BACKGROUND

Multiple sclerosis (MS) is a neurological condition that can affect children and adults. Due to advances in magnetic resonance imaging (MRI) scans, it is now recognised that the onset of MS can occur in childhood. Most research about childhood MS has looked at diagnosis, the disease course, and treatment options. There has been very little research about families experiences of childhood MS or about the appropriateness of current services.

The study aimed to find out:
• what life is like for families when a child has MS,
• what help and support children, teenagers and parents need,
• what families and professionals views are about the current organisation and delivery of services,
• how current services could be improved to better meet families’ support needs.

KEY FINDINGS

Family life with MS
• Obtaining a diagnosis of childhood MS could be a difficult and lengthy process for families
• Life with paediatric MS can be a challenging and distressing experience for families because of the uncertain and variable nature of the condition.
• Children/teenagers can look well but still experience ongoing symptoms that affect their daily lives.
• Children/teenagers and parents might experience feelings of anxiety and depression.
• Families are at risk of isolation because few have contact with other families experiencing childhood MS.

Families’ support needs
• Access to clear and accurate information about paediatric MS in age appropriate formats.
• Early access to disease modifying therapies (DMTs).
• Appropriate support to cope with the administration and side-effects of treatments.
• Prompt access to counselling services during and post-diagnosis.
• Prompt access to therapy to manage symptoms.
• Access to specialist educational support and career guidance.

Families’ and professionals’ perceptions of current services
• There are few specialists in paediatric MS and it can be difficult to access this expertise.
• There is a lack of suitable information resources for families.
• Access to DMTs can be delayed due to local policy and professionals’ limited experience of prescribing for this age group.
• The availability of therapy (including physiotherapy, psychology and occupational therapy) can depend on the organisation and provision of local services.
• It can be challenging for services to respond to the variable and unpredictable needs of children/teenagers with MS.
• Specialist nurses can play an important role in providing information and emotional support and being a key point of contact but not all families are able to access this support.

Recommendations for improving services
• Prompt access to centres with expertise in paediatric MS for diagnosis, treatment and support is valued by children/teenagers and parents, and seen as important by professionals.
• Professionals recommend an integrated approach to delivering services that incorporates psychology, physiotherapy, occupational therapy, social care services and specialist nursing support.
FINDINGS

Diagnosis
Diagnosis can be a challenging, lengthy and frustrating process for families and clinicians. Children/teenagers and parents can find it difficult to communicate with some doctors and can feel that their concerns about their child’s health are dismissed without appropriate investigation. Some children/teenagers are diagnosed with other conditions before being diagnosed with MS and neurologists can use different labels to describe the child’s illness. This can be confusing for families, making them question the accuracy of the diagnosis and the neurologists’ expertise. General paediatricians and some paediatric neurologists can find it difficult to make this diagnosis because they have limited experience of paediatric MS.

Variability of MS
MS affects children/adolescent in variable and unpredictable ways when the condition flares up: some experience difficulty with everyday activities such as getting dressed while others have more severe physical and cognitive impairments. Some children/teenagers experience ongoing issues such as chronic fatigue and depression that affect their daily lives. The variability of MS means it is difficult for families to predict what help children need and for professionals to plan appropriate services and support.

Information
Families need more information about childhood MS. Children/teenagers and parents can be uncertain what symptoms/signs indicate a relapse, when/who to contact about a suspected relapse, and how to manage ongoing symptoms. Some parents find voluntary organisations and/or internet discussion forums useful sources of information. Children/teenagers can express concerns about searching for information because they fear encountering negative descriptions of MS. They are reluctant to contact voluntary organisations as they feel these are for adults. Professionals only have information resources for adults with MS and are not aware of any resources specifically for children/teenagers about MS.

Managing Medications
Children/teenagers take different medications to manage their condition. Professionals report that access to disease modifying therapies (DMTs) varies depending on local guidelines and neurologists’ experience of prescribing DMTs for children/teenagers under 18 years old. Families can wait several months for DMTs to be organised. Children/teenagers sometimes find DMT injections painful and are helped by parents providing emotional/practical support. Most children/teenagers tolerate DMTs well but some stop treatment due to side-effects/disease breakthrough. Corticosteroids can lead to side-effects such as mood swings, weight gain and excess hair growth which children/teenagers find difficult to cope with.

Emotional well-being
At times children/teenagers can feel very worried and distressed about having MS and some report feelings of depression. They can worry about what will happen to them in the future and the impact MS will have on their family. Some children/teenagers say that speaking to a counsellor/psychologist helps them to manage their feelings. Parents can also experience considerable distress and fear for their child’s long term health and wellbeing. Some parents feel depressed and/or access counselling services. Professionals feel that psychological support should be available for families but they can find it difficult to organise this support.
Support networks
Peer support and acceptance is very important to children/teenagers. They can be reluctant to tell others about their condition because they do not want to be labelled as ‘different’ although friends and family can be good sources of support. However, some children/teenagers do experience bullying by their peer group and need support to manage this. Parents value the support of family and friends although some parents may have a limited social network. Families are at risk of isolation because many do not know another family experiencing paediatric MS.

School
Families can be concerned about how MS will affect their child’s academic progress especially during key examinations (e.g. GCSEs). Some children/teenagers can require extra help to complete their school work due to absence, fatigue, problems with memory and concentration and/or learning difficulties. Schools may provide additional support but parents can be uncertain what help is available or how to access it. Families can feel that teachers lack understanding about their child’s ongoing support needs. Some specialist nurses liaise with schools to help teachers support children/teenagers. Professionals also feel that an educational psychologist should assess children/teenagers to identify their specific learning needs and facilitate access to appropriate educational support.

Variability of Service Provision
The availability of support services can vary. Children/teenagers can receive support from continence services, counselling/psychological therapy, dietetics, educational psychology, mobility services, occupational therapy, physiotherapy, psychiatry, and speech and language therapy. Access depends on if these services are provided through a neurology department or available in the families’ area of residence.

Transition to adult MS services
Some families are already connected to adult MS services via adult MS nurse specialists or neurologists. However, if this is not the case transition to adult services can be problematic. Some paediatric neurologists report difficulties liaising with adult neurology services about transition. Teenagers aged 16-17 years old at diagnosis can be ‘in limbo’ between children’s and adult health services; too old for children’s services and too young for adult services.

Specialist Nursing Support
Families value specialist nursing support. Specialist nurses play an important role in providing information and support to the whole family; particularly in relation to emotional support, managing MS, accessing treatment/services, school liaison and being a key point of contact. However, access to specialist nursing support varies. Some families are supported by paediatric neurology nurse specialists who have expertise in working with families but can lack MS specialist knowledge. Some families are supported by MS specialist nurses who have expertise in MS but can lack confidence in working with children/teenagers. In some areas MS specialist nurses are unable to support children/teenagers under 16 years because of local policy and families may have no specialist nursing support.

Lack of Specialist Expertise
A range of different service models are evident. Some families have access to paediatric centres with expertise in MS for diagnosis, treatment and support. However, others receive care from generalist paediatricians and/or adult MS specialists who can lack knowledge of appropriate services or families’ support needs. Professionals feel families require access to specialist knowledge and support both before and after diagnosis.
IMPLICATIONS

• Organising health and social care support for children/teenagers with a rare and unpredictable health condition can be challenging. The absence of a nationally coordinated service for paediatric MS means service provision can be variable and uncoordinated. Currently NICE guidelines exclude paediatric MS.

• There are examples of multi-disciplinary service models that integrate treatment, therapy and support for families and facilitate joint working by specialists from child and adult services, although not all families receive this model of support.

• Information needs to be developed for families that describes the support available and how to manage the condition and its psycho-social consequences.

• Families require prompt access to specialist support in relation to the diagnosis, treatment and management of the condition. This should include prompt access to DMTs and therapy including counselling and/or psychological services to promote children’s/teenagers’ and parents emotional well-being.

• Children/teenagers need access to specialist educational support and career guidance to achieve their academic and social potential.

• Specialist nurses could play an important role in the provision of information and emotional support and in the coordination of services.

ABOUT THE STUDY

This study was conducted between October 2012 and September 2014. Families were recruited across the UK through the NHS, voluntary organisations and social media. In total 21 children/teenagers with MS, 31 parents and 20 healthcare professionals from a range of specialities were interviewed for the study. This work was supported by the Multiple Sclerosis Society in the UK, grant reference 958/11.

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