaves the school and loses contact with the school completely’. The same teacher said that the hospital school would request the school to remain the child’s seat in the classroom, to put the child’s name in the administration list, and to keep contact with the child in hospital, so that both of the ill child and peers in the class understood that the child did not leave school but was just absent from school (JP3).

Secondly, an obstacle to continuity of education was identified by a hospital teacher (JP2), who mentioned that boundaries of administration sometimes caused an obstacle to provide home teaching or study at teaching centre after the child left hospital school. Both forms of education were for children who lived within the authority, therefore children in other authorities were not able to access them (JT2). According to this teacher, there were cases that children stayed at home without appropriate educational support because there was not such support system in the child’s residential area,

Thirdly, the primary school teachers pointed out an obstacle. They said that information about hospital school and home teaching / teaching centre was not well known to school (JT5, JT6). A teacher (JT5) said that lack of information might have caused low awareness among teachers about educational support for ill children while they were away from school. Absence due to illness was often considered as

authorised absence and teachers paid little attention to providing educational support to a child who was ill (JT5).

Table 6.11. Continuity of education: People who provided education (Japan)

Themes		Categories	Codes
Continuity of education	In hospital	Provisions that the child received	Hospital school / support from school
		Reason for receiving education in hospital school	Academic support / mental support / social support
		Reason for not receiving education in hospital school	No hospital school provided / health condition / to prevent separation from main school
		Facilitating factor to access hospital school	regulations / system / communication
		Obstacles to access hospital school	System / regulations / fear of separation from main school/ lack of awareness of educational right
	In recuperation at home	Provision that the child received	Home teaching /teaching centre/support from school / no provision
		Reason for receiving home teaching	Academic support / mental support / social support
		Reason for not receiving home teaching	No service provided / lack of information
		Facilitating factor to access hospital school	regulations / system / communication
		Obstacles to access home teaching	System / regulations / lack of communication/lack of information
	Return process to school	Provision of returning to school	gradual process to return to school / provision within a school
		Facilitating factor in return process to school	Interagency meeting / school visit by hospital staff / information to share with teachers, peers/gradual return process
		Obstacles in return process	regulations / system / perceptions of roles

As regards the process of returning to school, the hospital school teachers (JT1, JT2) said that gradual process was helpful for children who were not fully recovered to go back to school. In this process, children remained on role of the hospital school / home teaching and received support from them while they also started to go to school some days a week until their conditions became well enough.

Although many children used this system in this hospital school, the same teacher (JT2) identified an obstacle to this. As only few authorities accepted this system, some children could not have benefit of this system unless it was available in their residential area.

6.3.3. Health conditions and medical care related needs

Hospital school teachers stressed the importance to understand the individual child's health conditions including possible impacts of treatment that the child was receiving on the child's physical and mental conditions (JT1, JT2, JT3). They said that, as their condition and needs might be changeable and individually different, it was important for them to understand such conditions and needs well so that teachers could respond to their needs appropriately (JP1, JP2). Flexible adaptation of lesson plans (JT3), one to one lesson, a small group of teaching (JT2, JT3), team teaching (JT2, JT3) and collaboration with medical staff (JT2, JT3) were mentioned as facilitating factors.

As it was important to share information about child's needs among teachers to prevent inappropriate support in hospital, a teacher (JT3) stressed that lack of communication among teachers, medical staff should be avoided.

A hospital teacher (JT3) said that how children understood their own illness and treatments was one of crucial information that hospital school teachers needed to share with parents and medical staff. In cases of children with cancer, some children

Table 6.12. Health condition and medical care related needs: People who provided education (Japan)

Themes		Categories	Codes
Medical needs and support	In hospital	Child's needs due to health condition	Limit of physical function / limit of strength / impact of mental illness / impact of treatment / unstable conditions/change of conditions
		Facilitating factors in responding to health condition and medical care needs	Collaboration with medical staff (meeting, sharing information), education plan that corresponds with treatment provision, flexibility (timetable, lesson plan), team teaching / understanding individual condition and needs, sensitivity
		Obstacles to responding to health conditions and medical care needs	Lack of communication / Child's understanding about own illness
	In convalescence at home / at school	Child's needs due to health condition	limit of physical function / limit of strength / tiredness/ unstable conditions/change of conditions/ appearance change
		Medical care related needs	Place and time for medical care / teacher's awareness of needs / protecting privacy
		Facilitating factors in responding to health condition and medical care needs	Flexibility (timetable, use of facility, rules) / understanding of needs and condition/ sensitivity / communication
		Obstacles to responding to health conditions and medical care needs	lack of understanding of needs and condition / lack of sensitivity / lack of communication

were not informed their diagnoses. They were just explained about their condition or told a false name of illness, because parents wished to prevent threatening the child by knowing the diagnosis (JT3). Because the child did not know the diagnosis, it sometimes became difficult to explain their condition to school and peers at school later when they return to school (JT3). Normally, peers were told a little information

which fits the explanation that the child believes, in some cases, insufficient information resulted in misunderstanding among children at school (JT3).

In terms of medical needs at school, both hospital and primary school teachers similarly said that children had needs that teachers' should understand such as lack of strength and tiredness (JT2, JT3, JT5, JT6). A health teacher (JT6) and a teacher (JT4) were also concerned with dealing with medical care at school.

As facilitating factor to respond the child's medical needs, the teachers mostly mentioned communication to share information. They were, for example, collaboration between hospital and main school (JT2, JT3, JT5, JT6) and parents' role to share medical information to school (JT4) to improve understanding of needs among teachers at school. However, difficulties were also identified in terms of communication, such as arrangement of meeting (JT3, JT6), sharing information among teachers in school (JT6), and keeping balance between sharing information and protect privacy (JT4).

6.3.4. Academic needs

This section presents the findings of the participants' perceptions about children's academic needs, facilitating factors to respond to the needs, and obstacles to the needs in hospital, in convalescence at home, and at school (see table. 6.13).

Hospital school teachers commonly mentioned that children had academic needs to overcome delay of study and to prepare for examinations for secondary students (JT1, JT2, JT3).

In terms of curriculum, a head teacher said that their school applied the national curriculum flexibly to respond to individual child's needs. This was allowed for hospital school/ home teaching because the government stated that curriculum in the special school for children with medical needs should be selected prioritizing the fundamentals and considering the child's condition and the allowed lesson hours (MEXT, 2003). A hospital teacher (JT3) said that, if the child's condition was stable, teachers, parents and the pupil had a consultation to make the Individual Education Plan (IEP) in which academic plan was involved. They decided what to study in the limited time in hospital. According to this teacher (JT3), pupils study either hospital school provided curriculum or the home school provided material. It was not common that mainstream schools regularly send study works, therefore hospital teachers prepare lessons so that the student were able to make similar progress as the peers in home schools.

Table 6.13. Academic needs: People who provided education (Japan)

Themes		Categories	Codes
Academic needs and support	In hospital	Academic needs	overcome delay of study / preparation for examinations / sitting examinations
		Facilitating factors in responding to academic needs	Curriculum / teaching style / individual support / collaboration with main school
		Obstacles to respond to academic needs	Impact of health condition / impact of admission patterns / limits of environment (time, facilities) / teachers' specialism / curriculum/lack of collaboration with school / regulation of examinations

	In convalescence at home	Academic needs	Overcome academic delay / preparation for examinations / sitting examinations
		Facilitating factors in responding to academic needs	learning in small groups / individual support / collaboration with school
		Obstacles to respond to academic needs	Limits of environment (time, facilities) /teacher's specialism / lack of collaboration with school
	At school	Academic needs	Overcome academic delay / preparation for examinations / Sitting examinations
		Facilitating factors in responding to academic needs	Teacher's attitudes (awareness of needs), Teacher's support
		Obstacles to respond to academic needs	Teacher's lack of awareness of child's needs

As a significant obstacle to respond to the academic needs, a hospital teacher (JT3) mentioned that children in hospital often had disadvantages in sitting entrance examinations of senior high schools. The regulation of examinations tended to allow little adjustment nor flexibility in schedule, timetable and place to have examination (JT3). This teacher said, *'High schools often said that they would not allow any flexibility in sitting examinations for the fairness for all other applicants. But because of this, ill children may lose opportunities to go to high school. I think it is unfair.'*

In terms of academic issues after children goes back to school, the participants said that individual teachers' awareness of child's needs and supportive attitudes were important factor to support children (JT2, JT3, JT4). Hospital school teachers said that they made academic records and passed them to the school when the child returned to school in order to enable the teachers to understand what the child had done in hospital (JT2, JT3).

6.3.5. Social emotional needs

Hospital teachers often said that children's needs were individually different, especially social emotional issues needed to be considered carefully (JT2, JT3). In hospital, teachers said that it is important to pay attention to the child's anxieties and stress that health condition, treatment and hospitalisation might have impact on them (JT2, JT3). A teacher (JT3) said, *'What they feel, how they want to deal with such feeling are individually different Teachers need to be sensitive, and be ready to provide supports flexibly when it is needed'*.

The teachers (JT2, JT3) mentioned that such communication and various learning activities in hospital were considered to be important for children to gain their positive attitudes, a teacher (JT2) also pointed out that *'the hospitalisation period is getting shorter recently. I think many children who left hospital and stayed at home needs social and emotional care'* (JT2).

In the process of return to school, some children studied in home teaching or teaching centres (JT1). A teacher (JT3) said, *'For children in teaching centre, it is important to have experiences to gain self esteem as they often have low self esteem. Sometimes they have difficulties in interacting with people.'* She said that a teaching centre provided children learning opportunities to improve child's social skills.

Both in hospital and in recuperation at home /teaching centre, communication between the child and school was considered to be important factor to maintain the child's social relationships with peers (JT2). However, whether there was communication or not was different in individual cases of children (JT2). A health teacher (JT6) mentioned that lack of information about what school could do to

support the child in hospital was a obstacle to provide support, as well as teacher's lack of awareness about child's needs.

Table 6.14. Social emotional needs: People who provided education (Japan)

Themes		Categories	Codes
Social emotional needs and support	In hospital	Child's social emotional conditions	Anxiety about future, fear of death, stress, loneliness, anxiety about communication with peers
		Facilitating factors in responding to child's social emotional conditions	Communication with children / staff in hospital / understanding of individual needs / communication with peers and school teachers/ counselling, distractions
		Obstacles to responding to child's social emotional conditions	Lack of communication with children with similar condition, lack of communication with peers / school teachers, inappropriate facilities in hospital / pattern of admissions
	In convalescence at home	Child's social emotional conditions	Anxiety about future, fear of death, stress, loneliness, low self esteem
		Facilitating factors in responding to child's social emotional conditions	Communication with children / staff in hospital, communication with peers / school teachers, counselling, distractions , social skills training, progress in study
		Obstacles to responding to child's social emotional conditions	Lack of communication with peers/school teachers,
	At school	Child's social emotional conditions	Difficulties in peer relationship / difficulties in relationship with teachers / low self esteem / withdrawal from school
		Facilitating factors in responding to child's social emotional conditions	Communication between the child and other pupils, teachers / teacher's awareness of the child's social emotional conditions / inclusive school ethos/ head teacher's leadership
		Obstacles to responding to child's social emotional conditions	Lack of communication / teacher's lack of awareness of the child's social emotional conditions

Children's social emotional issues were also considered to be important at school, (JT4, JT6), however, primary teachers (JT4, JT5, JT6) said that teachers might not be aware of difficulties that the child had because they were busy to look after many other children. A teacher suggested promoting communication between teachers and parents to raise awareness of teachers (JT5).

6.3.6. Interpersonal relationships

Regarding interpersonal relationships between parents and teachers, participants commonly acknowledged that communication is important to share information of child's needs and to provide appropriate support (JT1, JT2, JT3, JT4, JT5, JT6).

Hospital school teachers (JT2, JT3) said that they often had opportunities to have communication with parents in an official way such as consultation meetings, and in an in-official way, such as having conversation when parents visited children in ward. In contrast, three school teachers mentioned about obstacles to communications with parent when the child was in hospital. Firstly, two teachers (JT4, JT6) said that teachers might not be certain whether it was appropriate or not to contact the child and the parents especially when the child was in hospital for serious illness. Secondly, another teacher said that teachers might not know what was the appropriate ways to contact (JT6). Thirdly, teachers might not be aware of their role to support the child after the child moved their enrolments from their school to hospital school (JT6).

A head teacher of hospital school (JT1) mentioned that the school had a consultant system for both school teachers and individual parents of children with medical

conditions. This school invited parents and mainstream school teachers to make an inquiry about any school related concerns that children with health conditions might have. However teachers interviewed in this study did not have experience to use this system.

Table 6.15. Interpersonal relationships: People who provided education (Japan)

Themes		Categories	Codes
Interpersonal relationships	Parents and teachers (hospital school, home teaching centre)	Positive issues	Communication tool, understanding of role, teacher's understanding of illness and needs, teacher's supportive attitudes, parents' positive attitude, mediatory role
		Negative issues	parents' unsupportive attitude, teacher's unsupportive attitude
		Obstacles in relationship	Lack of communication
	Teachers in hospital and main schools	Positive issues	Collaboration in teaching, awareness of role, sharing information
		Negative issues	Lack of collaboration, negative impact on child (feeling of isolation)
		Obstacles in relationship	Lack of communication, lack of awareness of role, teacher's workload
	Interdisciplinary relationships	Positive issues	Communication, Collaboration in providing support, facilitating meeting
		Negative issues	Difficulty in communication
	Teachers within main school	Positive issues	Sharing information, collaboration among teachers
		Negative issues	difficulties in collaboration, lack of awareness of needs
		Obstacles in relationship	Difficulties in sharing information among teachers, lack of awareness of child's needs, lack of awareness of regulations, workload, unsupportive system within school

6.3.7. System and practice

Teachers were mainly concerned about three problems about systems (see table 6.16). Firstly, school enrolment system was considered to be barrier for some children to entre hospital school. Secondly, regional difference in available support was considered to be a barrier for some children who could not access appropriate support such as home teaching. Thirdly, as there was a regulation about teachers' placement, teachers need to move to another school after thy work in one school. It was consider to be a barrier to for teachers to gain enough experience to develop specialism in teaching ill children (JT2). However, advantage was also identified, as one teacher said (JT1), teachers gain experience and skills in different school and special school.

Table 6.16. System and practice: People who provide education (Japan)

Themes		Categories	Codes
System and practice	hospital school and home teaching	Regulations of receiving alternative education	school policy, entry process, access information, durations of providing support
		Issues in support provided	Differences in different councils (system, facility, size)
		Issues in teachers' expertise	Teacher training, placement of teachers
	Return process to school	Issues in support provided	Different system in different councils
	School	Issues in collaboration with alternative education	Role of people involved, Information sharing
		Issues in collaboration within school	Different system in different schools

6.4. Summary of chapter six

This chapter presents provision of education for children with chronic illness through perceptions about education for children with chronic illness that people who received education (young people who experienced hospitalisation in childhood, parents of children with medical needs) and people who provided education (teachers of hospital and mainstream schools).

Continuity of education in hospital and in recuperation at home was maintained by hospital schools, home teaching, teaching centre and main schools. However, rigid regulation about school enrolment might have caused an obstacle to continuity of education. In a case, a child did not move registration to hospital school as she thought changing school would separate her from school completely. Participants also considered that this system might have caused a lack of support from school for children when they were in hospital. As school teachers did not have legal responsibility about support children in hospital, availability of support was considered to be depending on individual teachers. From a teacher's perspective, it was not easy to keep awareness about the child who was not enrolled and not in their responsibility officially, as teachers had a high workload with many other children.

Insufficient number of hospital schools, regional difference in available support, and boundary of administration were identified as obstacles to accessibility to education and also to equality of education.

In terms of health condition and medical care related needs, both parents and teachers stressed that teachers needed to understand child's individuality, impact of illness, and

child's conditions. In order to promote teacher's understanding, parents suggested enhancing communication between teachers and parents.

Academic needs of catching up delay of study were commonly acknowledged by participants. As facilitating factor, participants experienced supplementary lessons in secondary school. But an obstacle was found in rigid regulations of examination, by which pupils in hospital might have a disadvantage in sitting examination to have a placement in senior high school

Participants in different groups commonly mentioned that illness and hospitalisation have had an impact on child's social emotional difficulties. Anxiety of illness, stress of hospitalisation, loneliness in hospital was identified by young persons, parents and hospital teachers. Peer relationships and relationships between teachers were considered to influence children's emotional well-being. Participants identified lack of understanding of illness and negative image of certain illness, lack of sensitivity among teachers and peers. Unsupportive attitudes and inappropriate support were considered to have negative impact on the child.

Hospital teachers and some parents mentioned that supporting children's positive attitude to deal with difficulties in various areas including academic, social emotional and health related difficulties were crucial for the child's well-being. According to hospital school teachers, more children had short and recurrent hospital admissions recently, therefore children who were at home and who returned school might need such support. Participants who had such children were mainly concerned that system

and school environment did not fit for children who were under treatment or had unstable condition but who were not in hospital and went to school.

Chapter Seven

Data Analysis and Discussion

7.1. Introduction

This chapter presents the analysis and discussion of cases in England and Japan. The aim of the discussion is to consider the participants' perceptions about obstacles to education for ill children in terms of systems and practice on national, local and interpersonal level at school. There are two stages in the analysis and discussion. In the first stage, I analyse data of systems and practice on national and local level in cases in the two countries. In the second stage, I analyse interpersonal data on practice level in the two countries, focusing on the participants' perceptions about interactions between the ill child / parents and teachers.

Firstly, I contrast systems and practice on national and local level in the two countries, which the participants were concerned about. I examine whether there were any differences of interpretation of the systems among different groups of people, how the interpretations of the systems were put into practice, and what the impact on the child was. I then consider what might be barriers to provide education for children in system and practice on national and local level.

Secondly, I examine the interpersonal level of practice in both countries. I put the focus of analysis on the participants' perceptions about interaction between the child and teachers. I examine what they thought about 1) teachers' supportive and unsupportive attitudes, 2) teacher's awareness and lack of awareness, and 3) influential factors to teachers' supportive and unsupportive attitudes. I then attempt to describe two scenarios of positive and negative consequences of teachers' attitudes to

discuss whether there are any common issues to influence teachers' attitudes. I consider what the influential factors for positive consequences may be and whether there are any obstacles in the system for teachers to lead to positive outcomes.

Finally I consider possible areas for improvement in England and Japan in order to promote education for ill children in and after hospitalisation and supportive school environments.

7.2. Systems and practices in England and Japan

This section presents the details of the analysis of similarities and differences in systems and practice in England and Japan undertaken in this study. Bronfenbrenner (1979) suggests to consider how people interpret the environmental factors around them and how such interpretation may influence the child. In this study, I examine the systems on a national and local level that participants mentioned and that I considered relevant to my study. I examine whether there were any differences of interpretation of the system among different people, how such interpretations were put into practice, and what the impact on the child was. Table 7.1. shows the findings of similarities and differences of systems on national levels and local levels in England and Japan, which the participants identified.

Table 7.1. Systems on national and local levels that participants identified in England and Japan

Participants' identified systems	England	Japan
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National level	Statutory frameworks	Education Acts 1996 / The Access to Education (DfES,2001)	Enforcement Regulations for the School Education Law,
	School enrolment system	Mainstream school ownership / Dual registration	Single registration
	National Curriculum	No legal obligation to offer the National Curriculum	Flexible adaptation of the National Curriculum
	Types of school	Special school or PRU	Special school or PRU
	Teachers' employment	Individual school, and PRU	Local authority
Local level	Regional differences in available supports, boundary of administration, accessibility to information		

7.2.1. Guidelines and obligation of mainstream school

In both cases, England and Japan, the head teachers of hospital schools and PRUs mentioned that one of the purposes of the school was to support ill children while they were away from mainstream schools and support their return to schools (ET1, ET5, ET10, JT1). In order to achieve this, collaboration with mainstream school was often mentioned among the participants.

I found two clear differences in the participants' comments between the two countries about the systems on national level. Firstly the participants in England referred to the statutory guidelines about the ill children's education as the basis of their practice; Japanese participants did not mention such guidelines. Secondly, while the English participants stressed the mainstream schools' statutory obligation to support ill children, none of the participants in Japan explained the mainstream schools' support as statutory.

In England, there are guidelines about education for children with medical needs (DfES, 2001a), which clarify the roles of LEAs, schools, hospital schools/PRUs, and parents in providing educational support. These guidelines state that mainstream school has a vital role to ensure the children who are absent from school receive support to maintain their education (ibid, 1.17). Participants in England (ET1, ET3, ET10, ET11) referred to these guidelines in order to explain the school enrolment system, that is, the child remains enrolled at mainstream school while they are in hospital school / PRU. This is a reason why the participants (ET1, ET3, ET11) stressed the mainstream school's obligation, which means that main school has the responsibility to support the ill children while they receive education in hospital schools and PRUs.

That is, for example, to arrange meetings between mainstream school and hospital school when it is needed (ET11), and to supply study materials for the child who is in hospital or who studies in the home teaching service (ET3, EY10).

Contrary to this, in the case of Japan, there seemed to be no statutory documents which clearly identified the mainstream school's obligation to arrange education for children who are absent from school for medical reasons, although there are relevant educational laws (JT1). It seemed that this caused a burden for some parents (JP3, JP7) to arrange education for their children unless schools were supportive. Japanese participants also mentioned that the school enrolment systems might have affected the education that the ill child received (JT2, JT3, JP3, JP5). The rigid school enrolment system in Japan allows children to register only with one school, therefore, the child needs to move their enrolment from school to hospital school. In one case, a child decided not to receive education in hospital in order to remain enrolled at their main

school, because she thought that she would be separated from school completely if she changed school (JT6). One registration system was considered to affect teachers' attitudes to support children. As the child moved registration from one school to another, the teachers did not have any obligation about the child officially. The unclear role of the mainstream school teachers in the support of children in hospital was in one case thought to have caused difficulties for teachers in taking action to support the child (JT6).

What is noteworthy is that, whatever the system was, participants in both countries similarly said that it might depend on individual teacher's awareness and decisions whether main schools provide support to ill children or not (ET2, ET10, JT2, JT3). Although participants in both countries reported that there were many supportive schools regardless of whether the child was on roll at the school or not (JT1, JT2, JP1, ET3, ET10), they also identified cases that some children did not have any contact from schools in spite of remaining on roll at the main schools (JT2, ET3, ET10, ET11). Whether the child had contact with school or not was considered to be important among young persons (EY1, EY2, JT1) and parents (JP1, JP3, JP5, JP7) to maintain their social relationships and maintain emotional well-being.

Even where there were guidelines in place in England, there was one case in which a teacher did not know the schools' obligation to support the ill children in alternative education (ET13). In this case, it seemed that the school teachers were not well informed about the guidelines and were not aware of their statutory duties. What may influence individual teacher's supportiveness is discussed later in this chapter.

7.2.2. National Curriculum

Regulations about adapting the National Curriculum were found to be similar in both England and Japan. In England, the guidelines (DfES, 2001a) noted that The National Curriculum was not obligatory in hospital school / home teaching. In Japan, flexible adaptation of the National Curriculum was allowed to provide education which was considered to be appropriate for the child's condition and hospital environment (MEXT,2012). In both countries, hospital schools, home teaching and teaching centres developed their own schemes of work which were based on the National Curriculum (ET1, ET10, JT1). According to teachers (ET1, ET10, JT1, JT2), pupils and parents, teachers made Individual Educational Plans, in which they decided on the priorities of study considering the child's needs, condition and allocated time.

7.2.3. Types of school and teacher's employment

In England, hospital schools, home teaching and teaching centres are mainly provided by special school or PRU for children with medical needs. In Japan, similarly, special schools and PRUs take charge of this education. The differences are that, while PRUs in England are maintained by LEAs (DfES, 2001a), the PRUs in Japan are maintained by special school or mainstream school (NISE,2010).

Participants in both countries (JT3, ET6, ET10) said that teaching ill children required teachers to have knowledge and skills to teach children with various conditions and needs. One teacher said that teachers shared experiences, knowledge, and teaching skills, which were useful to develop specialisms in teaching ill children (ET6).

However, one participant (JT3) reported a concern that teachers' employment system in Japan may have impacted on teachers' developing specialisms. While teachers in England are employed by each school or PRU (ET10), Japanese school teachers are employed by local authorities (JT3). They need to move to different schools within the authority after they have worked in one school for a few years (JT1). According to one head teacher (JT1), this system had the advantage that teachers may expand their knowledge and teaching skills in different special and main schools. However, one teacher was concerned with a disadvantage, which was that teachers might not gain enough experience and expertise in dealing with the various needs that ill children may have (JT3). One parent (JP1) critically mentioned that teachers' specialism was not consistent among hospital schools.

7.2.4. Inequality in opportunity

In terms of the local level of systems and practices, participants in both countries were similarly concerned about regional differences in the available support which pupils receive, the boundaries of administration and accessibility to information.

In Japan, the regional differences in the educational system may have caused inequality in the education that children received. Firstly, inappropriate numbers of hospital schools in Japan may have caused inequality of educational opportunities. A participant (JY3) claimed that not all hospitals had hospital schools. This opinion is common in other studies, which found that significant numbers of children in hospitals in Tokyo could not receive education in hospitals because of insufficient numbers of hospital schools (Ikari *et al.* 2002; Takigawa, 2010).

Secondly, there was an issue when the child returned to school. A teacher (JT2) said in the interview that some children were able to be gradually reintegrated to mainstream school by attending both hospital school and mainstream school for variable amounts of time. That is, they returned to mainstream school for some days, but they were also able to attend hospital school whenever necessary. But this was available only when the authority where the child lived operated this system. In England, the guidelines suggested to arrange for such a gradual process to return to school. Many cases of this practice were found in the interviews in England (ET 3, ET5, ET7, ET11). This process was considered to be effective not only for the child, but for the school to understand the child and to prepare appropriate support for the child (see 5.2.2.).

In England, teachers talked about differences in the educational support provided by different authorities. An interviewed teacher at a PRU (ET5) suggested that there were no standards for PRUs with regard to the medical conditions of children, therefore, the quality of education that children received might be affected by the facilities and support provided by the authority. Another teacher in a PRU (ET6) was also concerned with the regional differences within the financial system. She said that the balance of charges, which schools needed to pay for the child in PRU to local authority, and the financial support that school received were different in different authorities (ET6). Teachers in different PRUs (ET5, ET6, ET11) commonly considered that the schools' budgets might be an issue which affected schools' decisions about whether they referred a child to a PRU or not. A headteacher (ET5) said, 'it's an unfair system, it just depends on where you live what you get'. Although the teachers said that these regional differences were an influential factor in the

child's education, whether there is such regional difference or not may be an issue that requires further research.

Two common issues in terms of inequality of educational opportunity were found between England and Japan. Firstly, support for adolescent over 16-year-olds seemed to be a significant problem. Hospital school teachers and home teachers in England and Japan (ET5, ET10, JT1, JT3) commonly reported in the interviews that adolescents over 16 years old who could not go to school due to medical reasons were not legally supported in their education. In England, Site A provided post 16 education but PRUs (Site B, Site C) did not provide education for adolescents over 16 years old. Whether such adolescents could access hospital education or not seemed to depend on the local authority.

Secondly, parents' access to information about educational support was considered to have an impact on whether the child received education or not. Parents did not seek support because of lack of awareness about their child's entitlement. In one case in Japan, teachers and the children themselves thought that an ill child should not worry about school in order to concentrate on the treatment (JP5). In England, one parent did not know there was a support system for the child who could not go to school for mental health reasons (ET6). Systems to access information may be an issue to be considered. If the system offers only one way to access information and services, the parents' decision may have been affected by the information that they are able to obtain. In one case in Japan, a child and her parents decided not to enter hospital school because of the insufficient information that they obtained from a social worker in hospital (JP5) (see 6.2.2.). Although there is a system to provide support for

children, parents' awareness about the support system and access to information may also have an impact on the child's opportunity to receive educational support.

7.2.5. Reasonable adjustment

A clear difference was found in terms of equity in sitting examinations. In both countries, examinations seem to be serious academic concerns for pupils especially for secondary school students. In England, students take national examinations to obtain qualifications. In Japan, year nine pupils need to take examinations in order to secure a place in senior high school. According to teachers in England (ET3, ET6, ET10, ET11), there is a system in England to make reasonable adjustment for pupils who have a disadvantages in sitting examinations, which is managed by the organisations responsible for carrying out the examination. For example, pupils were able to take examinations at hospital schools or at teaching centres where they were accepted as official examination centres (ET3, ET6, ET10, ET11).

In Japan, the regulations of examination seem to be different in different authorities and different high schools. A one hospital teacher (JT3) said, the regulations tend to allow little adjustment or flexibility in schedule, timetable and place to carry out the examination (JT3). It was rare that examinations took place in hospitals, and little adjustment was made for the pupils' health conditions (JT3). If no reasonable adjustment is made, students who have a serious condition which may affect their academic performance in examinations may have significant disadvantages. Reasonable adjustments in examinations in Japan is considered to be an issue which needs to be researched further.

7.2.6. Summary of the section

This section examines the differences and similarities of systems in national level and local levels in England and Japan from the point of view of some key personnel (teachers, parents, young persons who experienced hospitalisation in childhood). Clear differences in opinions about national levels of support were found in relation to the guidelines of education for children with illnesses and the school enrolment system.

While the mainstream schools' statutory obligation to support children with medical needs is clear in England, the mainstream school's role is not clear in Japan.

Similarities were found in opinions about the flexible adaptation of the National Curriculums. Types of hospital school appeared to be similar in both countries; however, the difference of teacher employment systems may have an impact on teacher development in Japan. At local level, regional differences in the available support and boundaries in administration appeared to have existed in both countries which may have had an impact on the equality in education that children received. The educational support system for adolescents over 16 years old is one of the areas which may need to be improved in both countries. In Japan, it is unlikely that regulations of reasonable adjustment in examinations are established. This may be one of the areas which needs to be researched further.

Although there are some similarities and differences in the systems on national and local level between the two countries, participants' concerns in the individual interactions showed similarities. Support from main school to the ill child when they

are in hospital and when they return to school were commonly considered to be important among the participants in both countries. However whether the child could receive support or not was also considered depending on the individual teachers' decision. In the next chapter, I examine what may influence teachers' supportive and unsupportive attitudes.

7.3. Teacher's supportive and unsupportive attitudes

Participants in both countries often mentioned that whether pupils received appropriate support or not depended on individual teachers (ET3, ET5, ET10, EY2, EY3, JT3, JP3, JP1, JT8). Although there may be various reasons for different behaviours in different teachers, are there any common issues which may impact on teachers' attitudes and their support for the ill child?

In this section, I analyse the data related to the participants' perceptions relevant to teachers and attempt to describe two situations. One is the situation in which teachers showed supportive attitude and provided support for the ill child, and the other one is the situation in which teachers did not show supportive attitudes and provided little support. In order to do this, I analyse the data on the basis of concepts inspired by Bandura's theory of self efficacy. I consider the relationship between teachers' attitudes and conceptions of knowledge which Bandura suggested as influential factors to enhance people's self efficacy (see 3.3.1.).

By contrasting the concepts and attempting to describe two scenarios of supportive and unsupportive actions, I consider what issues may be influential on teachers' attitudes. The aim of this section is to identify possible factors that may influence

teachers' positive attitudes. I consider this further in the final discussion, i.e. whether there are any systematic issues which may have prevented teachers to take positive action.

7.3.1. Unsupportive attitudes and obstacles

Table 7.2. and 7.3. show categories and codes about unsupportive and supportive attitudes of teachers as developed out of the data.

Table 7.2. Teachers' unsupportive attitudes

Categories and Codes	Examples of the comments
Influential factors	
Lack of experience, knowledge of teaching ill children	I think it is because the teacher had no experience...as she always say, 'your child is the first case of a child with cancer in this school' (JP5)
Lack of information about support system	They do not know what hospital schools do and how to access them (JT5)
Lack of communication with the child / parents	Without communication, teachers would guess and do what they think good for the child. This may cause misunderstanding and damage on relationship. (JP5) I didn't want to talk with such teachers (EY2) Talking with the head teacher was stressful. I wanted to contact her as little as possible. (JP5)
Lack of information about child's difficulties / condition / illness	The teacher had a prejudice towards child cancer. (JP4)
Unsupportive leadership	If the headteacher's does not understand the needs, teachers cannot afford time to visit hospital to attend the meeting. (JT6)
Teacher's lack of awareness	
Lack of awareness of own role	It's like 'out of sight, out of mind'. They forget about the child who is not in front of them. (ET10)
Lack of awareness of the child's needs	Teacher did not know that my child felt difficulties in making friends (JT2)

Lack of plan	Teachers do not know what they can do for the child in hospital. (JT6)
Teacher's unsupportive attitudes	
No contact with the child / parents	There were neither visits nor phone calls from the teachers. It seemed that he thought my son was not belonging to the school anymore. (JP7)
Overlook / misunderstand the child's needs	Most teachers did not understand my difficulties. (EY2)
Inappropriate support / evasion of support	The head teacher said that they would not take my child to school trip. School would not provide support who cannot follow group behaviour (JP5)
Lack of sensitivity	She was asking me in class, 'when are you coming back to school properly? When is the condition going to end?' (EY3)

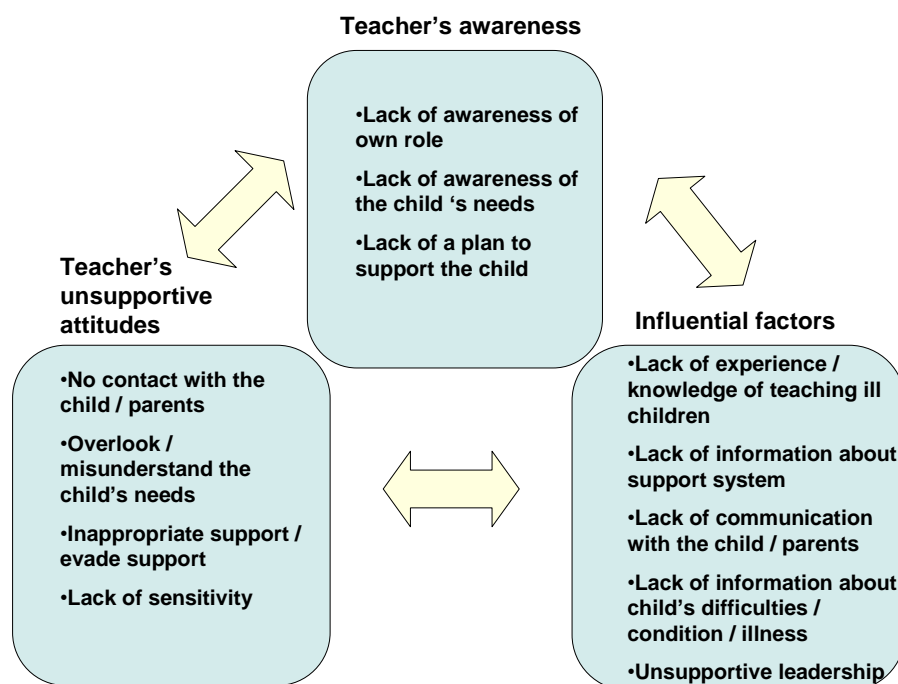
From these tables, I develop a model which demonstrates the interactions between the categories. I put different data sets of unsupportive and supportive attitudes to see how they look (see figure 7.1. and 7.2.). The reason why I put both the tables and figures is to show the key examples of comments as evidences of the categories.

I develop these models adapting the theoretical model by Bandura (1997), which, I believe may help to understand the real world events behind the data in my study. I design two models which show the interactions between the three categories in order to attempt to explore details about the teacher's attitudes when aiming to support the ill child and hope that this may help to explain the different outcomes observed in the data.

Although my models are developed adopting Bandura's causation model of self-efficacy, my study is not about self-efficacy. I consider relations of teachers' attitudes, their awareness, and influence. I do not intend to suggest a causation model of

teachers' behaviour by these models, as I understand that teachers' decision making processes may be complex and be influenced by various factors which cannot be explained by simple cause-and-effect relationships, as the original theory implies. Rather, by contrasting two models which I develop from the data, I attempt to consider how various factors interacted and may have impacted on the teachers' supportive and unsupportive attitudes in these particular cases.

Figure 7.1. The attitudes / awareness / influence model: unsupportive attitudes



The negative impact of influential factors on teachers' awareness and unsupportive attitudes are demonstrated in Figure 7.1. In this model, the elements in the group of *Influential factors* show the participants' perceptions about the potential causes of teachers' unsupportive behaviours. The elements in *Teachers' awareness* show the participants' perceptions about teachers' lack of awareness which may not motivate

teachers to show supportive behaviours. The elements in *Teacher's unsupportive attitudes* show what the participants considered unsupportive about teachers behaviours. If the teacher was not aware of their own role in supporting the children, they may not have sought information about the available support systems. In consequence they may not have been able to refer the child to the appropriate support. Unsupportive school leadership may have further negatively influenced the teacher in actively communicating and seeking information.

It was a common theme in different groups of participants of the study in England and Japan that lack of experience was associated with lack of knowledge and skills to teach ill children (ET10, ET6, JT2, JT3, JP3). Knowledge of teaching ill children involved practical knowledge of teaching strategies and skills to respond to the child's needs and how to avoid the risk of imposing any harm on the child's health at school. One parent reported that the teacher themselves often stressed their lack of experience when school could not provide support (JP5). In some cases, insufficient knowledge of dealing with the child's difficulties in social peer relationships caused teachers' lack of awareness of the child's needs, which resulted in inappropriate support (JP4). Some other cases exposed that insufficient knowledge of the child's condition caused teachers' excessive concerns to manage health related risks of the child, which resulted in schools' adverse attitude about providing school activities to the child (JP5). One teacher (ET5) said that there were cases in which the lack of knowledge of teachers about how to deal with children's behaviour, which was caused by certain mental health conditions which the child had, often caused the teachers' inappropriate attitudes towards the child. It often affected their relationships which prevented teachers from finding what the child's real needs were.

Lack of information about support system was identified by parents (JP7, JP8) and teachers (JT6, ET6). There were cases in which teachers could not refer cases to appropriate services because they did not know about the system (ET6, JP5, JP8). As absence due to illness was often treated as authorised (ET6), both teachers and parents often did not know the system which was in place to secure the child's rights and respond to their educational needs and their own role to access support for the child (ET5, ET6). As a result the child could not receive support (ET6).

Lack of communication was often mentioned including young persons, parents and teachers. An example was that a teacher talked about the child's illness in class without obtaining consent from the parents and the child (JP3). This teacher was not aware of the child's wishes that information regarding their illness needed be treated sensitively. This parent said, if the teacher had had a talk with them, such a mistake could have been avoided.

Lack of information about the child's difficulties, condition and illness were also serious concerns. Teachers sometimes had a negative image about cancer (JP2, JP5) and some teachers did not understand the complexities of the child's condition and illness (EY3). In both cases, teachers showed negative attitudes towards the children. Two parents in these cases thought that inaccurate information and the biased image of their child's illness might have prevented teachers to be aware of what the reality was, which caused their inappropriate support for the child.

There were many cases in which teachers did not understand the difficulties that the child had in their school life (EY2, EY3, JP1, JP3, JP6, JP7, JP4). In one case, the teacher did not understand the child's difficulties to follow the lesson, the teacher did not provide appropriate support for her to deal with the problem (EY2, JP3,JP6).

It was also found both in England and Japan that unsupportive school leadership affected the education for the ill child negatively (EY2, JP5). Where head teachers had evasive attitudes towards involving the ill child in school activities, it seemed to be difficult for individual teachers to provide flexible support, which resulted in providing inappropriate support for the children. These negative results seemed to cause distrust of school within the parents or child, which prevented communication between them.

The concept of the three categories as represented in figure 7.1 may suggest reciprocally influences. For example, a teacher (JT3) reported a case in which the teacher was not aware of his role to make contact with the child in hospital. He did not have communication with the child. Lack of communication resulted in the child's needs being overlooked.

7. 3.3. Teacher's supportive attitudes

In this section, I consider the relationship between the teachers' awareness, supportive attitudes and influential factors to them (see Table 7.3.). Figure 7.3. is the model of teachers' supportive attitudes developed out of the table.

Table.7.3. Teacher's supportive attitudes

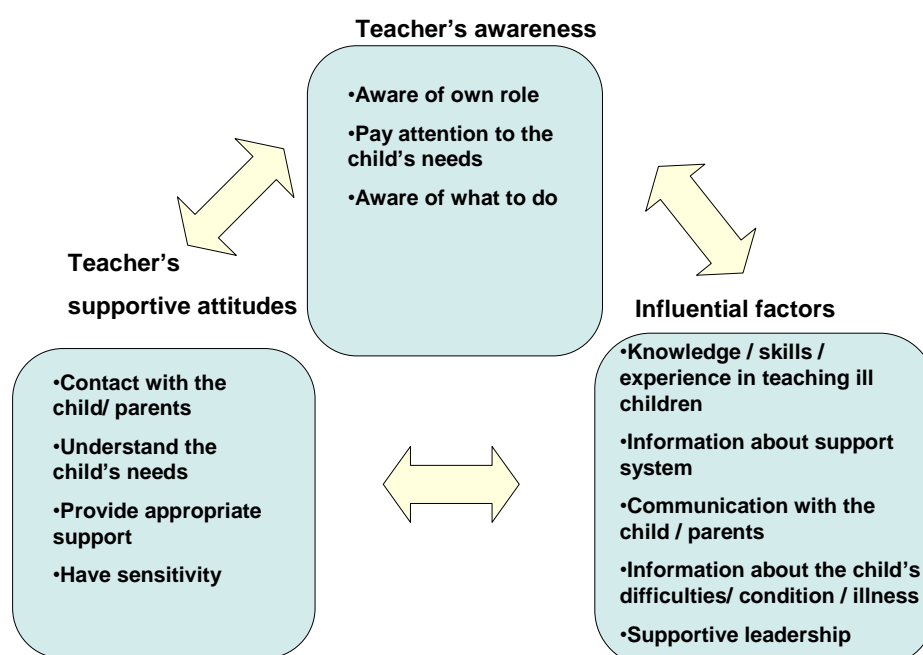
Codes	Examples of the comments
Influential factors	
Knowledge / skills in teaching ill children	I want teachers to learn how to support children who do not have disability but who are not healthy (JP1)
Information about support system	He suggested me to contact SENCO in the school. (JP4)
Communication with the child / Parents	It's important to keep contact with parent to let them know that the child is still in class (JT3)
Information about the child's difficulties/ condition / illness	I usually talk with parents about the medical condition...what they can do, what cannot do. (ET7)
Supportive leadership	The head teacher often made an opportunity to share information...(JY1)
Positive teacher-child / parents relationship	Teachers in college were good. I openly talked what I needed and what I didn't need. (EY2)
Teacher's awareness	
Aware of own role	They regularly sent the worksheet for the child. (ET2)
Pay attention to the child's needs	In the college, teachers asked me what I needed. (EY2)
Aware what to do	She suggested my son to write a letter to the class. (JT7)
Teacher's supportive attitudes	
Contact with the child/ parent	The form teacher regularly sent the letters of children to my son. (JP1)
Understand the child's needs	Teachers understand what problems you might have, what problems you are likely to cause, I think that's important. (EY1)
Provide appropriate support	Some teachers understood me and they allowed me to leave the class five minutes before the end of class in order to go to the next classroom. (EY2)
Sensitivity	She asked me what we want her to tell about my child's illness to the classmates. (JP2)

In this model, the elements in the group of *Influential factors* show the participants' perceptions about the potential causes of teachers' supportive behaviours. The elements in *Teachers' awareness* show the participants' perceptions about teachers' awareness which may motivate teachers to show supportive behaviours. The elements

in *Teacher's supportive attitudes* show what the participants considered supportive about teachers behaviours.

As an example, knowledge in teaching ill children may affect teacher's ability to decide what to do to support the ill child, and it may influence their attitudes to provide appropriate support. Such supportive attitudes may make positive relationships between the teacher and the child / parent, which may affect active communication between them. If the teacher is aware of their own role to support the child, they may seek information about the child's needs and condition, which may impact on their attitudes to understand the child's needs. Supportive school leadership may support teacher's positive attitudes to promote communication and to seek information about the child as well as appropriate support system for the child.

Figure 7.3. Attitude / awareness / influence model : supportive attitudes



Teachers both in England and Japan who taught children with medical needs mentioned that they obtained practical knowledge and skills of teaching ill children from their experiences or shared such knowledge with their colleagues (ET3, ET6, JT2, JT3). Two teachers said, because some specific illnesses were associated with specific needs, experienced teachers' skills and knowledge were useful for planning appropriate teaching for the child (ET5, ET6). In one case in a mainstream school, a teacher who had an experience of teaching a child with cancer helped another colleague who taught a child with cancer for the first time by offering their knowledge about teaching the ill child, which helped the inexperienced teacher to understand the sensitivity of ill children and to start communication with the parents of the child (JT5). In another case, a hospital teacher suggested to a main school teacher of the child, who was in hospital at the time, what the child's needs were and how to communicate with them. This improved the communication between the child and the teacher (JP7).

Having information about support systems may raise teachers' awareness about their role and may provide practical knowledge about how to make use of the system. In one case, a child in hospital was left without contact with school. The child's father obtained a booklet from a social worker which explained the system of education for ill children, the child's needs, the school's role and a list of accessible specialist agents. He passed on this booklet to the school. This resulted in the teacher to have a consultation to discuss how to support the child (JP7).

Communication seems to be an influential factor to enable teachers to obtain information about the child, about needs and appropriate support. A teacher suggested

parents to have contact with teachers to inform them about the child's difficulties and needs whenever any change of condition or need occurred (JT5). She suggested that such communication is considered to be helpful to raise awareness of teachers about the child's needs, especially when the teachers did not have knowledge and experience to teach the ill child. One participant in England (EY2) explained the effectiveness of the communication from the child's point of view. When teachers had good communication with the child by asking her opinions, needs and difficulties, they understood what she needed and supported her appropriately. She stated: 'the teachers understood me' and this feeling resulted in building trust between her and the teachers, which promoted good communication.

School leadership may have influenced individual teachers as well as it may have facilitated teachers to work as a team. One teacher said, whatever needs the child may have, it is usually not only one teacher who supports the child but other teachers as well. They help each other to support one child while they teach many other children. When positive school leadership developed such a positive ethos, individual teachers were able to pay attention to children and work as a team in order to provide appropriate support for children (JP7). In another case, a head teacher often contacted the parent and the child while the child was long-term absent. The parent thought that such positive attitudes seemed to have a positive impact on other teachers in supporting the individual child's needs. In some cases, such leadership provided flexible support for the child.

7.3.4. Adaptations to the model suggested in this study

The assumed multiple complex interactions in the model may result in negative outcomes as well as positive ones, depending on the nature of the interactions. That is, the positive model could potentially produce a negative outcome if any of the categories or factors is changed. Likewise, the negative model is not thought to be static either and could produce positive outcomes if individual categories are changed. In the final discussion, I suggest different ways of how such positive outcomes could perhaps be triggered by making changes in influential factors.

7.3.3.1. Teacher's actions and influential factors

Influential factors

According to Bandura (1989), human behaviour is regulated by the ability of predicting likelihood of outcomes. When people are confronted with a task, they consider the possible consequences of their performance, establish a goal, and plan courses of performance. In this process, people judge the expected outcome. If the outcome seems to be beneficial, people have positive motivation to carry out the action. In case that an adverse outcome is expected, people also may restrict their actions. Moreover, even if there is positive outcome expectancy, if people doubt their ability to achieve the anticipated outcome, it is unlikely that actions take place. If people believe that they have ability to control the difficulty and be able to achieve positive outcome, it is likely that actions take place. Bandura call such self-belief about people's own ability self efficacy (Bandura, 1989; Bandura 1995).

Taking an example of a case in Japan, a child with cancer was prevented from joining a school trip, because the head teacher thought that it was risky to take a cancer patient to a school trip (JP5). Referring this case to the theory, the headteacher seemed

to anticipate negative outcomes, for example that the child's condition might have got worse during the trip and the school may have been blamed for it. There might have been various reasons for the head teacher's decision, but according to the theory, one of the reasons might have been that this head teacher did not have high self-efficacy to portray herself as successfully managing the task to achieve the positive outcome.

Another example can be seen in a case in England in which a student was restricted to the number of subjects to sit for GCSE by the head teacher after the child's long term absence. According to this student (EY2), this was because the head teacher underestimated the student's academic ability and wanted to avoid the risk of her failing which might have influenced the school's reputation negatively. In this case, the teacher prioritised preventing a possible negative outcome of the student's failure over a potential positive outcome which may have been, for example, providing the same opportunity of taking exams for all pupils including the ill student. This could have been achieved by supporting the student so that she would have been able to obtain satisfactory results.

There may have been several reasons behind this head teacher's decision; therefore, it may not be suitable to describe it just from the perspective of the teacher's forethought associated with self-efficacy. However it can be said as one of the possibilities that the teacher might have displayed low self-efficacy to achieve a positive outcome. If the head teacher had had positive belief in the school being able to provide effective support for the child and that she would obtain satisfactory results, he might have provided an opportunity to this student to take examinations in more subjects.

Although I have mentioned a number of negative cases, it is not my intention to consider the negative consequence as the teachers' failure. Rather, my interest is what may have influenced their decision. Therefore, my focus is on the possible influential factors with regard to the teachers' attitudes, especially, what may be potential factors to result in positive consequences. The aim of this discussion is to consider whether there are any systematic problems which hinder possible positive influential factors.

From these cases, it seems important to clarify what the concepts are, which may have impact on peoples' forethought and self efficacy, because there may be potentially a lot of different ways in which people think which may control behaviours.

Bandura (1989: 1181) suggests conceptions of knowledge as influential factors to enhance people's efficacy. They are knowledge gained through **observational learning, experiences, verbal instructions** and **pre-existing knowledge**.

In my study, I developed five influential factors of the teachers' actions from my data. These five categories and the elements within them signify the factors that the participants of my study considered influential for teachers to decide their actions in the context of my study.

In this section, I examine the concepts and categories developed in the context of my study and how they may be linked to Bandura's suggestions of knowledge. I examine some cases reported in my study and consider possible ways to change the teachers' actions.

Knowledge of teaching children with medical needs

The amount of knowledge about teaching strategies and the nature of children with medical needs are considered to be one of the issues which may affect the teacher's attitudes towards the children. If teachers have enough knowledge and skills to teach a child with a certain illness, it may be easier for the teachers to identify the child's needs and provide appropriate support.

As the findings presented earlier suggest, teachers often have concerns about their lack of experience of teaching children with certain illnesses. This issue was often mentioned especially in the Japanese cases. There were cases in which teachers felt anxious about teaching children with cancer which they had not experienced before (JP2, JP3, JP4, JP5). It seems that these teachers much relied on pre-existing knowledge and other preconceptions about teaching the ill child, but paid less attention to other concepts which may have guided their performance such as acquiring new knowledge and skills through observational learning and verbal instruction. Performance of other teachers who had similar experiences could have served as a model to observe and learn as it was shown in a case in which teachers in a school shared the knowledge (JT5). Any forms of instructions about teaching the ill child may increase the teacher's knowledge. If they can access appropriate resources

such as educational consultants who are specialised in teaching ill children and apply the acquired knowledge into the cases of their pupils, this experience may increase the teachers' self belief in teaching children with similar types of illnesses. The knowledge of how to gain the skills may be helpful for a teacher later on, so that the teacher may apply it when they have different cases of children with other diseases.

In some cases in Japan and in England, teachers made evasive decisions and, for example, restricted the opportunities of the ill child to be involved in school activities in order to prevent potential risks which may have been induced by involving the child (JP5, EY2). Due to the small scale of the study and the limited number of cases, this study cannot provide suggestions of what may happen in similar cases. However, some other cases, in which teachers accepted the ill child and flexibly dealt with the difficulties, implied that teachers were not always persuaded by potential threats. Some teachers emphasised the potential risk in some circumstances, others did not. From the perspective of self-efficacy theory, threats are assumed to be conceptualised by human judgement (Bandura, 1989). If people believe that they can control potential difficulties, such difficulties may not be a threat which restricts their performance. However if teachers expect that they can not control the potential negative consequence, they may feel anxious about it and restrict their action to avoid the threat. That means, excessive threat may be avoidable by raising teachers' perceived self-efficacy. If teachers obtain sufficient knowledge about teaching the ill child and acquire skills to manage potential risks, teachers may not feel excessively stressed about the risk and may provide suitable support for the child.

As teachers' working environments have various aspects, the individual teacher's knowledge and skill may not be the only factor that determines their actions. However,

it appears that such knowledge and skill may be one of the influential factors. In order to promote teachers learning and support their positive expectations (which encompasses knowledge and skills) and their readiness to learn, accessible resources and a positive ethos within the school to support the teacher's learning seem to be important. If teachers have practical skills and knowledge of teaching or knowledge about how to access information and increase their own self-efficacy to teach, such positive behaviour may impact on developing a supportive environment for them to collect information, learn from each other, and promote positive communication with the child and parents.

Information about support system

In England and Japan, there are nationally or locally stipulated systems to provide education for children with medical needs. However, ill children seem to be left without receiving support in the system often. One teacher (JT5) pointed out that there was a tendency that not only teachers, but children with illnesses themselves as well as parents thought that the child had to keep from studying and meeting friends because they were ill. She said,

For any children, even if they are too ill to live long, it is natural that they wish to play and learn. It is necessary to prepare opportunities for children with nay conditions to do the same as other children. But I feel like the norm in school is not like that. (JT5)

I appears that accessing information about the system is an important environmental factor to influence the teachers' awareness for two reasons. Firstly, if teachers obtain

this information, they are able to understand what their role is in terms of education for the ill children. Secondly, as the system involves interdisciplinary teams, teachers are able to access resources which supply practical information and specialist support which enrich teacher's knowledge and skills.

Some mainstream school teachers in England who took part in the study did not know the statutory obligation of school to provide education for children who are away from school for medical reasons. They were not aware of their own role to address additional support for those children. This may not only be because of the individual teacher's lack of awareness, but because of the school's ethos. If the school developed a clear policy to provide support for ill children, which is coherent with the national statutory guidelines, it would be helpful for the individual teachers to gain awareness of the system and understand their own responsibility. Clarifying their own responsibility seems to be useful for individuals to understand their own role and what they are expected to do and set a goal of their own performance.

According to self-efficacy theory, goals influence people's motivation strongly because they provide a 'sense of purpose and direction' (Bandura, 1988). In England, the Access guideline (DfES, 2001a) clarifies the statutory obligations of mainstream schools and local authorities. If each school has a clear policy and a system within the school about the education for children with medical needs, individual teachers understand their own role and how they work with others to accomplish their roles. This may be effective to increase teachers' motivation and sense of efficacy. Although the Access guideline (DfES, 2001a) requires mainstream schools to develop a policy dealing with education for pupils who are unable to attend school due to

medical needs, the researched mainstream schools did not have specific policies to cater for this.

In the case of Japan, there is no statutory obligation to mainstream schools to provide additional support for children who are in hospital or at home although collaboration with hospital school is recommended. In addition, as mentioned earlier, the school registration system in Japan seems to affect teachers' cognition about their responsibility to the ill child in hospital. The system requires children to transfer their registration from their mainstream school to hospital school when they receive education in hospital or at home. Although hospital school or home teaching teachers requested the mainstream school to maintain relationships with the child and support their education in liaison with hospital school/home teaching, it depended on the individual teacher's generosity whether they developed such collaboration or not because they legally did not have any responsibility for the child. This collaboration seemed to be based on teachers' voluntary dedication rather than their statutory responsibility. While there were many cases of successful collaborations between mainstream school and hospital schools, it also appeared that some teachers thought it was difficult to do such voluntarily work in addition to their regular work. Under these circumstances, it may not be clear for teachers what they should do to support children who are not in their school any more.

According to self-efficacy theory, when people do not have a clear vision about what they are trying to achieve, they have low motivation which may result in a lack of continuous effort (Bandura, 1988). In order to increase teachers' motivation, it seems to be important to clarify their statutory responsibility as a teacher. It is also required

to clarify responsibility of mainstream schools and local authorities to establish a practical system to support individual teachers to accomplish their work.

Moreover, as pointed out in previously, it is essential to distribute information about the support system to schools and teachers. Such an environment may develop a clear sense of responsibility among teachers which may increase their motivation to acquire knowledge and skills, and seek information to identify the child's needs. All of these may result in appropriate support for the child. By seeking information and communication with the child and parents, teachers may obtain knowledge of teaching the ill child and provide appropriate support for children. The feedback about the support, which teachers obtain by communication with the child and parents, may increase teachers' self efficacy and may also create a more informative and supportive environment.

Another benefit of accessing information about the system is that teachers may be able to obtain practical information and specialist support which may enrich teacher's knowledge and skills. Such knowledge and skills are often provided by interdisciplinary work for the ill child.

As the Access guideline (DfES, 2001a) describes, interdisciplinary teamwork is promoted in education for children with medical needs. As suggested in the initial findings, the hospital schools and home teaching services in Japan and England collaborated with other agents including mainstream schools to support the children. In both countries, the researched hospital schools and home teaching teachers have a role as mediators between schools and other agents by providing information and

organising interdisciplinary meetings among stakeholders for the children who are studying in hospital or home teaching. As one home teacher in England pointed out (ET11), hospital or home teaching teachers, who work as a facilitator of an interdisciplinary meeting, obtain basic knowledge of the child's condition and treatment. The facilitator will also know who in the hospital/social work/ education may be the key person to work with to respond to certain needs that the child has at the moment or will have in the near future when the treatment progresses, and will have the knowledge and tools to make contact with such key persons.

Linking with an interdisciplinary team in liaison with hospital/ home teachers may bring considerable benefits to the school. It may provide a rich resource of medical, educational and social welfare information about the child from the involved specialists and collaborative work to support the child. When a school is concerned about their lack of experience of teaching a child with a certain disease and seek advice from a specialist who has the ability and skills which they need to acquire, the hospital and home teacher provide the required information. Hospital and home teachers also may have a role to mediate between parents and the school.

In Japan, there seemed to be several environmental barriers for teachers to access such resources and mediatory support. Firstly, it seemed that the mediatory function and resource provider role that hospital and home teaching had were not well known to mainstream schools and parents. Parents and children sometimes chose not to register with hospital school to keep their registration with home school. One of the forum participants (JP5) provided an example of this. This participant said that she had huge stress and difficulties later to deal with the unsupportive attitude of the school.

In order to distribute information about the system and raise awareness of mainstream school teachers, the association of head teachers of special schools for children with health impairment in Japan introduced a list of hospital schools and support organisations as informative resources in a leaflet to mainstream schools. Such a list may be useful for schools to seek information.

However, there seemed to be a problem in terms of people's attitude to access information. In England and Japan, participants said that some schools were reluctant to seek support from outside (JT3, JT5, ET6). As one of the interviewed mainstream school teachers in Japan (JT5) said, there seemed to be a norm in some schools that a child's problem at school should be dealt with by the parents and the school directly, therefore, making contact with other agents was considered to be unfavourable.

Even if a parent contacted outside agents and provided an opportunity to teachers to access information or practical support, the same teacher said that it may negatively impact on the relationship between the parent and the school (JT5). If the school had such an ethos, it may be difficult for the individual teachers and parents to access information and support from outside agents.

Moreover, another concern was that not all hospital and home teaching services in Japan provided mediatory support and information resources. As a recent report revealed (Takigawa, 2010), numbers of outreach teaching units in hospitals is increasing. These rely on teaching staff from local secondary and primary school which are located near the hospital. Those teachers are not necessarily well

experienced in teaching ill children or have a good network with relevant specialists. One parent pointed out this problem in their comment (JP1).

In order to develop a supportive environment which provides information of the support system, hospital and home teacher training may be required to acquire specialist knowledge, and schools may be required to have positive attitudes towards working collaboratively with outside agents and support the individual teachers' ability to utilise such systems. If such an environment is prepared, and teachers can access the existing support system, it may increase the teachers' self-efficacy in providing support and risk management by acquiring knowledge and practical support. It also promotes teachers' motivation to seek information which may cause more active communication and appropriate support.

Information about the child's difficulties, condition and illness

Information about the child's condition and illness is important for teachers to understand the child's needs and provide appropriate support. Although information regarding the child's condition and the school's risk management is obviously important for teachers, the information that the parents wanted the teachers to understand was not only simple information about the child's condition but more diverse information. Two parents suggested to inform teachers about 1) what the child's difficulty and condition were like, 2) what support they needed 3) when they needed support, and 4) why certain support was necessary (JP1, JP3).

There seem to be several types of information that need to be obtained. Firstly, accurate information about the illness appears to be important. The participants in both countries often stressed that accurate information was important in order to prevent pupils and teachers misunderstanding certain illnesses (JP1, JP2, JP5, EY2, EY3). Secondly, medical care and medical needs related information may be considered to be vital to avoid the risk of a harmful impact on the child's condition. Thirdly, the impact of the illness, condition and absence from school on the child seems important and needs to be considered from various aspects. Possible difficulties may be physical mobility and strength, academic progress and ability, social development and relationships with others, and emotional well-being.

As a participant from the group of young persons and teachers (EY3, ET3, JT3) mentioned, the condition and impact may be different from child to child even if they have the same diagnosis. Therefore, accurate information about the individual child has to be collected. If any additional support is required, it needs to be determined what support is needed, when it is needed, and why it is needed (JP1,JP3). The timing of obtaining information may also be considered to be important as the child's condition is changeable (JT1, EY3).

There were cases in which school did not understand the child's difficulties and conditions (JP4, EY3). It was suggested in the interviews that presenting evidence that certain medical information is from reliable sources such as medical staff was useful to convince people to understand the child's difficulties and promote support (JP4, JP5).

The method of distribution is considered to be the most important issue that teachers have to consider, because health information often involves sensitive issues. One participant (JT5) suggested that it has to be clarified in discussions with the child and the parents what information should be shared with the whole staff, and what information should be restricted to certain members. It was also suggested in the interviews that teachers must make sure how the child understands their own illness and what the child and parents want pupils in the class to understand about it (JT3, JT2, JP1).

Collecting appropriate information and treating it in an appropriate way to share with other teachers and to present to other pupils seems to be an important skill for teachers. If teachers manage this well, it may influence their relationships with the child and parents positively, and it may also develop the teacher's self-efficacy and supportive attitudes.

Communication with the child / parents

When a child was left without contact from school, the child often felt loneliness, anxiety and a sense of lack of belonging, which were serious concerns among participants in both countries. Whether there was contact or not was one of the factors which appeared to influence the participants' image of teachers' attitudes.

Both teachers and parents reported (ET6, EY2, JY1, JP7, JT3) that the frequency of contact with the ill child and parents, and the relationship with them may have

influenced teachers' awareness of the ill child's needs. It may have consequently impacted on the quality and quantity of support that teachers provided for the child. Some young persons (JY1, EY2) and parents (JP7, JP4) mentioned that a lack of contact may have had a huge negative impact on the child socially and emotionally. Therefore, they often felt anxious about the lack of communication with school and felt difficulties to make contact with teachers (JT1, JT7, EY2).

What communication was considered to be helpful for the child was different from one individual to the next. Some children appreciated letters from the whole class (JP2), but other children preferred keeping communication with close friends and a close teachers only (EY3).

There seemed to be no ideal pattern of communication, but the findings suggested that it was helpful for children who were absent from school to know that the teacher and classmates were concerned about them (JP7, JY1). Where the teacher provides any form of contact regularly, it may be helpful for the parent or child to make use of such contact to start more active communication with school when the child's condition is improving.

In terms of individual communication at school, participants in both countries stressed their wish to be treated the same as other children as far as peer relationships and relationships with teachers were concerned (EY2, EY3, JP4, JP5). They wished to have equality of opportunity such as attending school activities and examinations (JY5, EY2). They also wished to maintain their identity as a child not as a patient (EY2, EY3, JP4, JP5). One young person said:

First and foremost, children with medical needs are children, and you know, they happen to have medical conditions. But they're children first.(EY3)

The young participants often used the words 'normal' 'normality' 'ordinary life' (EY1, EY2, EY3, JY1) when they described something they wished for in their childhoods.

Ill children often experienced difficulties due to health condition and missed various experiences in daily life that healthy children normally had (EY3). Therefore, being treated as the same as other children and being able to enjoy school life as a child (EY3) was considered to be especially important. When teachers treated them differently, it often had a negative impact on the child's emotions and social relationships (EY2, EY3).

School leadership

As discussed in the earlier passage about support systems, school leadership may influence individual teachers when seeking information and support positively if such leadership promotes collaboration and interdisciplinary work. One teacher suggested that if schools are positive about collaboration with other agents, it may make it easier for teachers to access information and support from them (JT4). Examples of such positive influence of school leadership were seen in some cases of home teaching in England. Some teachers (ET6, ET8, ET11) experienced that some schools seemed to restrict referrals of pupils to their services for financial reasons. According to the interviewed teachers (ET6, ET8, ET11), the school budget was usually managed by the school's senior leadership team. Therefore their values were likely to determine

how they spent the budget and used other resources. Further examples of this were seen in Japan. While there were some positive examples in which school leadership provided a supportive environment in school (JP1, JP2, JP7), in another school, the head teachers' strong sense of risk-avoiding attitudes restricted individual teacher's flexibility to support the child (JP5). A teacher also wrote that it was unaffordable for a teacher to go to hospital to have a meeting with medical staff unless the school had allocated a supply teacher for that purpose (JT6).

As seen in the positive examples above, supportive leadership may not only promote individual teachers' learning and collaborative work, but a positive environment in which teachers support each other. Parents (JP1, JP2) reported that under a positive leadership, the school created an inclusive atmosphere among pupils regardless of whether they had illnesses, disabilities or not. In such an atmosphere, children may have learnt positive attitudes to accept any differences in other children and teachers. Such observational learning may be effective to enable them to show positive attitudes towards peers whatever differences they may have.

7.3.4. Summary of this section

In this section, I analysed what the participants in my study considered to be teachers' supportive and unsupportive attitudes, and what they considered to cause the teachers' attitudes. On the basis of the analysis, I attempted to describe two different scenarios of positive and negative consequences of teachers' attitudes in order to identify possible factors that may result in different outcomes. I did this in relation to self-efficacy theory. The teacher's positive attitudes involved four categories : 1) Having

contact with the child / parents, 2) understanding the child's needs, 3) providing appropriate support and 4) having sensitivity in dealing with the child's needs.

Teachers' attitudes without either of these elements were considered as 'unsupportive'.

The teachers' awareness about the child's needs and the teachers' own role was considered to potentially motivate teachers to take supportive actions as well as develop a practical awareness about what to do to support the child.

I suggested five categories which may have influenced the teachers' decision to take action: 1) Knowledge in teaching ill children, 2) knowledge about the support system, 3) communication with the child /parents, 4) information about the child's difficulties / illness / condition, and 5) school leadership. I further suggested that when the teacher improves either their own knowledge, skills or situation in these categories, it may be possible to enhance their self-efficacy to take action to support the ill child appropriately.

I also suggested that these different factors need to be thought of as interacting with each other, therefore, I did not consider it to be appropriate to explain this interaction as a cause and effect relationship. Rather, when any one element of the concept is changed, it may influence the other elements positively or negatively. For example, if a teacher, who is not aware of the child's needs, is informed about the child's difficulties, it may make them become aware of the child's needs and enable them to provide appropriate support.

Although I considered these five categories to be influential for teachers, it was not my intention to suggest that they are the only factors to determine the teachers' actions. Self-efficacy theory says outcome expectancy may have an impact on people's decisions to take action. However, in the real world, outcome expectancy may not be necessarily important for people to determine their actions. As regards the situations observed in my study, sense of responsibility as a teacher and empathy for the child, for example, may have been more important than outcome expectancy to motivate teachers to support the child. Therefore, I considered the five categories as one possible approach for teachers to enhance their to support the child appropriately.

7.5. Possible areas to be improved in related to systems and teacher attitudes

In the previous section, I examined the systems and practice at national and local levels as mentioned by the participants (see 7.2.). The analysis about the individual levels of practice found five possible categories of influential factors to teachers' actions and support (see 7.3.1., 7.3.2., 7.3.3.). In the following section, I consider how these influential factors may be affected by the system and what improvements in the system may be suggested.

7.4.1. Improvements to the system at local level

Knowledge of the system was considered to be important for teachers to provide appropriate support, to refer the child to the appropriate agents, and access

information in teaching ill children as well as to raise awareness of the teacher's own role in the system.

Although such knowledge was considered to be influential, if the support system itself was insufficient for a certain child who had any specific support, it was difficult for the teacher to access the appropriate support. It may sound like a contradiction, but one finding about the systems suggested that there were regional differences in the support available, for example, different regulations in gradual reintegration (Japan), insufficient numbers of hospital schools (Japan), lack of reasonable adjustment (Japan), different services available in different PRUs (England) and educational support for children over 16 years old (England, Japan). In order to improve the accessibility of education for children, and provide suitable support for individual children, improving systems and practices at local level seemed to be important.

In Japan, there was no guideline in a place, which may have caused the unclear image of the role of stakeholders. No clear description of the role of mainstream school was considered to be a cause of difficulty for teachers to support ill children in hospital, because such a child usually was not officially under their responsibility. A guideline about the provision of education for children with chronic illnesses seemed to be necessary in order to clarify the roles and also to provide suitable education in any different regions. However what should be included in the guidelines are issues for further research. If roles of stakeholders, such as school teachers, are clarified, the appropriate support system which enables the teachers to meet their obligation may become clearer.

7.4.2. Communication

My findings suggested that the children's health condition and medical care related needs were different from one individual to the other and often changed according to their conditions. The participants also stressed that obtaining accurate information with the right timing was important for teachers to understand the child and provide appropriate support. Hospital schools organised interagency meetings and liaised with the school and medical staff. However, the findings suggested that the availability of such collaboration was depending on the hospitals.

Some teachers in this study suggested that obtaining accurate information about the individual child's illness, their condition and how the condition and illness may have impact on the child's school life was important information. In order to enable teachers to obtain such information, supportive systems to promote communication between school, parents and medical staff seemed to be needed.

In the case of one hospital school (Site A), medical staff and hospital school teachers held workshops for school teachers about certain illnesses, which provided opportunities for teachers to talk with medical staff and gain accurate knowledge of illnesses and appropriate support. It seemed to be important to improve interagency work to provide opportunities for school teachers to learn about children's illness.

7.4.3. Teacher training

As discussed previously, teachers' knowledge in teaching ill children may be improved by gaining experience or learning through instruction. One of the areas that teachers may need to know about is the child's needs. As the findings suggested,

identifying individual needs was important for teachers (ET3, ET5, ET10, JP2,JP3). The findings also suggested that hospitalisation and illness had an impact on the child's social emotional needs in various ways (JY1,EY1,YE2,EY3). In order to identify the needs and to respond to social emotional needs, the importance of communicating with parents and the child were often stressed among the participants (EY2,EY3,JP1,JP5,JP6,JT2, ET6,ET10).

Knowledge about teaching may be acquired in teacher training to some extent. Such training may be useful for any teachers who teach ill children. Children with cancer often went back to school when they were still receiving treatment as outpatients (JP3, JP5, JP7, EY1). Two teachers in both countries commented that numbers of such cases were increasing (JT2, ET3). It appeared that hospital admissions for cancer were generally shorter than for any other illness (JT2, ET3). Under these circumstances, it may be important for primary and secondary school teachers to have some knowledge in teaching ill children. If teachers have any opportunity to acquire such knowledge in the initial teacher training, it would be helpful when they teach ill children.

Teachers may also need opportunities to develop relevant knowledge later in their careers. Providing sufficient learning opportunities for teachers may be an area to be improved. If the school management team are trained and well aware of educational needs of ill children, it may have an impact on the running of the school.

Specialisms of teachers in hospital school / home teaching / teaching centre may be one factor to impact on main schools teachers, as they may teach the child in collaboration with the school teachers. However, as it was reported previously (),

the teachers' employment and regulations about placement may impact on teachers' opportunities to gain experience positively and negatively, especially in Japan. As they need to change school to work every few years because of the regulations, there was a concern that they did not have enough time to gain experience.

They may need appropriate opportunities to develop their knowledge, for example, by sharing skills and knowledge with other teachers and attending training.

The current situation of initial teacher training and training for teachers needs to be researched further. However, if this area is improved and teachers at school have opportunities to develop their knowledge and skills in teaching ill children, it may be useful to create more supportive school environments.

7.5. Summary of chapter seven

This chapter presented the analysis and discussion of cases in England and Japan with regard to 1) similarities and differences in system and practice on national and local level from the perspectives of the participants in my study, and 2) interpersonal level of practice focusing on participants' perceptions about interpersonal interactions between the ill child and teachers. The purpose of analysis and discussion was to identify people's perceptions about barriers to education in terms of systems and practice at national and local levels, as well as individual levels of practice in order to consider possible areas for improvement in the systems.

In both countries, hospital school, home teaching, teaching centres provided educational provision for children with chronic illnesses in collaboration with

mainstream schools. While mainstream schools in England had a statutory obligation to support the ill children and the roles of the stakeholders were explained in the guidelines, in Japan, there were no guidelines and the mainstream school's obligation was not clear.

At local level, regional differences in available support and administration boundaries were identified as problems regarding the equality in education in both countries.

At interpersonal level of practice at school, the teacher's lack of knowledge in teaching ill children, lack of knowledge about the systems, the lack of information about the child's difficulties/ condition /illness, lack of communication, and unsupportive leadership were considered to be obstacles in raising the teachers' awareness about their own roles, the child's needs and provision of support. These factors were considered to be influential on teachers' unsupportive attitudes.

In order to promote the teachers' supportive attitudes, suggestions were made to gain 1) knowledge of teaching ill children, 2) information about the support systems, 3) information about the child's difficulties, conditions, illnesses, and to improve 4) communication with the child /parents, and 5) school leadership.

However, to promote teachers' learning and support, accessible resources, opportunities to learn, and a positive ethos within the school to support the teachers' learning seemed to be important.

The chapter concludes by giving suggestions about possible areas to be improved. They are improvements at local level in the systems, communication involving different agents, initial teacher training and teacher development. I suggest that these may improve the continuity of education and supportive school environments.

Chapter Eight

Conclusion

8.1. Summary of the study

The origin of my study was in my experience as a hospital school teacher in Japan. I found that some children had difficulties in accessing support in their regions, some children had difficulties in school life after they went back to school, and some others did not. Some schools were supportive and some were not. I asked the question ‘what may have caused these differences? What may be useful to improve education for ill children?’

Based on this experience, I developed three research questions: 1) What are the educational needs that the ill child have? 2) How do systems and practice work to respond to the needs?, and 3) What are the barriers to respond to the needs?

Having had the opportunity to study in England, I explored cases of provision of education for children with medical conditions in England and Japan through the perspectives of different groups of people. These were young people who experienced hospitalisation in childhood, parents of children with chronic illnesses, teachers in hospital school, home teaching, teaching centres and mainstream schools. I interviewed representatives from each group in face to face interviews or by email.

I analysed the data in two stages. In the first stage, I looked at the changing needs and environments of the children in the process of the child’s hospitalisation to return to

school. Social ecological theory enabled me to examine this process systematically. The data enabled me to explore systems and practice and to identify the children's needs, as perceived by participants.

In the second stage of the analysis, I examined individual levels of practice, namely, interactions between child and teacher. I looked at potential influential factors to impact on teachers' supportive and unsupportive attitudes. Self-efficacy Theory inspired me to examine the relationships between the teachers' awareness, the teachers' attitudes and influential factors in these areas as perceived by the participants.

The main findings regarding the child's needs were grouped in three areas, 1) academic needs, 2) health condition and medical care needs, and 3) social emotional needs. Academic needs, such as catching up with their studies and preparing for examinations were especially serious concerns for secondary school pupils. Health condition and medical care related needs involved fatigue, lack of strength, unstable conditions and needs of medical care at school. It appeared that flexible support and sensitivity were needed. Hospitalisation may have resulted in the child's loneliness, anxiety, low levels of self-confidence, and difficulties in social relationships in school. It also appeared that children needed to maintain their identities and normal lives as children.

Continuity of education in different settings was maintained by hospital school, home teaching, teaching centres and mainstream schools in England and Japan. Differences were found in school enrolment systems, which affected the mainstream schools' obligations in supporting the child who is in hospital and at home.

In Japan, insufficient numbers of hospital schools and the lack of reasonable adjustments in examinations were identified as potential obstacles to accessing education in some cases. In both countries, regional differences in the support available and a lack of support for over 16-year-olds were found.

With regard to interpersonal relationships I suggested that lack of communication, low awareness about the child's education, insufficient knowledge and skills in teaching ill children among teachers may exist. Lack of appropriate information about the child's illness and difficulties was considered to possibly cause a lack of misunderstanding about ill children and negative attitudes towards the ill children at school. Unsupportive school leadership was also suggested to be an obstacle to supportive school environments in some cases.

In order to provide appropriate support, this study suggests to consider improvements the following areas: 1) teachers' knowledge in teaching ill children, 2) and knowledge of support systems. 3) to improve communication, 4) to obtain sufficient information about the child difficulties and illness, and 5) to aim to provide supportive school

leadership. Further developments may be needed in inadequate systems, teacher training, and social emotional support for children.

8.2. Limitations of study

There are several limitations with regard to the suggested findings of the study.

Because of difficulties contacting relevant people in my study area, the number of participants for this study was limited and not well balanced. Examples of people who were not involved were children or young persons who experienced hospitalisation recently (England), parents of children with chronic illness (England), and PRU teachers and local authority (Japan).

Although this study did not intend to restrict the types of illness under investigation to certain ones, the findings are limited to the types of illness which were mentioned by the participants. Therefore, they may not reflect various other medical conditions and illnesses.

With regard to both countries, the findings may be limited to the areas where the schools, hospital schools and PRUs were located (i.e. Central England and Kanto district in Japan).

I investigated the systems and practice from the perspectives of the participants. Therefore, the findings may not reflect other relevant systems and policies which the participants did not refer to in the interviews. For example, in order to focus my study

on school issues for the ill children, other relevant areas such as medical systems, social welfare systems, and various support services by voluntary organisations were not considered.

8.3. Further development of the research

Given the limitations mentioned above, I suggest further development of this study in the following aspects may be needed:

Teacher's perspectives

This study examines different groups of people's perspectives about teachers' attitudes in supporting ill children. Further research may be needed to investigate the teacher's perspectives about barriers. The five categories of influential factors suggested in my study may need to be verified and further developed.

Children's perspectives

This study suggests that the periods of hospitalisation may be shortened and more children may study in mainstream schools while under treatment. The perspectives of

children or young persons about their experiences, their concerns, perceptions of met and unmet needs may be areas that need to be researched further.

Regional differences

One of the suggested findings of this study was that there may be regional differences of available educational support in both England and Japan, which may be considered as obstacles to continuity of education and to the quality of education that children received. What the differences are and how it may impact on the child may need to be researched further in order to improve educational services at local level.

Quantitative study

This study was a qualitative case study of two cases of provision of education for children with medical needs. Further development may be suggested to large scale of quantitative study. For example, questionnaire survey about necessity and availability of hospital school and home teaching in different countries may provide comparative statistical data to draw a global picture about the topic.

Glossaries

Hospital school

Hospital school provides education in a unit or a classroom type setting within hospital. Teaching occurs on either one-to one basis at child bedside in the unit or in a small group at a classroom allocated within the hospital. It is established as a discrete part of a special school. The Access Guideline (DfES, 2001a) defines *Hospital school* as ‘a special school maintained by LEAs, within the premises of a hospital which has local management and delegated responsibility for their budgets. (1.8)’.

Hospital and home teaching service

Hospital and home teaching service is registered LEA as PRU which provides education for children who cannot go to mainstream school for medical related reason. Teaching occurs in hospital, at home, or at a teaching centre. The Access guideline (DfES, 2001a) defines *Hospital and home teaching service* as

- a hospital and home teaching service as one PRU where there is one head of a integrated service.
- a confederation of PRUs in their area grouped under one teacher in charge, with one management committee.

Outreach education in hospital, hospital teaching

Outreach education in hospital or *hospital teaching* is a discrete part of *hospital school* or *hospital and home teaching service*. Education is offered in the designated hospitals in case referral is made for a school aged child in admission.

A teaching centre, a tuition centre

A *teaching centre* or a *tuition centre* is a place where education in a small group is provided as discrete parts of *hospital school* or *hospital and home teaching service*. The size of the centre is varied .Some have just a few rooms and some others have school size of building with various facilities such as playgrounds.

Home school

Children and young people who are taught in the provision of *hospital school* or *Hospital and Home teaching service* for children with medical needs remain on role at their schools. Although these children are dual registered, the schools have the responsibility of education, and these children are on the count dates of the schools including their absent days for medical reasons. In this study, home school means the school which children are on role at, whatever they are mainstream or special schools.

Pupil Referral Units (PRUs)

Pupil Referral Unit are defined as educational services established by an LEA which provide education for pupils of compulsory school age who cannot receive suitable education because of an illness or exclusion from school or otherwise (DfES, 2001a).

Home teaching

Home teaching is defined by Department of Education and Skills (DfES) as ‘education on one-to-one basis in the child’s home, perhaps with occasional attendance at a teaching centre’ (DfES, 2001a). It is a part of integrated service of hospital school or hospital and home teaching service.

Home teaching is differentiated from Home education. ‘Home education’ (DfCSF, 2007) means educational arrangement in which parents educate their children at home instead of sending them to regular school education. This is also called ‘Home schooling’, ‘Education otherwise’ and ‘Home-based education’. As this study investigates the system and practice within the local governmental initiatives, it does not include Home education.

Alternative education / Alternative provision

According to DfCSF (2008a), ‘*Alternative education*’ is education outside of school which is arranged by local authorities or schools. ‘*Alternative provision*’, ‘*alternative education provision*’, is the same provision for children outside mainstream and special school. It involves PRUs, hospital schools, hospital and home teaching services, tuition centres, e-learning centres, boarding schools and others.

Reintegration, re-entry to school

While children are away from the school due to medical reason, they are still on role at the school which has responsibility to support them.. “*Reintegrate*” and “*re-entry*” mean “to return” to school after a period of absence. Children may go to difference school, college, further education or work placement depends on condition.

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Appendix 1. An example of the request letter (English)

Mrs. XX XXXX
2008

Head teacher
Y School

7th September,

Dear Mrs. XX XXXX

I am currently conducting a research project about education for children with medical needs in the UK at University of Birmingham. I am looking at how hospital schools and home teaching meet individual educational needs of children with medical needs and support children to make a smooth return to mainstream schools. The aim of the study is to contribute to long-term improvements in this area of education.

I would be most interested in carrying out a short interview with the person in charge of this area at your centre to find out (a) what the educational needs children with medical needs have are like (b) how policies are implemented in practice to meet the children's needs and (c) how teachers rate their success and what areas they consider to be improved.

Being an experienced hospital and mainstream school teacher myself in my home country, Japan, I appreciate that you may not be able to devote a lot of time to such an interview and that you may not be able to discuss sensitive cases.

However, I would be most grateful if you could consider allowing me to gain an insight into the experiences you have made in your school, as this would be a highly valued contribution to my work.

I would appreciate it very much if I could talk with some secondary / primary teachers to ask their experience and opinions about teaching and learning at the centre / home teaching / hospital school and inclusion of those children into mainstream schools.

The interview will not take any longer than 40 minutes for each person.

My research is conducted under BERA (British Educational Research Association) regulations and I guarantee strict confidentiality in the conduct of the interview and the treatment of information.

I would appreciate it very much if you could consider this request, and send me your reply by Email.

If you have any questions about this research, please contact me or my supervisor, Dr. Chris Williams (Email [REDACTED])

Thank you very much for your consideration. I look forward to your reply.

Yours truthfully,

Airi Watanabe

=====

Airi Watanabe

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Appendix 2. An example of the request letter (in Japanese)

2008 年 4 月 26 日

X 県 Y 立 Z 学校長様

研究協力へのお願い

新緑の候、貴校におかれましては、皆様ご活躍のこととお喜び申し上げます。

私は、英国の国立バーミンガム大学大学院教育学部博士課程において、病弱児教育についての研究に携わっております渡部愛理と申します。病気の子どもの入院中から退院後における教育について、特に院内学級や訪問指導学級がどのように病気の子どもの支援しているか、イギリスと日本の現状を研究しております。

近年、病弱教育の必要性はますます高まっておりますが、病弱教育にかかわる学校現場の先生方のご意見を反映した研究はイギリス、日本ともにあまりなされておられません。この研究は、現場の先生方へのインタビューを通して病弱教育に関する経験や意見を集約し、病気の子どもの教育の現状を考察するもので、病弱教育の改善にむけて長期的な視点で貢献することを目的としております。研究にあたり、イギリスと日本の比較教育を行うために、両国の病弱教育の教育機関に研究への協力をお願いしております。

つきましては、貴校の先生方にインタビューへの協力をお願い申し上げます。ご検討いただければ幸いです。インタビューの目的は、（１）病気の子どもたちはどのような教育的ニーズをもっているか、（２）院内学級・訪問指導において、どのように子どもの支援が実践されているか、（３）病弱教育に関わる教員は病気の子どものを巡る教育の現状をどのように評価し、何を問題点と感じているか、の３項目について、現場の先生方のご意見をお伺いするものです。院内学級の小学部、中学部を担当なさっている先生、訪問指導担当の先生、また復学にむけての支援を担当している先生に、日本語によるインタビューをさせていただけますと幸いです。インタビューは、一人 40 分ほどを予定しております。インタビューは夏季休業中を予定しておりますが、日程についてはご相談いたします。

私自身、渡英前は、日本の特別支援学校の教員として勤務しておりましたので、学校現場の多忙な状況や、情報管理に関わる教員の守秘義務につきまして十分に認識している所存です。インタビューにあたりましては、先生方の負担にならないよう細心の配慮をいたします。

この研究は、バーミンガム大学の研究倫理委員会の承認を得ており、英国教育学研究協会（BERA, British Educational Research Association）の倫理規定に則っておこなわれます。インタビューを通して得た情報はすべて、協力いただいた方の個人および学校を特定できない形で取り扱い、プライバシーの保

護と守秘義務を厳守いたします。また、いかなる情報も当研究以外の目的には使用いたしません。以上を踏まえ、研究へご協力いただきたく、ご検討くださいますようお願い申し上げます。

当研究につきまして、ご質問等がございましたら、以下の連絡先宛に、私もしくは、担当の指導教官であるクリス・ウィリアムまでメールにてお問い合わせください。

連絡先： 渡部愛理

Airi Watanabe
PhD candidate
School of Education
University of Birmingham
Edgbaston
Birmingham B15 2TT
United Kingdom

Dr. Chris Williams

Email:

Centre for International Education and Research
School of Education
University of Birmingham
Edgbaston
Birmingham B15 2TT
United Kingdom

研究にご協力いただける場合は、5月末日までに、メールあるいは文書にてご返信をいただけますと幸いです。どうぞよろしくお願い申し上げます。

バーミンガム大学大学院博士課程
渡部愛理

Appendix 3. Interview schedules

1) Young people who were in hospital at school age

Introduction

- Greeting / Explanation of the project
- Explanation about voluntary participation, participant's rights, confidentiality and anonymity
- Obtain ethical permission
- Obtain permission of recording

Interview

1. Personal detail about hospitalisation

- 1-1 Which year were you in when you were in hospital?
- 1-2 May I ask what the reason for your hospitalisation was?
- 1-3 How long / often did you stay in the hospital?

2. Hospitalisation period

- 2-1 Could you please tell me your experience about education when you were in hospital?
- 2-2 What was your main concern when you were in hospital?
- 2-3 What was helpful / unhelpful for you to reduce your worries?
- 2-4- What do you think the reason for that?

3. Transition period

- 3-1 Could you please tell me your experience about school when you stayed at home after your admissions?
- 3-2 What were your main concerns then?
- 3-3 What was helpful / unhelpful for you to reduce your worries?
- 3-4-What do you think the reason for it?

4. After going back to mainstream school

- 4-1 Could you please tell me your experience about school when you return to school?
- 4-2 What were your main concerns when you returned to school?
- 4-3 What was helpful / unhelpful for you to reduce your worries?
- 4-4-What do you think the reason for it?

5. Others

- Do you have any suggestions to improve education for children who have medical needs?
- Do you have any suggestions to children who are in a similar situation as to you?
- Do you have any suggestions to teachers?
- Is there anything else you would like to say about education, schools and being in hospital?

2)Parents of children with chronic illness)

Introduction

- Greeting / Explanation of the project
- Explanation about voluntary participation, participant's rights, confidentiality and anonymity
- Obtain ethical permission
- Obtain permission of recording

Interview

1. Personal detail about hospitalisation

- 1-1 Which year was your child in when he/she was in hospital?
- 1-2 May I ask what the reason for the hospitalisation was?
- 1-3 How long / often did your child stay in hospital?

2. Hospitalisation period

- 2-1 Could you please tell me your experience about your child's school / education when he./she was in hospital?
- 2-2 What do you think were your child's concerns when he/she in hospital?
- 2-3 What do you think was helpful / unhelpful for you / your child to reduce the worries?
- 2-4- What do you think the reason for it?

3. Transition period

- 3-1 Could you please tell me your experience about your child's school / education when he./she stayed at home after admissions?
- 3-2 What do you think were your child's concerns then?
- 3-3 What do you think was helpful / unhelpful for you / your child to reduce the worries?
- 3-4- What do you think the reason for it?

4. After going back to mainstream school

- 4-1 Could you please tell me your experience about your child's school / education after he./she went back to school?
- 4-2 What do you think were your child's concerns then?
- 4-3 What do you think was helpful / unhelpful for you / your child to reduce the worries?
- 4-4- What do you think the reason for it?

5. Others

- Do you have any suggestions to improve education for children who have medical needs?
- Do you have any suggestions to parents who are in a similar situation as to you (in terms of school/ social life)?
- Do you have any suggestions to teachers?
- Is there anything else you would like to say about education, schools and being in hospital?

3) Hospital school / home teaching teachers

Introduction

- Greeting / Explanation of the project
- Explanation about voluntary participation, participant's rights, confidentiality and anonymity
- Obtain ethical permission
- Obtain permission of recording

Interview

1. Personal background

- 1 What is your position in the hospital school/ the PRU?
- 2 What year range of pupils do you mainly teach?

2. Child's educational needs

- 2-1 Could you please tell me about the needs that children who you mainly teach?
- 2-2 How do you support them?
- 2-3 Could you please tell me any problems that you experienced to support the child?
- 2-4 What do you think the reason for it?

3. System and practice

- 3-1 Could you please explain the process that child access your hospital school / PRU?
- 2-5 How do you support children in your hospital school / PRU/ when the child is at home after admission / after the child goes back to school?
- 3-3-What do you think the problems in education for children with medical needs are?

4. Others

- Do you have any suggestions to teachers?
- Finally, is there anything else you would like to add?

4) Main stream school teachers

Introduction

- Greeting / Explanation of the project
- Explanation about voluntary participation, participant's rights, confidentiality and anonymity
- Obtain ethical permission
- Obtain permission of recording

Interview

1 Personal background

1-1 What is your position in the hospital school/ the PRU?

1-2 What year range of pupils do you mainly teach?

2 Child's educational needs

2-1 Could you please tell me about your experience to teach children who are absent from school for illness?

2-2 How do you support them?

2-3 Could you please tell me any problems that you experienced to support the child?

2-4 What do you think the reason for it?

3. System and practice

3-1 What do you think is the problem in education for children with medical needs?

4. Others

- Do you have any suggestions to teachers whose pupils are in a similar situation as yours?
- Do you have any suggestions to improve education for children who have medical needs?
- Finally, is there anything you wish to add?

Appendix 4

Interview check list

- Welcome
- Explain the project briefly
- Make sure they are comfortable
- Explain the voluntary participation to the project
- Make sure the participant can stop and withdraw any point in the interview
- Explain how confidentiality and anonymity of the participant's data are protected throughout the process of project and in publication of the study
- Obtain ethical permission
- Obtain permission of audio recording
- Interview
- Check any unclear points
- Ask if there is anything the interviewee wants to add
- Tell the interviewee how they can get the findings
- Thanks

Appendix 5

1) A mail to the organiser of the online community (in Japanese)

ABC コミュニティー管理責任者 A 様

はじめまして。私は渡部愛理と申します。ABC コミュニティーのメンバーです。コミュニティの管理責任者である A 様にお問い合わせしたいことがあり、メッセージを送らせて頂きます。

私は、英国のバーミンガム大学大学院で病気の子どもの教育についての研究をしています。病気の子どもの教育は日本でも英国でも課題が多いものの、経験者の意見を反映した研究は進んでいるとはいえません。私の研究では、関係者（当事者、家族、教育・医療・福祉関係者）の見解を通して、病気の子どもの教育環境、支援の現状と問題点を考察し、今後の支援の充実に役立てたいと考えています。

貴コミュニティのなかで、学校についてのトピック「XX」は、様々な方の意見から現状をとらえたものとして貴重であり、ぜひ研究のデータのひとつとして使わせていただきたいと思います。具体的には、コメントの内容をテーマ別に分類して現状、問題点をまとめる予定です。投稿者に新たなインタビューを依頼するものではありません。

このトピックへの投稿者全員に個別にメッセージを送らせて頂き、コメントを研究に使用することを承諾してくださった方のみ、研究に使わせていただきます。つきましては、そのようなかわりについて、管理責任者である A 様に承諾いただけるかどうか、ご検討いただきたいのです。

システムの運営事務局に、リサーチ目的でのコミュニティの活用について問い合わせたところ、規約や禁止事項等を考慮してユーザーの自己判断でおこなってほしい、とのことでした。規約・ポリシー・禁止事項等を熟読したところ、関連するのは、個人情報、プライバシー、著作権の保護に関することと思われます。これについては、学術研究の倫理基準に則り、以下のよう厳守いたしますので、システム事務局が提示する規約や禁止事項に触れることはないと考えています。また、以下の事項を厳守することを前提に、この研究は大学の倫理委員会からの承諾を得ております。

- ・研究への活用の承認のあった投稿者からのコメントのみ使用する。
- ・研究の過程や論文で、個人が特定できないよう、MIXI の名称、コミュニティ名、個人のハンドルネーム、具体的な病名、居住地、病院、学校の所在地、などの情報は伏せる。
- ・論文において、オンライン上のコメントは文面を直接引用することを避け、文面から個人が特定できないようにする。（検索等で特定されるのを防ぐためです）
- ・コメントは、今回の研究目的以外には使用しない。

以上のことも、研究主旨等とともにメッセージに書き添えた上で、承認していただける方には返信して下さるようお願いするつもりです。医療者に守秘義務があるように、研究者にも守秘義務と研究に関係する方の意志を尊重する義務があります。返信・承認のないかたの意見は決して使わない、ということを説明することで、承認したくない投稿者がコメントをトピックから削除すること（他の方がコメントを読めなくなることを）を防ぎたいと思います。

貴コミュニティは、システム内に公開されておりますので、投稿者もシステムに所属する不特定多数の読者を想定してはいらっしゃると思うのですが、中には、コメントを研究に使用されることを不快に思う方もあるかもしれません。病気の子どもの支援の充実に、研究にご協力いただけると幸いです。コミュニティの目的や性格を熟知しておられる責任者様のご判断で、もし、このようなメッセージを投稿者におくることがコミュニティにとって良くない、と思われるようでしたらその旨お知らせ下さい。その場合は、メッセージを送りませんし、研究にも使用いたしません。

お忙しいところ、大変申し訳ありませんが、御検討のうえ、お返事をいただけると幸いです。どうぞよろしくお願い申し上げます。

バーミンガム大学大学院教育学部 博士課程
渡部愛理

2) A mail to the participants of the online community (in Japanese)

ABC コミュニティー Z 様

はじめまして。私は渡部愛理と申します。ABC コミュニティーのメンバーです。ABC コミュニティーメンバーでトピック「GG」に投稿された方全員を対象に、研究へのご協力をお願いしたく、メッセージを送らせて頂いています。

○研究への協力をお願い

私は、イギリスのバーミンガム大学大学院で病気の子どもの教育についての研究をしています。病気の子どもの教育は課題が多いものの、経験者の意見を反映した研究は進んでいるとはいえません。私の研究では、関係者（当事者、家族、教育・医療・福祉関係者）の見解を通して、病気の子どもの教育環境、支援の現状と問題点を考察しています。研究は学位論文として大学に提出しますが、将来的には今後の支援の充実に役立てたいと考えています。

ABC コミュニティーのなかで、学校についてのトピック「XX」は、様々な方の意見から現状をとらえたものとして貴重であり、投稿されたコメントをぜひ研究のデータのひとつとして使わせていただきたいと思います。具体的には、このトピックに投稿されたコメントの内容をテーマ別に分類して、現状や問題点を考察するためのデータとして使用する予定です。

投稿したコメントを研究に使用することを承諾してくださった方のみ、コメントを研究対象として使わせていただきます。承諾の可否をご検討いただきたく、お願い申し上げます。もし、こちらから更にメールでご質問させていただくことにご協力いただけるかどうかあわせてご検討いただけますと幸いです。

○個人情報、プライバシー、著作権の保護について

システムの運営事務局に、リサーチ目的でのコミュニティの活用について問い合わせたところ、規約や禁止事項等を考慮してユーザーの自己判断でおこなってほしい、とのことでした。規約・ポリシー・禁止事項等を熟読したところ、関連するのは、個人情報、プライバシー、著作権の保護に関することと思われます。これについては、教育研究の倫理基準に則り、以下のように厳守いたしますので、システム事務局が提示する規約や禁止事項に触れることはないと考えています。また、以下の事項を厳守することを前提に、この研究は大学の倫理委員会からの承諾を得ております。

- ・研究への活用の承認のあった投稿者からのコメントのみ使用します。
- ・研究の過程や論文で、個人が特定できないよう、ソーシャルネットワークシステムの名称、コミュニティ名、個人のハンドルネーム、具体的な病名は伏せます。また居住地、病院、学校の名称・所在地などが判明する可能性のある情報は伏せます。
- ・論文において、オンライン上のコメントの文面を直接引用しません。（文面の検索などで個人が判明することを防ぐためです）
- ・承諾いただいたコメントのみ研究対象とします。他のトピックへの投稿、日記やプロフィールなどは使いません。
- ・コメントは、今回の研究目的以外には使用しません。

○承認・不承認の確認方法について

コメントを研究に使っても良いと思われる方、また、後日メールにてインタビューをさせていただくことにご協力いただける方は、お手数ですが、**私宛てに、下記の文面をメールに添付してお送り下さいますよう、お願い申し上げます。**複数のコメントを投稿された方で「○番のコメントは使わないでほしい」などの要望がありましたらお知らせ下さい。9月末までにお返事をいただけると幸いです。

研究への参加は個人の意思が尊重されますので、承諾のご返事をいただいても、いつでも参加を取りやめることができます。

医療者に守秘義務があるように、研究者にも守秘義務と研究に関係する方の**意志を尊重する義務**があります。**返信のないかたの意見は決して研究に使いません**ので、承認なさらない方も、コメントをトピックから削除なさる必要はありません。

このメッセージはコミュニティー管理責任者 A 様の承認のもとにお送りしていますが、皆様からの返信の有無については、個人情報として取り扱い、管理責任者を含め第 3 者には伝えません。研究にご協力いただいた方には、後日、研究成果の要旨をメッセージにてお送りする予定です。

以上をご理解頂き、研究にご協力いただけると幸いです。長文をお読み頂きありがとうございます。お忙しいところ、大変申し訳ありませんが、御検討下さいますよう、どうぞよろしくお願い申し上げます。ご質問がございましたら、私宛にメールにてご連絡ください。

大学大学院教育学部 博士課程
渡部愛理

3) A consent form for the participants of the online forum

病気の子供の教育に関する研究 参加承諾書

バーミンガム大学大学院教育学部
渡部愛理 宛

私は、研究への参加が自由意志であり、いつでも参加を取りやめることができること、研究において個人のプライバシー、匿名性、個人情報が守られることを理解した上で、以下の形式での参加を承諾します。

(可能な方法に○をつけてください。また、お名前はコミュニティーでのハンドルネームをご記入ください。)

1. フォーラムに投稿したコメントのうち、次の日にちのコメントのみ、研究での使用を承諾します。
()
2. フォーラムに投稿したすべてのコメントの研究での使用を承諾します。
3. 私はメールでのインタビューに応じます。

年 月 日

名前

Appendix 6. List of themes, categories and codes

Themes		Categories	Codes
Continuity of education	In hospital	Provisions that the child received	Hospital school / support from school
		Reason for receiving education in hospital school	Statutory support / Academic support / mental support / social support
		Reason for not receiving education in hospital school	No hospital school provided / health condition / to prevent separation from main school
		Facilitating factor to access hospital school	regulations / system / communication
		Obstacles to access hospital school	System / regulations / fear of separation from main school/ lack of awareness of educational right/ lack of information
	In recuperation at home	Provision that the child received	Home teaching /teaching centre/support from school / no provision
		Reason for receiving home teaching	Academic support / mental support / social support
		Reason for not receiving home teaching	No service provided / lack of information/authority boundary
		Facilitating factor to access hospital school	regulations / system / communication
		Obstacles to access home teaching	System / regulations / lack of communication/lack of information
	Return process to school	Provision of returning to school	gradual process to return to school / provision within a school/ dual registration to alternative and main school / provision within a school
		Facilitating factor in return process to	Interagency meeting / school visit by hospital

		school	staff / information to share with teachers, peers/gradual return process
		Obstacles in return process	regulations / system / perceptions of roles
Themes		Categories	Codes
Medical needs and support	In hospital	Child's needs due to health condition	Limit of physical function / limit of strength / impact of mental illness / impact of treatment / unstable conditions/change of conditions/lack of strength
		Medical care related needs	plane and time
		Facilitating factors in responding to health condition and medical care needs	Collaboration with medical staff (meeting, sharing information), education plan that corresponds with treatment provision, flexibility (timetable, lesson plan), team teaching, understanding individual condition and needs, sensitivity
		Obstacles to responding to health conditions and medical care needs	Limited staff availability, severity of child's medical condition/ facility / numbers of staff
	In convalescence at home / at school	Child's needs due to health condition	limit of physical function / limit of strength / tiredness/ impact of mental illness / unstable conditions/change of conditions/ appearance change
		Medical care related needs	Place and time for medical care / teacher's awareness of needs / protecting privacy

		Facilitating factors in responding to health condition and medical care needs	Flexibility (timetable, use of facility, rules) / understanding of needs and condition/ sensitivity / communication
		Obstacles to responding to health conditions and medical care needs	Inflexibility (timetable, use of facilities, rules) / lack of understanding of needs and condition / lack of sensitivity / lack of communication
Themes		Categories	Codes
Academic needs and support	In hospital	Academic needs	overcome delay of study / preparation for examinations / sitting examinations
		Facilitating factors in responding to academic needs	teaching style / individual support / collaboration with main school/reasonable adjustment in examination
		Obstacles to respond to academic needs	Impact of health condition / impact of admission patterns / limits of environment (time, facilities) / teachers' specialism / curriculum/lack of collaboration with school
	In convalescence at home	Academic needs	Overcome academic delay / Preparation for examinations / Sitting examinations
		Facilitating factors in responding to academic needs	learning in small groups / individual support / collaboration with school
		Obstacles to respond to academic needs	Limits of environment (time, facilities) /teacher's specialism / lack of collaboration with school
	At school	Academic needs	Overcome academic delay / preparation for examinations / Sitting examinations
		Facilitating factors in responding to academic needs	Teacher's attitudes (awareness of needs), Teacher's support (additional lessons, work sheets), pupil's initiative

		Obstacles to respond to academic needs	Teacher's attitudes (lack of awareness of needs / low expectations), rigid timetable
Themes		Categories	Codes
Social emotional needs and support	In hospital	Child's social emotional conditions	Anxiety about future, fear of death, stress, loneliness, anxiety about communication with peers/identity as a child/
		Facilitating factors in responding to child's social emotional conditions	Communication with children / staff in hospital, Understanding of individual needs / communication with peers / school teachers, counselling, distractions, supportive attitudes
		Obstacles to responding to child's social emotional conditions	Lack of communication with children with similar condition, lack of communication with peers / school teachers, inappropriate facilities in hospital / pattern of admissions/negative attitudes/lack of awareness
	In convalescence at home	Child's social emotional conditions	Anxiety about future, fear of death, stress, loneliness, low self-esteem, identity as a child
		Facilitating factors in responding to child's social emotional conditions	Communication with children / staff in hospital, communication with peers / school teachers, counselling, distractions , social skills training, progress in study
		Obstacles to responding to child's social emotional conditions	Lack of communication with peers/school teachers, lack of awareness
	At school	Child's social emotional conditions	Difficulties in peer relationship / difficulties in relationship with teachers / low self-esteem / withdrawal from school
		Facilitating factors in responding to child's social emotional conditions	Communication between the child and other pupils, teachers / teacher's awareness of the child's social emotional conditions / inclusive school ethos/ head teacher's leadership

		Obstacles to responding to child's social emotional conditions	Lack of communication between the child and other pupils, teachers / teacher's lack of awareness of the child's social emotional conditions
Themes		Categories	Codes
Interpersonal relationships	Parents and teachers (hospital school, home teaching, school)	Positive issues	Communication, understanding of role, teacher's understanding of illness and needs, teacher's supportive attitudes, parents' positive attitude, mediatory role
		Negative issues	parents' unsupportive attitude, teacher's unsupportive attitude
		Obstacles in relationship	Lack of communication
	Teachers in hospital and main schools	Positive issues	Collaboration in teaching, awareness of role, sharing information
		Negative issues	Lack of collaboration, negative impact on child (feeling of isolation)
		Obstacles in relationship	Lack of communication, lack of awareness of role, teacher's workload
	Interdisciplinary relationships	Positive issues	Communication, Collaboration in providing support, facilitating meeting
		Negative issues	Difficulty in communication
	Teachers within main school	Positive issues	Sharing information, collaboration among teachers
		Negative issues	difficulties in collaboration, lack of awareness of needs
		Obstacles in relationship	Difficulties in sharing information among teachers, lack of awareness of child's needs, lack of awareness of regulations, workload, unsupportive system within school
Themes		Categories	Codes
Policy and practice	hospital school and home teaching	Regulations of receiving alternative education	school policy, entry process, access information, durations of providing support

		Issues in support provided	Differences in different councils (system, facility, size)
		Issues in teachers' expertise	Teacher training, placement of teachers
	Return process to school	Issues in support provided	Different system in different councils
	School	Issues in collaboration with alternative education	Role of people involved, Information sharing
		Issues in collaboration within school	Different system in different schools