doi: 10.1111/j.1369-7625.2011.00663.x

The role of support groups in facilitating families in coping with a genetic condition and in discussion of genetic risk information

Gillian Plumridge MA BA CQSW,* Alison Metcalfe PhD BSc RN,† Jane Coad PhD MSc BSc BA RN/RSCN‡ and Paramjit Gill DM FRCGP§

*Research Fellow, School of Health and Population Science, University of Birmingham, Edgbaston, Birmingham, †Senior Research Fellow, School of Health & Population Science, Primary Clinical Sciences, University of Birmingham, Edgbaston, Birmingham, ‡ Senior Research Fellow, The Centre for Child and Adolescent Health, University of West of England, Bristol and §Reader in Primary Care Research, School of Health and Population Science, University of Birmingham, Edgbaston, Birmingham, UK

Correspondence
Dr Alison Metcalfe PhD BSc RN
Senior Research Fellow
School of Health & Population Science
Primary Clinical Sciences
University of Birmingham
Edgbaston
Birmingham B15 2TT
UK
E-mail: a.m.metcalfe@bham.ac.uk

Accepted for publication
30 December 2010

Keywords: family communication, genetic risk, inherited condition, support group

Abstract

Background Giving children and young people information about genetic conditions and associated risk has been shown to be important to their identity, coping and decision making. Parents, however, find talking to their children difficult, and support from health professionals is often not available to them.

Objective To explore the role of support groups in family coping, and in assisting parents' communication about risk with children in families affected by an inherited genetic condition.

Methods Semi-structured interviews analysed using grounded theory and informed by models focusing on aspects of family communication.

Participants Affected and unaffected children and their parents, from families affected by one of six genetic conditions, that represent different patterns of inheritance, and variations in age of onset, life expectancy and impact on families.

Results Parents often sought support they did not receive elsewhere from support groups. They identified benefits, but also potential disadvantages to this involvement. These related to the specific condition and also whether groups were run solely by parents or had professional input. Support groups rarely helped directly with family communication, but attendance often stimulated family discussion, and they provided information that improved parents' confidence in discussing the condition.

Conclusions Support groups should be seen only as additional to the support offered by health and social care professionals. An increased understanding of the role of support groups in assisting families with genetic conditions has been highlighted, but further work is needed to explore more fully how this may be made more sustainable and far-reaching.

Introduction

When a member of a family is affected by chronic illness, there are many practical and emotional difficulties that all family members may have to cope with. Giving children and young people information is very important to their well-being, allowing them to express their feelings and discuss and correct distorted notions about the illness in their family.[1] In families affected by inherited genetic conditions, parents also need to be able to explain genetic risk information and its implications for children.[2] Giving children information about a genetic condition and associated risk, at a level appropriate to their developmental maturity, is likely to be more beneficial to them than trying to protect them, by keeping information from them.[3–5] This has been shown to lead to young people making better informed decisions about genetic counselling and testing[6,7] and subsequent health behaviour.[8] Talking to children, whilst minors, about a genetic condition is, however, something parents find difficult, their first instinct being to protect their children from difficult information.[6,9–12] Parents report that they are often advised by health-care professionals to talk to children, but they receive minimal advice from them, or from extended family, in how to do this.[3] A possible alternative source of advice is the 'support group', which parents might join or contact shortly after diagnosis.

A support group is usually defined as a group of people, sometimes led by a professional, who provide each other with moral support, information and advice relating to a shared characteristic or experience. Family members are able to meet others who share a similar situation to themselves and who can provide empathy, emotional support and first-hand experience.[13] They can share information[14] and friendships develop, reducing the isolation some individuals feel.[15] Studies have generally been positive about the role of support groups in mitigating the effects of living with a genetic condition[16,17] and have found that membership improved knowledge of the condition.[18,19]

Attending a support group, however, can also present specific problems for those affected by a genetic condition, as being confronted with a potential vision of their own future can be more distressing than helpful.[20] Additionally, support groups do not necessarily cater for everybody's needs and interests[21] and individuals' personalities may impact on how much benefit they are able to gain.

There have been many accounts and evaluations of support groups for specific health conditions, but few have assessed groups specifically for genetic conditions, or for the support they provide on particular aspects of care. We recently undertook a study to explore communication processes between parents and their children about genetic risk information. Part of the objective was to ascertain what support was available to families. This article explores the role of support groups, as defined by participants, in helping parents and children cope with a genetic condition, and particularly in facilitating discussion of genetic risk information.

Methods

Theoretical framework

Models of family communication were considered throughout the study. These focused attention on family members' roles and interactions, within and outside of the family (family systems theory[22]), the process of communication and language used (drawing on symbolic interaction theory[23]), and behavioural outcomes for children and parents' coping and adaptation.[24] These models informed the interview schedule design and were used in the analysis as part of the grounded theory development. Family systems theory is particularly relevant to considering the role of support groups; it views the family as a mini eco-system in which the interactions of individual family members with their external environment (support group peers in this instance) influence their functioning within their family system.[22]

Recruitment

Potential participant families were identified via voluntary and National Health Service support groups in England and Wales. Families with one of six genetic conditions were included: cystic fibrosis (CF), familial adenomatous polyposis (FAP), Duchenne muscular dystrophy (DMD), haemoglobinopathies (HbO), Huntington's disease (HD) and neurofibromatosis (NF). These genetic conditions represent different inheritance patterns, variations in age of onset and impact on families and include some with limited life expectancy. Families were given written information about the study, or witnessed presentations at conferences or support group meetings. They were asked to contact the research team if they wished to take part. Parents and all children within these families, whether affected, at risk, or unaffected, were invited to take part. The study was approved by the Liverpool Children's Research Ethics Committee (REC No:07/Q1502/16). In accordance with their stipulation, we only interviewed children aged 8 years or above, and for Huntington's disease 16 years and above.

Data collection

Semi-structured interviews were conducted with family members who elected to take part. Parents and children were interviewed separately, except when a child wanted a parent present. This was rare, and never required throughout a whole interview. Interviews took place between 2007 and 2009. Most took place within family homes, but a minority of families elected to come to the university or another location such as a community centre. Interviews with adults lasted up to 90 min and with children up to 45 min. Consent was obtained to audio-record interviews in all cases except one, and interviews were transcribed verbatim.

Table 1 Interview topics

Main topics discussed with parents
Parents' understanding of the causes of condition
How they found out about and responded emotionally to the existence of the condition in the family
Coping with the condition, practically and emotionally
Impact on and management of family life
How the genetic condition is discussed within the family generally
How, what, when they explained genetic risk to children and decisions relating to this
Children's responses, questions and level of interest
Impact of knowledge on each family member's behaviours and decisions
Available support and information – including from health-care professionals, support groups and wider family
Family history and parents' own experiences in relation to the condition
Preparing for the future
Main topics discussed with children and young people
Knowledge about condition
How, what and when they found out and associated emotions
How genetic condition is discussed within the family generally
Knowledge and use of relevant resources
Impact of condition on their life and other family member's lives
Understanding of heredity and genetics generally and in relation to risk information about the genetic condition
Who children talk to about the condition (wider family, friends, school etc.)
Support mechanisms internal and external to the family
Understanding of and expectations for the future
Decision making and communication in the family generally and in relation to the condition
Views about what, when and by whom children should be told about a genetic health condition in the family
Effect on choices and decisions about the future (if appropriate)

Interview schedules were developed from the literature review and discussion with the advisory and steering groups, and informed by the family communication models. Table 1 illustrates the main topics discussed with parents and with children. Participants were specifically asked about all forms of support they accessed or had accessed. Art materials were offered to all young people up to 16 years of age, to help to create a more comfortable environment for discussing personal and sensitive information.[25–27] They were asked to create an image of their family if they wished. Some did this and it aided discussion. Others declined, but used the materials to occupy them whilst talking, giving them, for example, the choice of when they wished to make eye contact. Others preferred to just sit and talk.

Analysis

Transcripts were analysed using social constructivist grounded theory.[28] Through an iterative process involving three researchers, separate frameworks for the analysis of parents and children's interviews were developed. Identified concepts were used to establish categories with clearly defined properties and dimensions. Data were then coded using the software package NVIVO 7, and investigated using a series of grounded theory questions, which had been developed through all stages of analysis from fieldwork to coding. These related to research questions and inductive ideas, and were informed by family communication models. Each researcher examined data specific to two genetic conditions using the agreed grounded theory questions. This was randomly checked for consistency by a second researcher, and any disputes discussed by all three researchers until consensus was reached. Consensus amongst family members, in terms of when and how the condition and associated risk was discussed, was established by examining the transcripts for all members of each family as a group. Finally, the differences and similarities in the findings for each of the conditions were explored using a constant comparative analysis.

Findings

We interviewed a total of 52 parents (including birth parents, step parents and guardians) and 44 children and young people from 33 families. Key aspects of the demographic profile of participants are provided in Table 2.

Focus and structure of support groups

Most of the support groups families accessed were provided by national charities or voluntary organizations, sometimes in partnership with statutory organizations. They operated at national or local level, or sometimes both. A small number were set up on an ad hoc basis by a group of like-minded individuals who had time, motivation and shared goals. Groups had a range of different foci and the main aims could be one or a combination of the following:

1. Psychosocial support network
2. Social gathering
3. Education and awareness raising for members
4. Raising public awareness and funds for research or support

Support groups offered support in different ways. Some provided opportunity for families affected by a specific genetic condition to meet each other face-to-face at regular intervals; others offered Internet or telephone support, or a worker to visit a family on an individual basis. Where groups met face to face, some were organized by a paid health or social-care professional, whilst others were run entirely by individuals from families affected by genetic conditions. Sometimes support was available to any family member, sometimes only to adults. Groups varied in size, organization, and in terms of the resources available to them. Some of the larger organizations offered all of the above and additionally offered annual conferences, newsletters, equipment or grants.

For some conditions, there were several support groups potentially available to families, whilst for others there was very little. Availability could also depend on where families lived, with national organizations sometimes

Table 2 Key aspects of demographic profile of participants

Individuals interviewed (*n*)	Age range of children Years (*n* and gender)	Ethnicity of families (*n*)	Genetic condition affecting families (*n* families, adults, children)	Status of children in relation to genetic condition (*n*)
Parents (52) [34 women & 18 men]	8–11 (5♀;4♂)	African-Caribbean or Black	Cystic fibrosis (4, 7, 5)	Affected or positively tested for genetic condition (20)
	12–14 (3♀;7♂)	British (5)	Duchenne muscular dystrophy (6, 10, 8)	
Children (33) [aged < 18 years]	15–17 (7♀;7♂)	Asian or British Asian or Middle East origins (3)	Familial adenomatous polyposis (6, 10, 11)	At risk of being affected or carriers (11)
	18+ (9♀;2♂)			
Adult children (11) [aged 18+ years]		White and from the UK (25)	Haemoglobinopathies (sickle cell or thalassaemia) (6, 7, 5)	Known carrier (1)
			Huntington's disease (7, 10, 8)	Unaffected siblings (12)
			Neurofibromatosis (4, 8, 7)	

The families represented a wide spectrum of religious beliefs and included: Atheism, Christianity, Church of England, Hindu, Humanist, Methodist, Muslim, None, Pentecostal, Roman Catholic and Sikh. There was also widespread variation of parents in terms of age and educational background.

offering different types and levels of support in different geographical locations. To state how many support groups were available according to condition would therefore be misleading in terms of what was available to individual families.

Involvement of children and young people

Some children and young people across all conditions had had the opportunity to attend support groups, and others knew their parents went, but said they had not been involved themselves. For some conditions, children and young people had been actively encouraged by the organizations running support groups to participate. Local meetings were open for children in families affected by HD or HbO to attend with parent(s), either regularly or on some occasions, and some young people had attended conferences. In some families with NF and FAP, children had occasional opportunities to attend support group events with parents. Some of these events were not specifically meant for children, whilst others were organized as family social events.

Some groups provided separate activities or support specifically for children and young people. Those with HbO, along with their siblings and friends, had attended their own workshops. Children learnt about sickle cell and thalassaemia, and how to care for and protect themselves. They were also offered trips and activities that allowed them to spend relaxed time with others affected by HbO, but were not directly related to the conditions. Young people in families with HD had the opportunity to attend a summer camp, which they saw as mainly offering respite, and a chance to meet others from families affected by HD in an informal setting. There was no formal discussion or education related to HD, but a chance to discuss with others informally if they wished.

Some children and young people in families with CF received a newsletter, written especially for them from a national charity, which also provided trained counsellors, who affected children and their siblings could talk to on the

telephone. Where support groups provided a link worker (NF), they usually met with affected children and supported them directly. For some conditions, especially DMD, parents and children thought that there was little support for siblings, despite the effect of the genetic condition on family life. There were no support groups or mechanisms specifically available to children and young people in families affected by FAP or DMD.

> I think they should do a kids' one [support group meeting] cause in our one… I thought to myself well I can hardly understand all the words they come out with so I don't think it would benefit (child)… they should do like a kids group where they can actually go and talk about it and not intimidated by other adults sitting there with them…if they were all just kids in the room I think they'd speak a lot better
>
> Parent FAP

Attitudes towards attending support groups

Whilst families were recruited via support groups, and all parents had experience of some involvement, this was at different levels. Based on the experiences of parents and the children and young people who were able to comment, there was a general consensus that support groups, particularly meetings, were not for everybody. Some said they joined support groups because they thought it was the only opportunity they had of finding out information, whilst for others there was a need for peer support. Parents were sometimes reluctant to join support groups because they did not want the genetic condition to become a focal point of their lives. A few parents and young people, particularly unaffected siblings, said they did not like to discuss the condition with strangers. On the other hand, many families received little emotional support from wider family or friends, and several said they sought and received what they felt was lacking by attending support groups.

> I think sometimes you get more support from outsiders than you do from your own family. Because your own family truly don't understand what's going on. So erm generally its people, the support will probably come from people that have got children with the same condition or similar conditions
>
> Parent DMD

Parents and children in some families affected by FAP, DMD and CF wanted opportunities for children and young people to meet others affected by the condition, and young people across conditions wanted Internet forums specifically for young people.

> Somewhere on the Internet like to chat more to people, like there's a message board on the website [of support group] but it's not really that good, there's nowhere for like children like my age to like talk about it with each other
>
> Young person at 50% risk for HD

Several parents and young people suggested that younger children were more interested and involved in family support groups. By teenage years, young people were less likely to continue their involvement. Some unaffected siblings were offered access to support groups as teenagers and this was seen as too late.

Support needs were reported to change over time. Parents of children with CF or DMD generally felt they did not want to face support groups immediately after diagnosis, but needed some time (usually 6–12 months) to begin to come to terms with the condition. Those running the HbO support group also discussed changes throughout the lifespan and were planning to target groups at parents with children in different age groups. Some families felt the benefits of attending groups focusing on psychosocial support or education could be exhausted once they felt they knew all there was to know. They then moved their focus to fund raising or raising public awareness, which they felt was more proactive. Others felt they benefited by making friends within the group, and then got support from them in a more informal way and no longer needed the group.

The role of support groups in supporting family coping and communication about genetic risk was examined. Responses highlighted the considerable benefits but also potential disadvantages that membership of support groups

gave to families, which had repercussions for family communication about genetic risk.

Benefits

For many families, the empathy and understanding of others who were in a similar position to themselves provided comfort, and parents and young people drew on others' experiences and advice to help them cope and reduce feelings of isolation. Many parents sought support groups to try to obtain more information as they struggled to come to terms with a diagnosis or test result.

> thinking about it I think probably the time when I came to terms with it, you never fully come to terms with it, but to come to terms with it as best you can, was probably after talking to other people that had the same condition, you know that had a child with the same condition … because you tend to think that there's no one else there

Parent DMD

Some parents felt they were doing something positive when they got involved in fund raising for research into cures and treatment. Support groups also provided advice about health and social care, including financial support via the state benefits system and sometimes charity donations. They could help parents find a way through the labyrinthine health and social care, social security and education systems they described.

When children attended support group meetings, there were mixed views amongst parents about the value of this. Some felt children learned useful information and benefitted from meeting other families affected by the condition. Others worried that children would learn information about the future development and outcomes of the condition, which they did not feel they were ready for. Children and young people who had attended the HbO workshops felt they received education about sickle cell or thalassaemia, including written information, and benefited from the shared experience. They felt that staff understood them as individuals and could be more supportive than health professionals. Parents appreciated that their children were given information about genetics and heredity and the more technical aspects of HbO.

Similarly, young people who had attended HD conferences said this had helped their understanding of the condition and how it affected people. When young people attended summer camps, the opportunity of getting together for a few days with others in a similar situation, allowed young people to get to know each other well enough to engage in some informal discussion about the condition. Being able to talk with people of their own age was particularly valued by children and young people.

> When we went on the weekend it was like, more like because we were there for like two nights, so on the second and third day you like knew each other really so you can ask it [about HD]

Young person at 50% risk for HD

> There's like girls at (support group) that I talk to that have it as well, so we just talk and we confer things and whatever…someone that knows what you're going through, someone that's the same age as you so it's better

Affected young person HbO

Potential disadvantages

For some participants, regular attendance at a support group, and seeing others deteriorate mentally or physically or both, provided too much of a reminder of the effect of the genetic condition.

Where parents ran the support groups as volunteers, they described the increasing difficulty they experienced in giving support and advice to new families joining the group, whilst their own family member's condition was deteriorating. Distressed and often distraught newly diagnosed families wanting to talk about their emotions and grief often caused the volunteer parent to relive their own grief and pain at diagnosis. This could happen many times over, and it is unclear whether the volunteer parents had received any training in coping with this emotionally taxing situation. Reliving the diag-

nosis and pain eventually left the volunteer parents feeling too emotionally burdened to be able to offer constructive help.

Comments from families at different ends of the disease trajectory triangulate the evidence about the experiences of parents. Several families described trying to find support groups to help them come to terms with the diagnosis when they were first given it, only to find groups of parents they described as negative and pessimistic about the condition.

> I found it really hard to be there because you're just meeting new people and you know, it is difficult because they ask you questions and you know, the woman was asking me a question and I said ''well do you want me to be nice or do you want me to be honest?'' you know… but that's the way I have to deal with it, you know, it's no good not letting people know.

Parent NF

> Parent A: and then [straight after diagnosis] we got in touch with the support group and we went to a meeting, didn't we. That didn't go particularly well
>
> Parent B: …I 'm not saying everybody, but there are people there with too much negativity, and the first person we came across was full of negativity of the condition. We came back feeling worse, didn't we from that particular…

Parents DMD

Another major issue for support groups was their own vulnerability; changes to funding could see services and supporting professionals removed, leaving families to struggle with coping with the outcomes. Groups could also fragment if alternative and diverging agendas arose.

The role of support groups in family communication about genetic risk

There was little suggestion from parents that support groups directly offered them advice in talking to their children about the condition. Where it was available, it often relied on support groups members' own experiences and views, which could vary widely.

In groups where parents had access to a support worker, they could offer them guidance, based on their observed experience. However, some young people complained that they did not have access to support workers directly, or they were not able to develop a rapport with care workers. In larger groups, where more individuals in the community were affected or at risk, *e.g.* haemoglobinopathies, a professional health or social care worker, supported by volunteers, worked with parents and children to develop their knowledge and understanding of genetic risk. Where a professional was supporting the volunteers in teaching and explaining genetic risk, with children learning over time and through play, many children and young people said they understood about the genetic condition and thought they learnt more.

> I used to come here and there was always leaflets and always stuff that you can read about it and everything, and people used to come in and tell us about it and everything… I knew but I didn't really understand it. I knew it was something like sickle cell but I didn't understand it and that's when I came here… and then when I was eight or ten I was gradually knowing about it and more thinking about it.

Affected young person HbO

Children and young people who had been given just one or two sessions with a care worker were less confident of their knowledge about the condition and associated heredity, particularly if parents had not followed up with further discussion.

When parents attended support groups, and openly discussed this with their children, this provided an opportunity to 'normalize' family discussions of the genetic condition and its risks, and made it less taboo. Family members, however, suggested that children's attendance at support group meetings or other activities was most likely to help with family communication. When children and young people attended with parents, this was seen to initiate discussion, including in families who did not talk about the condition much at other times. Similarly, when parents were involved in, or informed about children's activities, this allowed them to follow up learning at home. The idea that children were

imminently going to attend could also stimulate discussion.

> …and talking to people at (support group) and just hearing people talk, you know not just generally them talking to you, but hearing people talk in conversations and just sort of gradual accumulation of knowledge

Young person at 50% risk for HD

> (support group) did a workshop for children during the summer and one of the things they did was like a play and their slogan was 'I have sickle cell, sickle cell doesn't have me' and now I just try and give that to (daughter) really

Parent HbO

> (Support group) runs a summer camp and I thought well if I could get them on the summer camp that would be really good for them cause then they could talk to other children but I couldn't send them to the summer camp until they knew what the disease was, so that was another impetus for doing it (explaining HD)

Parent HD

Children said they learnt best about the condition when they received small bits of information over time. Attendance at support groups could contribute to this gradual learning, but not all parents saw or took the potential opportunities for family discussion that support groups offered. Whilst some actively discussed what had happened in the group with their children, others felt that simply taking them was enough, or that children would ask questions if they wanted to. Overall findings, however, suggested that children were often reluctant to ask questions for fear of upsetting parents.[3] In this case, merely attending support groups with no follow-up discussion may not be helpful to children's understanding. They could indeed be left with unanswered questions they do not feel comfortable to raise.

Parents also identified that support groups helped with family communication indirectly, by providing information about the condition so that they felt more confident in talking to their children. Some also suggested that the issue had simply not arisen and thought that help and support would be forthcoming if they requested it.

Who should run support groups?

Parents were often divided in who they thought should run the groups, some wanting the families only and others valuing professional support. However, almost all of the groups valued visits by 'specialists' in the care, treatment or research of the genetic condition their group was centred upon.

Discussion

In terms of general support offered by support groups, our findings broadly agree with those of the limited amount of previous work looking at support groups for genetic conditions. Whilst support groups offered emotional benefits and particularly the support of others facing similar experiences,[13] they were also seen to have emotional drawbacks such as the distress of being confronted with a potential vision of the future.[20] Lowit and Van Teijlingen[20] suggest that this does not fit with a 'taking one day at a time philosophy', a philosophy we also saw frequently, and a view our findings concur with. Participants agreed with the findings of McCabe *et al.*[21] that support groups do not necessarily cater for all. It has been suggested that for young people, online support can alleviate isolation[15] and offer anonymity, allowing individuals to discuss issues they may find difficult to raise in face-to-face situations.[29] However, young people in our study reported that appropriate online support was not available to them.

In terms of communicating genetic risk information, parents were often disappointed with the level of support and advice they received. The need for, and benefits of, communicating information to children and young people in families affected by genetic conditions are not always well understood by parents or by health-care professionals, and appropriate resources are not always available to support this.[3] It is therefore unreasonable to expect those running support groups to have any greater awareness of the need for this support, or the ability to offer it. Additionally needs, and thus the type and level of support required, evolve

along the disease trajectory and family life course. This suggests that parents and children need to be offered a range of services, from one to one with support group workers, through to larger community-based networks.

Consistent with family systems theory,[22] findings did suggest that although support groups offered little direct advice about talking to children, the interactions of various family members with them did sometimes impact on the nuclear family system. This was seen for example in the way that children's attendance at support groups could initiate discussion about the genetic condition and its risk, both so that children were prepared for what they might learn, and in response to what they learned.

Support from support groups should be additional and supplementary to that offered by health and social care professionals. However, many of these potentially vulnerable families appeared not to have access to more formal support via the NHS and social care system or sustained charity networks, when they or their family member was diagnosed, or found to be at risk of developing an inherited genetic condition. Families said they accessed support groups because of these deficits. They also provided an important source of social network, and some parents felt they replaced the networks they felt their families and friends were not providing. Many parents placed great value on support groups that depended on charitable funding. However, the limited formal structures that exist mean that these charities, and the support they provide, are very sensitive to financial pressures and often can provide only a limited and tenuous resource. This can result in care and support being removed from families that appear to rely on them quite heavily, particularly for psychological support, but also general advice on managing the genetic condition.

Deficits in statutory service provision are unlikely to relate to social class or education as findings were similar across the broad spectrum of participants' backgrounds. However, there were some variations depending on the genetic condition, with families affected by CF receiving more dedicated support from specifically assigned health and social care professionals.

The protocol required recruitment via support groups to ensure participants had support mechanisms should the research raise any difficult or personal issues for them. The group of participants may therefore be biased towards those who require higher levels of support, which may be for any number of reasons. However, little is known about families who have not accessed support groups. They may have been more successful in accessing health and social care services, or managed to find other sources of information, advice and support about living with the genetic condition, or simply have chosen not to seek help of this nature.

It is surprising how little work has previously been carried out examining the effectiveness of support groups based on the model, aims and funding mechanisms involved. This is particularly salient given the emphasis many families placed on their reliance on such groups and the deficits experienced in health and social care. Few studies have explored: the nature of support groups and how they dovetail or not with health and social care service provision; the characteristics of individuals who elect to use them, and how they compare to those who do not; or the models of support they prefer. It is also important to ascertain whether support group attendance confers more benefits or drawbacks than non-attendance, and how changes in use and preference might evolve over the disease trajectory or family life course. This might determine whether particular models of support group are more beneficial than others, and whether greater financial support to enable stability would improve long-term outcomes for families' coping and adaption to living with a genetic condition and its associated risks.

Findings suggest that families have preferences for different types of management approach for the support group they join, including family-led as well as professional-led. To help families positively assist each other, without psychological detriment to volunteers

who are observing changes in their own family members' illness, providing parent-led groups with more training and support also needs to be considered.

There are limitations to our work. It was conducted with a relatively small number of families and the role of support groups in assisting families was not the main focus. However, the findings have raised an important issue on the nature of support groups and the role they have in health and social care provision for families affected by inherited genetic conditions, that appears to have gone largely unrecognized by the health and social care systems. Therefore, further work is required to try to find ways of helping these charitable organizations provide sustainable long-term support and care to families, and to ensure the volunteers have appropriate training for the benefit of their own psychological health, and that of people accessing their organization.

Conclusion

Support groups should not be expected to fill gaps in statutory services, but can play a useful and important role in supporting families to share information with children about a genetic condition and associated risk. It is important that support from support groups is only seen as additional to that offered by health and social care professionals; there are differences in structure in groups, not all families have access to them or wish to attend, and the nature of funding is tenuous. However, an increased awareness and understanding of the role support groups do play and could play in assisting families affected by genetic conditions has been highlighted. Further work is required to explore their role more fully, and how it might be made more sustainable and far-reaching.

Acknowledgements

We would like to thank the parents, children and young people for participating in this study. We also wish to acknowledge the invaluable contribution of the advisory and steering groups.

Source of funding

The Study was funded by the Department of Health, UK, who had no role in it, and findings do not necessarily reflect their views.

Conflict of interest

All authors have declared that they have no conflict of interests in relation to carrying out or reporting this study.

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