SOCIOLOGY OF HEALTH & ILLNESS

Sociology of Health & Illness Vol. 33 No. 1 2011 ISSN 0141–9889, pp. 81–95
doi: 10.1111/j.1467-9566.2010.01277.x

'One wants to know what a chromosome is': the internet as a coping resource when adjusting to life parenting a child with a rare genetic disorder

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Abstract The internet has democratised access to health and diagnostic information, enabling patients to mobilise social support from peers and advocate their interests in encounters with medical personnel. Research has shown that these possibilities are particularly important for patients and caregivers confronting a rare medical condition. However, little research has focused on how the act of searching for and accumulating information via the internet can be important for coping emotionally with a situation characterised by uncertain prospects and inadequate information from health personnel. This paper explores the experiences of 10 Norwegian parents whose children have different rare genetic disorders and who used the internet as a resource. The analysis draws on the theoretical framework of the medical sociologist Aaron Antonovsky, who emphasises people's inherent ability to manage extremely stressful life experiences. Analysing the process of adjusting to and coping with life parenting a child suffering from a rare genetic disorder, this study shows that becoming knowledgeable about a child's condition is essential for gradually comprehending and managing a situation that initially seems unmanageable and distressful. It also suggests that as parents adjust, so do the frequency and purpose of their internet searches.

Keywords: rare disorders, coping, Antonovsky, internet, parents

Introduction

The internet is a powerful infrastructure that democratises access to health and diagnostic information for patients and carers (Hardey 1999), giving access to a wide variety of information as well as social contact and communication. This paper explores how the internet can be a coping resource for individuals adjusting to a life disrupted by chronic illness, more specifically for parents of children with a rare genetic disorder.

Cunningham (1994) describes adjusting to life with a disabled child as a journey that involves a 'cognitive reconstruction', implying that the parents must adjust their expectations about the future. Upon learning of their child's disability, parents often experience stress, shock and disbelief (Case 2001, Graungaard and Skov 2007, McLaughlin 2005). Initially they must understand what the disorder implies for themselves, for their family and for the disabled child's future (Graungaard and Skov 2007, Heiman 2002), and they continually

Published by Blackwell Publishing Ltd., 9600 Garsington Road, Oxford OX4 2DQ, UK and 350 Main Street, Malden, MA 02148, USA

need information regarding the treatment options, services and resources available for their child (Dale 1996, McWilliam and Scott 2001).

Numerous studies have found parents of children with disabilities to be dissatisfied with the information they receive from health personnel (Case 2000, Fisher 2001, Graungaard and Skov 2007, Hedov *et al.* 2002, McLaughlin 2005, Skotko 2005). It may be even more difficult for parents of children suffering from rare genetic disorders to obtain sufficient information because health personnel often have little information to share. Additionally, diagnosing the disorder can be difficult; for a large proportion of people with suspected genetic conditions, the underlying causes remain unresolved (Lenhard *et al.* 2005), complicating the situation even further.

The internet is one way for parents to obtain information about their child's condition. They use it to gain direct access to genetic databases, scientific research on the human genome and genetic disorders, diagnostic tools, online social networks formed around specific genetic conditions, and other resources related to medical information (Schaffer *et al.* 2008, Skinner and Schaffer 2006).

Previous analyses of patients' and carers' reasons for seeking information have emphasised the necessity of having knowledge in order to regain control and be able to advocate their interests in encounters with medical professionals (Ayers and Kronenfeld 2007, Broom 2005, Fisher 2001, Morahan-Martin 2004, Porter and Edirippulige 2007). According to Ziebland (2004), changing relationships between patients and doctors, a decline in patients' trust, and easier access to health information thanks to the internet can lead to the emergence of a patient-felt imperative to be in a position to question medical advice and locate effective treatment. Accordingly, parents of children with rare genetic disorders have been reported as feeling a sense of obligation to keep searching for information and marshalling evidence to secure the best care for their children, even though the result may be information overload that causes additional anxiety (Schaffer *et al.* 2008, Skinner and Schaffer 2006).

In short, these studies focus on how parents use the internet to acquire information with the direct aim of helping their children. Previous research also shows that online social networks and support groups are important arenas for mutual help and encouragement among parents facing similar situations, especially during difficult times (Baum 2004, Fleischmann 2005, Huws *et al.* 2001, Leonard *et al.* 2004, Zaidman-Zait and Jamieson 2007). Still, no studies have investigated whether the activity of searching for information, *in itself*, can help parents get over the stressful hurdle of becoming a parent of a child with a genetic disorder. And if it can, how do the specific characteristics of information searching via the internet facilitate this process? By analysing qualitative interviews with parents who have experienced just such a challenge, the research described in this paper investigates how the internet can function as a resource that parents can draw on to cope with their situation.

Theoretical underpinnings

The experience of and adjustment to becoming parents of a child with a disability has commonly been analysed as a 'no win situation': parents are characterised either as unable to cope or, if they appear to cope well, as deluded or in denial of reality (as summarised in Reed 2000). However, in the last two decades there has been a growth in alternative analytic approaches to research on these parents, focusing instead on the diversity of their experiences, including rewards, stresses, happiness, love and disappointments (Fisher and Goodley 2007, McLaughlin and Goodley 2008, Reed 2000, Runswick-Cole 2007, Landsman 2009). In accordance with this shift, this study looks at parents as actors trying to cope and adapt to the reality of parenting a child with a rare genetic disorder.

To help analytically frame parents' experiences, I use the theoretical framework of medical sociologist Aaron Antonovsky (1979, 1987, 1993). Antonovsky was dedicated to understanding how people managed to stay well despite going through extremely difficult life experiences. He contends that the explanation is to be found in people's capacity to manage stressors, *i.e.* 'demands to which there are no readily available or automatic adaptive responses' (1979: 72). A stressor need not develop into a state of stress, *i.e.* 'a situation appraised as taxing or exceeding the persons' resources and endangering his or her wellbeing' (Antonovsky 1987, Lazarus and Folkman 1984). How a person experiences or manages a stressor depends not only on its characteristics, but more importantly on how that individual deals with challenges in life. According to Antonovsky, this depends on the person's 'sense of coherence'.

'Sense of coherence' is a concept that intends to capture a person's global orientation towards life events. Antonovsky describes sense of coherence as a continuum, stretching from strong to weak. A person with a relatively strong sense of coherence has a tendency to view the world as *comprehensible, manageable and meaningful*. Comprehensibility refers to a person's need to understand his or her situation and to be understood by others. Manageability implies the need to feel that the resources necessary to meet the demands posed by a stressor are available. Meaningfulness refers to the extent to which a person is motivated to mobilise energy and engagement to deal with problems and demands as they are encountered, to participate in the process shaping one's destiny as well as one's daily experiences.

For people to experience the world as coherent, all three components have to be present. Nevertheless, meaningfulness, in the sense of being motivated, is the key factor for maintaining a sense of coherence when encountering a stressor. People who possess a relatively strong sense of coherence will tend to choose coping strategies appropriate for a given stressor, and they are likely to feel engaged and willing to cope with the stressor. In contrast, individuals with a weak sense of coherence will tend to give up in advance of any attempt to make sense of a stressor, and they may lack or be unable to mobilise stressor-appropriate strategies for coping (1987: 138). Like Lazarus and Folkman (1984), Antonovsky defines coping as a constantly changing cognitive and behavioural effort to manage stress.

According to Antonovsky, people tend to develop and stabilise their sense of coherence with age, as most people's ability to handle stressors grows with life experience. However, individuals' sense of coherence may alter if they have particularly difficult life experiences, or what Antonovsky (1987: 29) terms 'a major stressor life event', *e.g.* the death of a child, divorce, job loss. Becoming a parent of a child suffering from a rare genetic disorder can be seen as a 'major stressor life event'. When they experience such an event, people are knocked off balance and the world becomes *incoherent* (1987: 124). People's experience of the world as incoherent may be temporary or long-term. According to Antonovsky (1987: 29, 124), the outcome depends on a person's initial tendency to view the world as coherent and on the availability of appropriate resources for coping with the stressor (1979: 189).

This paper recognises the internet as a resource that can play a part in helping a person re-establish a sense of coherence after experiencing a 'major stressor life event'. The powerful information infrastructure has made previously difficult-to-obtain resources like health and diagnostic information and social networks increasingly accessible, at least in most Western countries (Ayers and Kronenfeld 2007, Hardey 1999, Schaffer *et al.* 2008, Skinner and Schaffer 2006). This study investigates how parents use the internet as a resource in their effort to cope and restore a sense of coherence after they experience a 'major stressor life event'.

The Norwegian context

Norway is characterised by a high level of internet access. Internet use among the Norwegian adult population (16-67 years of age) has increased from 7 per cent in 1997, to 35 per cent in 2001, to 85 per cent in 2007, and today 98 per cent of households with children have access to the internet at home[1].

The Norwegian health system is predominately a public, tax-financed, government provision, strongly resembling the National Health Service (NHS) in the UK. Entitlements to healthcare encompass medical services by general practitioners (GPs) and specialists. According to the Norwegian Biotechnology Act[2], parents are entitled to genetic counselling before and during genetic testing if suspicion of a genetic disorder exists and after testing if a diagnosis for their child's disorder is confirmed.

In Norway, the definition of a rare genetic disorder is 100 per one million inhabitants, and an estimated 30,000 people suffer from rare congenital disorders[3]. Norway's population is 4.8 million, and the population density is low. This suggests that professionals have only a modest chance to build expertise and knowledge about rare disorders through their daily practice. Consequently, clients and their carers risk meeting professionals who have never heard of, or met clients with, a particular disorder. To help address this situation, the Government of Norway has established 16 national centres of expertise to ensure satisfactory services and the building of expertise, with each centre responsible for one or more rare disorders. The centres' main tasks are to develop expertise and convey knowledge to professionals, carers, and people with a rare disorder by means of seminars, courses, pamphlets, and internet pages. The centres' services are free of charge, and participation is granted upon successful application.

The study: method and data

The analyses in this paper are based on data from qualitative interviews with three fathers and seven mothers of 10 children aged 18 months to 16 years. Four of the children have genetic disorders so rare that only a few cases are reported worldwide; the other six have disorders with a prevalence of 1:2,500 to 1:15,000 newborns. The interviews are part of a larger study that also comprises a survey on the use of the internet by parents who have a child with a rare genetic disorder and are searching for medical information and social support. The overall aim of the project is to develop a thorough understanding of the role the internet plays for parents whose child suffers from a rare condition that entails developmental and/or physical problems. With the endorsement of the Regional Committee for Medical Research Ethics, and the Norwegian Data Inspectorate for the Social Sciences, the survey and most of the interviews were carried out in 2007.

In order to investigate the role of the internet, I aimed at recruiting parents with different backgrounds and with some experience related to searching on line for information about their child's disorder. Professional and personal acquaintances helped me recruit four mothers. Three mothers and one father volunteered after receiving information about the study at a seminar arranged by a centre of expertise for parents engaged in support work. The objective was to interview the same number of mothers and fathers, but recruiting fathers proved difficult. Eventually two more fathers were engaged through contact information on the survey[4].

Five mothers were interviewed in their homes; the husbands of the four who were married were not present. Two fathers were interviewed in my office, one mother in her office, and one mother and one father at a café. Before the interview, each parent received information

about the study's purpose, and written informed consent was procured. The interviews, each lasting from 1.5–3 hours, were digitally recorded and transcribed. Pseudonyms are used to ensure confidentiality.

The parents ranged in age from 28 to 42 years. One had less than high school education, three had high school or equivalent, five held a bachelor's degree, and two had an advanced university degree. Two were divorced and eight were married. All but one parent described their child as having some degree of learning difficulty. All of the children had disorders involving latent medical problems, three had problems affecting their daily life to some extent, *e.g.* allergies and epilepsy, and two had severe physical and learning problems. All the parents had internet access at home and used it to search for information. Further, they all demonstrated a strong drive to actively deal with their situation after learning about their child's suspected or confirmed condition. This motivation to act indicates that they did initially have a sense of coherence, as defined by Antonovsky.

In the interviews, I used an open approach to explore each parent's reasons for using the internet and the ways it functioned for them, asking them to 'tell their story' from when they first learned about their child's condition up to the time of the interview. Topics covered included their experiences with health personnel, their social networks and need for social support, and if, why and how they used the internet as a source for information and social support. During the interviews, there was little need to interfere or guide the parents because all had experiences to share.

As recommended within the interpretative tradition in qualitative research (Blanche and Durrheim 2004), I sought in-depth understanding of the respondents' experiences before attempting to interpret them. After transcribing the interviews consecutively, I went through them several times in order thoroughly to acquaint myself with each one. I coded each interview manually for important themes and then, using these themes, conducted systematic comparisons to find confirming, differing and contradictive narratives among and within the parents' stories.

Several important themes emerged in the interviews. One assumption underlying the study was that a main stressor for parents would be their worries for their child, *i.e.* not knowing what the disorder might mean for the child's prospects and prognosis. This assumption was confirmed, as was the assumption that parents would use the internet to find information about these issues. Another theme that emerged was parents' use of the internet to cope with their own emotions. This theme led me to interpret the internet as a resource for managing 'a major stressor life event', as defined by Antonovsky, and as a resource for re-establishing a sense of coherence. Finally, time surfaced as an extremely important factor, as the type of information the parents needed changed in step with their ongoing (re)appraisal of their life situation.

The following sections describe and analyse the parents' experience of loss and subsequent re-establishment of a sense of coherence following this major stressor life event. The primary focus is on the role played by the internet in this process.

Confronted with an unknown destiny

Confronted with an unknown destiny, the world becomes incoherent

Parents described the experience of learning from doctors that their baby most probably suffered from a rare genetic disorder that could entail both intellectual and physical impairments as unexpected and distressing. They used words like surprise, worry, scary, guilt, and grief in connection with their reactions. None of them had previous experience with rare disorders, and their knowledge about genetic disorders was usually confined to Down's

syndrome. Moreover, they commonly sensed that doctors had limited information to share about the suspected or confirmed disorder.

The stress these parents experienced typically related to a combination of factors: fright related to the present and to an unknown future; uncertainty as to what the condition would mean for their child and themselves; and insufficient information. Gry gave an example of this when talking about her experiences and feelings as she, after having waited a year, finally received a diagnosis of her child's disorder in 1992:

> The doctor told us he had […] syndrome, and then the consultation was over. Then we sat there and did not know what to do. Even though it was a relief to have a confirmed diagnosis, it was also terrible to have your worst suspicions confirmed. Moreover, not knowing what […] syndrome implied…the baby was taken care of, but no one thought about us – and I had a mental crisis and my husband withdrew and did not want to talk about it. It was a tough time.

Five parents learned about their child's suspected genetic disorder shortly after birth but had to wait between one and three years for a confirmed diagnosis. They all claimed that not having the condition clarified in the form of a diagnosis was extremely difficult. Before receiving a confirmed diagnosis, they found the doctors with whom they interacted to have very little information to share about their child's prognosis and prospects. In general, these parents described the situation as completely incomprehensible; they did not know probable medical, intellectual or social consequences of the condition, if their child would live or die, or if they were to blame for the condition.

The combination of having a child with a suspected rare genetic disorder and not receiving adequate information can cause strong feelings of loneliness and worry. Maria said that the doctors had suspected right after her now three-year-old son's birth that he had a specific rare genetic syndrome. However, the genetic test was negative and she and her child went home from hospital without a diagnosis:

> I was scared; I could hardly breathe the first year. It was a terrible phase and that enormous feeling of loneliness – to be sent home from hospital with no one to contact. They could at least have given me a brochure or told me about a parental advocacy group, or something. It was so awful.

Some of the parents found doctors pessimistic regarding their child's prospects and prognosis when advising them of the suspected or confirmed genetic disorder, leaving them with a feeling of hopelessness. Robert had a three-year-old daughter with a rare syndrome. Because of symptoms like severe respiratory difficulties, poor muscular tonus and particular facial features, the paediatrician suspected a genetic disorder and summoned the parents to a meeting:

> The doctor on the postnatal ward told us that this could be serious. My wife asked, 'Do you mean she could be intellectually disabled?' He said that was very likely. That was a brutal message, not giving us much hope actually.

As these quotes show, learning of their child's disorder was an extremely difficult life situation for each parent. Communicating a worst-case scenario to parents has been found to increase their anxiety by confirming that this truly is an awful thing that has happened to them and their child, and no future or quality of life for the child or the family can be

envisaged (Bartolo 2002, McLaughlin 2005). Here the suspected or identified disorders were 'stressors' in Antonovsky's sense; they were demands to which there were no readily available or automatic adaptive responses (1979: 72). Not knowing what their child suffered from, or knowing the diagnosis but not the implications, made it very difficult for the parents to know what to do.

Maria, Robert and Gry described situations in which their world seemed incoherent. Their world seemed incomprehensible; they felt incapable of understanding what was going on and what was going to happen. The world around them seemed unmanageable; they were left with a sense being without resources to meet the demands posed by their child's disorder. Finally, they felt powerless to influence their child's destiny, and they had no knowledge of how their everyday life with the child might unfold. In Antonovsky's terms, the world did not seem meaningful. However, in the retrospective interviews, these parents looked back at the initial all-encompassing stress of this period as something they had gradually become able to cope with.

Acting in order to cope

Many parents talked about a felt need to do something in this initial period of stress. Although the internet was not publicly available before the mid-1990s (Hardey 1999), Gry, working as a computer programmer at the time of her son's diagnosis (1992), used her computer and telephone at work to search different US-based databases and make calls to an association for parents in the US organised around the genetic disorder her son had. She said, 'I find that knowledge helps me to handle difficult situations, so searching for information helped.'

In contrast, Robert, who received his daughter's diagnosis in 2004, had access to the internet at home:

> I had to do something in the evenings when I came home from the hospital. One gets worried, wondering what it can be; and because I have internet at home, I searched and searched.

Robert used the internet in an effort to find a diagnosis for his daughter's condition. By entering search terms based on her symptoms and on what doctors had told him, he was able to identify her syndrome: the same diagnosis initially considered by her doctors and soon after confirmed by them. However, after receiving the official diagnosis, Robert, like the other parents who were interviewed, felt that the information he had received from the doctors and other health personnel was insufficient. He therefore started looking for all available information on the medical aspects of the syndrome, searching medical websites and online patient and advocacy group sites written in Scandinavian, German, and English.

Maria also had internet access at home but very little experience with information seeking. She described how she combined watching her baby and searching the internet, hoping to make a diagnosis by entering search terms based on her child's symptoms and terminology she had picked up in conversation with heath personnel. To help her translate medical terms, she had bought a medical dictionary. Searching the internet, she discovered thousands of rare disorders, learned about the difficulties of diagnosing genetic and chromosomal disorders, and discovered that many parents never get an official diagnosis for their children's disorders. She said that this knowledge made her feel sad, but, at the same time, it helped her feel less lonely: 'I found it really helpful – to know that there were more of us in this world'. In addition, she emphasised that reading about other parents who were doing all right gave her great comfort.

Learning basic facts about genes and chromosomes can also help parents control their worrying. Victoria had to wait nearly a year for the doctors to reach a diagnosis for her child's suspected genetic disorder; in the meantime, she used the internet to find information:

> Knowledge makes it less scary. I find it easier the more knowledge I have. Therefore, I learned all about *chromosomes*, *delusions*, *translocations*; all of them became common words to me… One wants to know what a chromosome is, how it is constructed. That little thing, why can't you just take it away … you know, inject something that will repair it?

The internet is an information resource that made it possible for Maria and Victoria to increase their knowledge and understanding, which in itself seemed important for their ability to reduce some of the stress they felt, even when the information was not directly associated with a diagnosis.

At the same time, seeking information on the internet about genetic disorders means exposing oneself to potentially frightening information about symptoms, prospects and prognoses (Zaidman-Zait and Jamieson 2007), which can increase rather than ease emotional distress. Kate, the mother of a child diagnosed with an extremely rare genetic condition 18 months after suspicion arose, described how she, in an effort to diagnose her child, explored medical web sites and the web page of a national centre of expertise on rare genetic disorders:

> I looked at different diagnoses to see if I could find out anything, matching Tina's symptoms with symptoms of different syndromes. However, all the different diagnoses and progressive syndromes I read about on the internet scared the shit out of me, so I stopped.

When comparing her daughter's symptoms with those of the syndromes she read about, Kate found none matching completely. Additionally, she thought her daughter functioned quite well compared to the descriptions of certain syndromes, the symptoms of which in some ways matched those of her daughter. Kate thought that finding a diagnosis would help her discover a reason for her child's condition, but this problem-focused strategy failed because the information she found increased her anxiety instead of reducing it. Kate decided to accept her child's challenges without having a diagnosis. As she put it, 'We wanted to start living, so we accepted that she had her challenges, and we don't know why.' This change of focus directed her to other coping strategies like finding out how to help her child reach optimal development. After a while, she began looking for information on pedagogic and physical training programmes on websites formed around syndromes with symptoms similar to her child's, *e.g.* Down's syndrome.

Maria seemed to experience her situation as mother of a child with severe disabilities as understandable; she had learned all about genes and chromosomes, knew her son's needs and how to deal with them, and described life with her child as 'fantastic – I think about what other people miss out on'. However, the question of whether she had something to do with her child's disorder, by inheritance or by something she had done during pregnancy, was a stressor that continued to haunt her. Thus, Maria was not willing to have her child remain undiagnosed. When the doctors gave up on trying to determine a diagnosis, she continued to use the internet in the hope of finding something that could help her resolve the matter. Eventually, she learned about a particular genetic test that made a diagnosis possible; and, as a result of her own efforts, her child was diagnosed at three years old. Learning that her child suffered from a random genetic condition made it easier for her to accept the situation: 'It is easier to bear; this is how he is, he is my child and I'll make the best out of the situation'. In

Maria's case, the internet was the resource that made her quest for a diagnosis both possible and successful.

Most of the parents in this study perceived in-depth knowledge as essential to their ability to cope during the first stage and to accept facts related to their child's disorder. As the foregoing accounts show, searching for information was an activity that helped alleviate some of the stress that they felt in their new situation. Rather than remain passive and wait for doctors to provide information, they chose to become knowledgeable on their own and/or facilitate the process of obtaining a diagnosis, feeling that in this way they were, at least to some extent, able to take control of their situation.

Towards a re-established sense of coherence

In the course of adjusting to and accepting their new reality, parents' internet use changed. As time went by, all parents received a diagnosis for their child. They then turned to the internet for information about treatments and medication to minimise consequences of the disorder. Searching national and international databases for medical research and papers, parental and diagnostic support groups, and the web sites of centres of expertise provided them with the realities of prospects and treatment possibilities. As McLaughlin and Goodley (2008) found in their study, most parents said that learning these facts helped them accept their child's challenges and shift their expectations about the future. Consequently, their information-seeking purpose changed from primarily resolving medical questions towards integrating all aspects of life relevant to caring for a child with a rare disorder, *e.g.* pedagogic and training programmes to help their child develop physically, mentally and socially. They also expanded their information sources to include patient associations, other parents in the same or similar situation, and centres of expertise.

Over time, most of the parents considerably reduced their information seeking activity. Robert, who used the internet on a daily basis when he first learned about his child's disorder because, as he said, 'I am the kind of person who needs to have thorough understanding', reduced his information searching activity to twice a year in conjunction with follow-up meetings at the hospital. Like nearly all the other parents, his general experience with medical doctors was that they lacked sufficient knowledge and experience related to his child's syndrome. Worrying that a doctor on shallow ground would deny his child hormone treatment, he used the internet to prepare his argument and reduce stress related to each forthcoming medical encounter:

> I have heard that many parents have trouble getting [the treatment] started, although all new research I have read says that the earlier you start the better it is. In the US, they start almost in infancy with growth hormones. Therefore, I read and prepared myself to argue for treatment.

Robert actively participated in shaping his own and his child's destiny; he had control in that he was able to define the challenge and the steps he needed to take, and his ability to use the internet provided him with the resources to meet the demands of the situation.

Involvement in online social interaction also changed as the parents adapted to their new situation. Parents said that after learning about their child's diagnosis, they experienced a lengthy process of accepting that their child would always be extraordinary. Most said that facing other children with similar conditions was difficult at first; hence, they tried to shield themselves by avoiding online exposure to personal stories and pictures of children and adults with genetic conditions. However, as time passed they became more open to reading

about such individuals and interacting face to face with them, even more so with parents of children who had the same rare disorder as their child.

Some of the interviewed parents had had an opportunity to meet in person with other parents in similar circumstances. Eight had participated in a seminar arranged by a centre of expertise for parents of children born with specific syndromes, *e.g.* Williams syndrome, and for parents of children with various extremely rare genetic disorders, *e.g.* 9q34. There they had established contact with others with whom they had continued to have sporadic face-to-face and e-mail contact. These parents said that they (now) greatly appreciated talking to others who had similar experiences and instantly understood what they were dealing with, and with whom they could laugh and cry without having to explain or make excuses for their reactions. They also noted that they occasionally used the internet to read about other parents' experiences in such areas as children's development, medical treatment and social services; but they mainly described their searches as purpose oriented and said they did not use the internet for social chatting. This could indicate that, when available, social interaction with 'offline contacts' tends to replace online contact with strangers.

For some parents, however, such offline contacts were not available. Two parents, Maria and Ann, said that the centre of expertise had rejected their applications for participation in a seminar, which was a main reason they were eager to use the internet to communicate with other parents. Because their children had especially severe physical and developmental challenges, they experienced continuing stress related to negative prospects regarding the children's futures. They used the internet extensively to seek information that could help them with daily practical and emotional challenges. As Maria described it, social interaction over the internet seemed to fill the same need for face-to-face relationships that the other parents had satisfied through connections established at the centre of expertise.

Like Maria, Ann was also an avid user of the internet: 'The internet is my number one asset. It gives me all the information and knowledge I need to cope with the situation'. She also talked about how she used the internet as a tool in her process of accepting the prospect that her seven-year-old child's progressive disorder would involve a short life expectancy. Ann was a member of an US-based web site for parents of children with the same syndrome as her child's. Ann had friends and family who supported her. Nevertheless, she found it highly beneficial to communicate with parents in the same situation, who immediately understood what she had to deal with. She found it particularly helpful to have a place where she could share her thoughts and vent her emotions without risking negative reactions:

> I have told our story many times. We all have our vicissitudes, and sometimes I just have to let it all out, positive as well as negative thoughts and feelings. In addition, you get a sort of temperature check, and sometimes I receive positive and other times negative responses. These responses allow me to organise my thoughts and help me think about which step to take next.

The interview material indicated clearly that online or face-to-face social interaction with others in a similar situation was not something that these parents got involved in immediately after becoming aware that their child had a genetic disorder. This suggests that social interaction with strangers was difficult when they felt completely 'off balance'. Being able to establish (some kind of) a relationship with strangers seemed to require a certain sense of coherence. Against the background of Antonovsky's concepts, this is not surprising: a minimum level of understanding of one's situation is necessary to convey to others the kind of circumstances one is facing and to find it meaningful to engage in interaction with others.

Discussion

> It is better to know because that gives you a chance to work with your sorrow; then you can accept the reality.

These words from one of the parents illustrates how these mothers and fathers felt about having adequate information: 'knowing' was the basis on which they could begin the emotional work of grief and acceptance and thereby learn how to manage the situation of parenting a child with a rare genetic disorder.

Antonovsky argues that a sense of coherence is necessary for successfully coping with extremely difficult life experiences, and this sense of coherence depends on one's ability to see the world as comprehensible, manageable and meaningful. For the parents in this study, news of their child's rare disorder became a stressor that was difficult to handle when, at the outset, it turned their existing world upside down. Nonetheless, all showed a determination to make sense of and manage their new circumstances and to have a role in shaping the future for both their child and themselves. To get started on this process, they turned to available resources, primarily the internet. By obtaining information on their child's condition and prospects, they gradually rebuilt a sense of their world as comprehensible and manageable.

The internet allows parents to find information for themselves. Previous research has found that the ability to work actively to gain knowledge increases the quality of life for patients facing uncertainty related to their illness (Bury 1982, Faircloth *et al.* 2004). Being able to go online the minute they think of a new question may increase parents' sense of being able to manage. It may also help abate feelings of powerlessness, which parents have previously been reported to experience when they learn about their child's suspected or confirmed diagnosis (Dale 1996, Seligman 1997).

In accordance with previous findings (Rosenthal *et al.* 2001), parents in this study said that having a diagnosis was important. Compared to parents who receive a diagnosis relatively early, parents of undiagnosed children experience greater stress and isolation and more difficulty accepting their child's challenges (Fleischmann 2005, Lenhard *et al.* 2005, Taanila *et al.* 2002). They have also been found to use ineffective coping strategies like wishful thinking, avoidance, and distancing (Lenhard *et al.* 2005), strategies regarded by Antonovsky as obstructions to the resumption of a sense of coherence (Antonovsky 1987). The internet may well be particularly important for these parents, as it enables them to act and use problem-focused strategies that can lead to a resolution of the question of diagnosis. For all parents, learning basic facts about chromosomes and genetics can increase understanding and thereby reduce stress related to the uncertainty of the situation

The interviewed parents had different starting points in their use of the internet in connection with their child's disorder. Five parents learned about their child's rare condition before access to the internet was widespread; two of them got help from colleagues and family to search the internet, three had access to the internet but very little experience looking for this type of information. However, for these five parents the seriousness of their situation seemed to be an important incentive for learning how to use the internet.

The parents in this study had different educational backgrounds. Previous research has questioned whether such differences influence people's ability to search for and make use of information found on the internet (DiMaggio *et al.* 2001). Parents had different preferences regarding information sources; some preferred to get their information from forums and online social support groups, while others looked to more scientifically oriented sites. The information source preferred seemed to vary according to parents' education; however, the

sample size is too small to draw conclusions about such patterns. Nevertheless, the material does demonstrate that the internet can be a resource that enables people with different information gathering preferences and skill levels to increase their understanding of a difficult life situation; it does this by allowing them to manage their individual information needs.

According to Antonovsky (1987), resources like information and social networks are *potential* resistance resources, meaning that they can facilitate successful coping if they are mobilised and applied when they can be useful. Information, however, can also be counterproductive for successful coping if, for instance, it comes in the form of information overload. One potential disadvantage of the internet is that it makes accessing information so easy that parents may feel compelled to use it (Ziebland 2004), even if the information being sought could prove scary and increase their anxiety. Findings in this study suggest that when parents are initially 'knocked off balance', access to the internet can hamper their ability to judge how much information they need. One of the parents who had encountered relatively qualified health personnel from the beginning felt that she had benefitted by postponing intensive information seeking. Instead, she had allowed herself to digest the news, slowly increasing her comprehension of her new life situation. Clearly, the initial information and advice provided by healthcare professionals is of the utmost importance in helping to reduce parents' uncertainty, and give them a chance to reflect on their early information needs.

In keeping with findings of other studies, the majority of parents in this study said they benefited from using online social support groups to find information (Baum 2004, Fleischmann 2005, Leonard *et al.* 2004, Zaidman-Zait and Jamieson 2007). All the parents regarded social support from other parents in similar situations as essential for helping them cope with their feelings of loneliness and uncertainty (Beresford 1994, Heiman 2002). However, only two used online support groups with whom to interact and get parent-to-parent support. Importantly, neither of these parents had received an invitation to participate in parent seminars arranged by a centre of expertise, and both had children with severe physical and learning impairments. This finding indicates that the severity of the child's medical condition and the existence of alternative support networks may influence whether parents use the internet for social and emotional support.

Conclusion

This study found that seeking information and becoming knowledgeable were tremendously important for parents learning that their child has a rare genetic disorder. In line with findings from other studies, a main reason for these parents' intensive information seeking, facilitated by the internet, was their experience with the health system; the medical personnel they dealt with were unable to provide them with sufficient information, and they therefore felt a strong imperative to become 'experts' capable of advocating their child's interest.

The main contribution of this study is that it points to the important role information and knowledge play in the emotional wellbeing of parents in this situation. By becoming informed, they become increasingly able to comprehend and manage a situation that at first seemed unmanageable and distressful. As their understanding increases, they develop a sense of control over emotional as well as practical issues. This sense of control and confidence allows them to focus on their child as part of their everyday life in such a way that the disorder is not the overarching concern. This makes time and resources available to the parents for coping with new challenges as they emerge.

Antonovsky's theoretical framework makes it possible to conceptualise parents' adjustment to life parenting a child with a rare genetic disorder as a process of gradual and

increasing comprehension and acceptance. His perspective enables us to see how parents adapt to this situation in a way that makes it possible to speak of a life that has returned to 'normal'. The framework also reveals a distinction between coping that takes place when a person is in a constant state of stress and coping that occurs when a person has regained a sense of coherence following an extremely stressful life situation. It thus becomes possible to acknowledge parents' feelings of distress when they first learn about their child's disorder, while simultaneously recognising that these same parents can eventually arrive at a place where life is not constantly stressful.

This study raises questions concerning the generalisability of Antonovsky's framework, as described here, to other parents in similar situations or other groups experiencing stressful life events. The study also points to the need for further studies on the usefulness of the internet for information gathering and social support for caregivers and patients in different situations and with various needs and preferences.

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Acknowledgements

I wish to thank Dr Lise Kjølsrød and Dr Lars Grue and the two anonymous reviewers for their insightful comments on earlier drafts, and my colleague Cand Polit Ingrid Smette for ongoing discussions about my work. Funding for this study was provided by Norwegian Social Research (NOVA).

Notes

1 http://www.ssb.no/english/subjects/10/03/ikt_en/
2 http://www.bion.no/lov/Biotechnology_act_MASTER.pdf
3 http://www.rarelink.no
4 Origially, 10 fathers provided contact information. Four did not respond to a request for an interview, and four others were ruled out because they lived too far away, which made their participation practically and economically difficult

References

Antonovsky, A. (1979) *Health, Stress, and Coping*. San Francisco, CA: Jossey-Bass.
Antonovsky, A. (1987) *Unraveling the Mystery of Health. How People Manage Stress and Stay Well*. San Francisco, CA: Jossey-Bass.
Antonovsky, A. (1993) The structure and properties of the sense of coherence scale, *Social Science and Medicine*, 36, 6, 725–33.
Ayers, S.L. and Kronenfeld, J.J. (2007) Chronic illness and health-seeking information on the internet, *Health*, 11, 3, 327–47.
Bartolo, P.A. (2002) Communicating a diagnosis of developmental disability to parents: multiprofessional negotiation frameworks, *Child Care Health and Development*, 28, 1, 65–71.
Baum, L.S. (2004) Internet parent support groups for primary caregivers of a child with special health care needs, *Pediatric Nursing*, 30, 5, 381–90.

Beresford, B.A. (1994) Resources and strategies: how parents cope with the care of a disabled child, *Journal of Child Psychology and Psychiatry*, 35, 1, 171–209.

Blanche, M.T. and Durrheim, K. (2004) *Research in Practice: Applied Methods for the Social Sciences*. Cape Town: University of Cape Town Press.

Broom, A. (2005) Virtually he@lthy: the impact of internet use on disease experience and the doctor-patient relationship, *Qualitative Health Research*, 15, 3, 325–45.

Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health and Illness*, 4, 2, 167–82.

Case, S. (2000) Refocusing on the parents: what are the social issues of concern for parents of disabled children?, *Disability and Society*, 15, 2, 271–92.

Case, S. (2001) Learning to partner, disabling conflict: early indications of an improving relationship between parents and professionals with regard to service provision for children with learning disabilities, *Disability and Society*, 16, 6, 837–54.

Cunningham, C. (1994) Telling parents their child has a disability, In Mittler, P. and Mittler, H. (eds) *Innovations in Family Support for People with Learning Disabilities*. Whittle-le-Woods: Lisieux Hall.

Dale, N. (1996) *Working with Families of Children with Special Needs: Partnership and Practice*. London: Routledge.

DiMaggio, P., Hargittai, E., Neuman, W.R. and Robinson, J.P. (2001) Social implications of the internet, *Annual Review of Sociology*, 27, 307–36.

Faircloth, C.A., Boylstein, C., Rittman, M., Young, M.E. and Gubrium, J. (2004) Sudden illness and biographical flow in narratives of stroke recovery, *Sociology of Health and Illness*, 26, 2, 242–61.

Fisher, H.R. (2001) The needs of parents with chronically sick children: a literature review, *Journal of Advanced Nursing*, 36, 4, 600–607.

Fisher, P. and Goodley, D. (2007) The linear medical model of disability: mothers of disabled babies resist with counter-narratives, *Sociology of Health and Illness*, 29, 1, 66–81.

Fleischmann, A. (2005) The hero's story and autism – grounded theory study of websites for parents of children with autism, *Autism*, 9, 3, 299–316.

Graungaard, A.H. and Skov, L. (2007) Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled, *Child Care Health and Development*, 33, 3, 296–307.

Hardey, M. (1999) Doctor in the house: the internet as a source of lay health knowledge and the challenge to expertise, *Sociology of Health and Illness*, 21, 6, 820–35.

Hedov, G., Wikblad K and G, A. (2002) First information and support provided to parents of children with Down syndrome in Sweden: clinical goals and parental experiences, *Acta Paediatrica*, 91, 12, 1344–9.

Heiman, T. (2002) Parents of children with disabilities: resilience, coping, and future expectations, *Journal of Developmental and Physical Disabilities*, 14, 2, 159–71.

Huws, J.C., Jones, R.S.P. and Ingledew, D.K. (2001) Parents of children with autism using an email group: a grounded theory study, *Journal of Health Psychology*, 6, 5, 569–84.

Landsman, G.H. (2009) *Reconstructing motherhood and disability in the age of 'perfect' babies*. New York: Routledge.

Lazarus, R.S. and Folkman, S. (1984) *Stress, Appraisal and Coping*. New York: Springer.

Lenhard, W., Breitenbach, E., Ebert, H., Schindelhauer-Deutscher, H.J. and Henn, W. (2005) Psychological benefit of diagnostic certainty for mothers of children with disabilities: lessons from Down syndrome, *American Journal of Medical Genetics Part A*, 133A, 2, 170–5.

Leonard, H., Slack-Smith, L., Phillips, T., Richardson, S., D'Orsogna, L. and Mulroy, S. (2004) How can the internet help parents of children with rare neurologic disorders?, *Journal of Child Neurology*, 19, 11, 902–07.

McLaughlin, J. (2005) Exploring diagnostic processes: social science perspectives, *Archives of Disease in Childhood*, 90, 284–87.

McLaughlin, J. and Goodley, D. (2008) Seeking and rejecting certainty: exposing the sophisticated lifeworlds of parents of disabled babies, *Sociology*, 42, 2, 317–35.

McWilliam, R.A. and Scott, S. (2001) A support approach to early intervention: a three-part framework, *Infants and Young Children*, 13, 4, 55–66.

Morahan-Martin, J.M. (2004) How Internet users find, evaluate, and use online health information: a cross-cultural review, *Cyberpsychology and Behavior*, 7, 5, 497–510.

Porter, A. and Edirippulige, S. (2007) Parents of deaf children seeking hearing loss-related information on the Internet: the Australian experience, *Journal of Deaf Studies and Deaf Education*, 12, 4, 518–29.

Read, J. (2000) *Disability, the Family, and Society: Listening to Mothers*. Buckingham, UK: Open University Press.

Rosenthal, E.T., Biesecker, L.G. and Biesecker, B.B. (2001) Parental attitudes toward a diagnosis in children with unidentified multiple congenital anomaly syndromes, *American Journal of Medical Genetics*, 103, 2, 106–14.

Runswick-Cole, K. (2007) The Tribunal was the most stressful thing: more stressful than my son's diagnosis or behaviour, *Disability and Society*, 22, 3, 315–29.

Schaffer, R., Kuczynski, K. and Skinner, D. (2008) Producing genetic knowledge and citizenship through the internet: mothers, pediatric genetics, and cybermedicine, *Sociology of Health and Illness*, 30, 1, 145–59.

Seligman, M. (1997) Ordinary families, special children: a systems approach to childhood disability. In Darling, R.B. (ed.) New York: Guildford Press.

Skinner, D. and Schaffer, R. (2006) Families and genetic diagnoses in the genomic and internet age, *Infants and Young Children*, 19, 1, 16–24.

Skotko, B. (2005) Mothers of children with Down syndrome reflect on their postnatal support, *Pediatrics*, 115, 1, 64–77.

Taanila, A., Syrjala, L., Kokkonen, J. and Jarvelin, M.R. (2002) Coping of parents with physically and/or intellectually disabled children, *Child Care Health and Development*, 28, 1, 73–86.

Zaidman-Zait, A. and Jamieson, J.R. (2007) Providing web-based support for families of infants and young children with established disabilities, *Infants and Young Children*, 20, 1, 11–25.

Ziebland, S. (2004) The importance of being expert: the quest for cancer information on the internet, *Social Science and Medicine*, 59, 9, 1783–93.