Seeking advice about children’s health in an online parenting forum

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INTRODUCTION

There has been considerable interest in recent years in the subject of online health information. Research has largely focused on how people use the internet for advice on self-management of symptoms, to clarify information they have been given about diagnoses, or to seek more detailed information than they have been given by a professional (McMullan 2006). Less visible is the provision of health-related advice and social support through online networks, although there is growing interest in the sociological literature (Netleton et al 2002). A review of literature on internet social support in health identified the availability of online support for example for people with cancer and diabetes; carers of people with Alzheimer’s disease; and mothers of children with disabilities (Scharer 2005). These support sites are often excluded from evaluations of health information online (Sillence et al 2006) and so less is known about the type of information and advice that is available and how it is being used. Targeted online social support seems to be more readily available for people with serious or chronic illnesses and for parents of children with disabilities or special needs than for those who are dealing with everyday illnesses in children. However instead of, or as well as, using dedicated health sites, people can access information and support via topical message boards or chat forums on websites which do not necessarily have a health focus. There has been a recent increase in interest in the use of websites as sources of advice and support for parenting (O’Connor & Madge 2004; Madge & O’Connor 2006; Plantin & Daneback 2009), and this can include advice around children’s health.

Online support bears many similarities to that offered by more traditional face-to-face support groups. In particular, face-to-face groups are thought to value the experiential knowledge of members (Kelleher 1994). The concept of experiential knowledge was in fact originally introduced as a way of theorising self-help groups and was defined as ‘truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others’ (Borkman 1976: 446). Burrows and Nettleton (2002:265) have noted this privileging of experiential knowledge in the online context. Support groups also offer a mixture of opinions and advice, and equally a study of bulletin boards found that the most useful responses contained ‘personal opinions, actionable advice, and concrete information’ and, where appropriate, urged users to seek professional medical help (Suzuki & Calzo 2004: 696). This encouragement to seek help is an example of what Freidson termed a ‘lay referral system’, that is ‘a network of personal influence along which the patient travels on his [sic] way to the physician’ (Freidson 1960: 374). These concepts of experiential knowledge and lay referral provide a useful starting point for understanding the advice available in online forums.

This paper emerged from preliminary research as part of a study about the illness behaviour of callers to NHS 24 (a Scottish telephone-based service which provides health assessment, advice and, where necessary, referral to other services in the out-of-hours period). When
exploring how people make decisions about use of health services I began to read discussions involving lay referral to NHS 24 on the UK parenting website Mumsnet. It became clear that the website is a significant source of health advice, information and support for many of its users, and that as well as lay referral to out-of-hours health services, parents were offering each other a wide range of advice based largely on experiential knowledge. This paper will outline how online peer support and advice is accessed by parents in making day-to-day health decisions for their children. Specifically it will look at three forms of advice: to seek medical help; to push for access to further or specialist care; and to self-care. In discussing these examples I will note the strength of lay referral networks and the weight that seems to be given to experiential knowledge in this online community.

MUMSNET

Mumsnet is a website which was set up in 2000 by two mothers as a forum for parents to share information. The site gets nearly 5 million visits each month and has, according to political commentators, developed huge political influence across all parties in the UK (Phillips, Total Politics 2012). It was described by former prime-minister Gordon Brown as a ‘national institution’ and despite the fast pace of change in cyberspace, ‘Mumsnet's capacity to hold decision-makers to account shows no sign of fading’ (Henderson, BBC News 2011).

However it must be noted that the site has been criticised in the press as being unrepresentative of the majority of parents (Young, The Telegraph 2011) and indeed a ‘Mumsnet census’ of more than 5,000 users carried out by the site in 2009 showed that the majority of users (63%) are between 31-40 years old; female (98%) from the UK (95%)-mainly the south-east; and have children under 6 years old. 75% were educated to at least degree level and 94% identified their ethnicity as white. Most were married or living with a partner (94%) and only 10% had an average household income of less than £20,000 per annum (Mumsnet census 2009). This presents a picture of a group of well-educated, middle class mothers rather than a cross-section of parents in the UK. Pedersen and Smithson (2013) have argued that Mumsnet is in many ways atypical of online parenting communities, and that this is in fact part of its appeal to users. In response to a question about reasons for using Mumsnet, 76% of respondents to the census said that they use it for advice and 75% said for information (Mumsnet census 2009).

In many ways, the Mumsnet community can be likened to a self-help group in that members turn to each other for advice, support, reassurance and practical advice based on experience. Some of the anonymous user comments in the Mumsnet census give an insight into the sort of support network that Mumsnet provides, with people referring to it as a ‘sisterhood’ or ‘just like my mum - occasionally prickly and infuriating but generally an informative, hilarious and pivotal part of my life. And always there when I need it’ (Mumsnet census 2009). This perception of the site as a supplement to (or possibly substitute for) familial support is reinforced by accounts of what users feel it provides for them: ‘It's a lifeline for me as a new mum, giving me advice, information and diversion. It's allowed me to figure out what kind of parent I want to be, confident in the knowledge that there are a million different ways to do it, each as valid as the other’ (Mumsnet census 2009).

‘Mumsnet Talk’ is the discussion forum on the site. It gets about 25,000 posts each day. Discussions cover a wide range of topics such as pregnancy, childcare, education, travel, food, politics and health. Within the health section, discussions are categorised as: allergies; child/adolescent mental health; children's health; family planning; general health; life-limiting illness; menopause; mental health; swine flu; and vaccinations. As is clear from the categories, parents use the forum to discuss their own health as well as their children’s
health. The advice and information shared is as varied as the questions asked and represents a diversity of perceptions of health and models of healthcare from technological interventions to home remedies and alternative or complementary therapies. The open and largely unmoderated nature of the forum allows opinions and ideas to be challenged and for a range of opinions to be represented.

METHODS

I focused my attention on the ‘Children’s Health’ section of Mumsnet Talk and used the search term ‘NHS 24’ to identify discussions which may be of relevance to my research. Searching from 2002-2012, (the first ten years of NHS 24’s existence in Scotland), returned 278 discussion threads. For the purpose of this paper, I reduced the search parameters to one year- from September 2011 to September 2012- the most recent year at the time of analysis. This returned 42 threads, of which 8 did not actually mention NHS 24 and were discounted. This left 34 discussions, containing a total of 823 individual posts. These posts were copied, analysed and coded thematically with the aid of NVivo software (QSR International, UK). This approach has been described as a combination of document analysis and ‘a form of observation’ where ‘naturally occurring interaction between the forum members’ can be witnessed without intervention (Turkmendag et al 2008: 293-4).

There are challenges in the use of internet discussion forums for social research, including methodological and ethical challenges (Wilson & Peterson 2002; Hamman 2004). However, collecting data from online communities has become more common as researchers have grown aware of the advantages, such as being able to observe real interactions in a non-obtrusive way (Pacagnella 1997). Much of the debate around ethics in online research is centered on three main issues: the definition of public and private spaces; informed consent; and anonymity (Knobel 2003: 190). I gave these issues careful attention and followed guidelines from the Association of Internet Researchers (AoIR 2002) which advise consideration of website users’ likely perceptions of how public their discussions are. The distinctions between public and private domains are blurred in interactive online media and ethical considerations are often, by necessity, context-specific (Snee 2008). Mumsnet Talk forums are publicly visible, even to non-members of the site, and as this is stated clearly on the site the discussions can be seen as public (Rodham & Gavin 2006; Hine 2012) - although I am aware that this is a contested position (Berry 2004). The issue of informed consent is also problematic, as I was looking at archived discussions from up to a year ago in which participants use pseudonyms and do not provide contact details. In addition, ‘assurances of participants’ anonymity in research reports are deeply problematic in the archived and searchable network of cyberspace’ (Knobel 2003: 188). All posters on Mumsnet use a pseudonym and are not identifiable from their posts. Despite this, I have not attributed remarks to contributors’ pseudonyms in this paper out of respect for their online identities (Pacagnella 1997; Knobel 2003; Hine 2012).

The discussions I looked at ranged from simple questions with one or two straightforward responses, to lengthier conversations including one thread which was active for almost a month. In analysing these discussions I identified a range of issues which led parents to seek advice from the Mumsnet community. In this paper I focus on three forms of advice which were commonly given: to seek medical help; to push for access to further or specialist care; and to self-care. These examples were chosen for their relevance to my interest in how lay consultations impact on help-seeking behaviour. They provide some insight into how lay referral and the exchange of experiential knowledge are performed in reports of real-life situations.
FINDINGS
Advice to seek medical help

In the discussions analysed, parents frequently encouraged each other to seek professional care. This included advice to contact NHS 24, NHS Direct (as it was then), the local out-of-hours service, a GP, or to go to a hospital Emergency Department. To an extent the advice varied depending on the time of day and the perceived seriousness of the situation. However as Mumsnet is used by people all over the UK, it also to some extent depended on what services were available in the poster’s own area. For example, NHS 24 and NHS Direct were used almost interchangeably, and in the out-of-hours period it was sometimes unclear if advice to ‘call OOH’ meant to call NHS 24/ Direct or to contact the local out-of-hours GP service.

In an example of how lay referral is enacted on Mumsnet, one mother posted a message asking what to do about a six week old baby with a temperature of 38 degrees. She had only used a crude strip on the forehead and wanted advice on how to get a more accurate temperature. There was nothing obviously wrong with the baby, he was ‘just a bit off’ and had sneezed a couple of times. She said:

_I can hardly look at him for fear, he’s so little and how can I tell if he’s sick?_

Within an hour there had been 18 replies, most of which advised the mother to seek medical advice from NHS Direct or NHS 24, the Out of Hours service or a GP. Respondents frequently phrased their advice in terms of what they would do themselves in a similar situation:

_I’d ring for NHS for advice if I was you. He is very young and better safe than sorry._

_I’d get off Mumsnet and call nhs 24 now if I were you._

One person replied by supplying a link to an NHS website, and posting the relevant guidelines on temperature in small babies which suggested that medical advice should be sought, and one person stated that they were a paediatrician and would also advise a consultation. However most people who responded did not declare any medical knowledge and seemed to be basing their advice on a feeling that the age of the baby meant the mother should not take any chances:

_If you are worried then phone out of hours - you don’t want to mess around with a tiny baby._

Respondents sometimes offered their own interpretations of symptoms and possible diagnoses based on their own experience and that of people they know. This often emphasised the potential seriousness of the situation and thus justified their insistence that professional care should be sought.

_I’ve always been told to add a degree to underarm temp. I would call OOH GP now if I were you. My [daughter] had this last weekend, same age and it was bronchialitis [sic] and a chest infection. You also say his soft spot is sunken, this is a dangerous sign._

The following morning the opening poster replied to say that she had brought the baby to the GP the night before and that everything was fine. She added:

_Thanks for spurring me to act last night. Fear tends to paralyse me_

In this case lay referral had encouraged and legitimised help-seeking, in an example of what has been termed by Zola (1973) as ‘sanctioning’.
Advice to push for access to further or specialist care

In a study about lay peoples’ use of online health knowledge, ‘a number of participants reported that they had renegotiated treatment for themselves or their children with their GP on the basis of information they had found on the internet’ (Hardey 1999:829). Equally on Mumsnet worried parents are frequently encouraged to challenge practitioners and to attempt alternative routes to care if they are not satisfied with what they are told. This can include advice to seek a second or specialist opinion, or to demand attention and recognition of their fears.

One mother posted a message asking how long she should wait before phoning the out of hours service about her 2 year old son who was constipated and in pain. She wasn’t sure if the problem was even ‘doctor worthy’ at all. It had been going on for a couple of days and the child was lethargic and shivery. As in the example above, many of the responses advised the poster to seek medical advice, and again they emphasised the potential urgency of the situation based on experience:

> I would take him to OOH. He may need a glycerine suppository/ lactulose/ some numbing cream to help him pass it - my [son] had something similar when he was 2.5, and it caused us problems for months as he got a tiny fissure when he eventually passed it, and it scared him so much he ended up chronically constipated. I don’t mean to scare you, but it might be best to see someone. Hope he’s all sorted soon.

In this case the mother did phone the out of hours service the next day (Sunday) and the child was seen by a paediatrician and given a prescription. She also took him to her own GP on Monday. She continued to update on the child’s progress and by Tuesday there was no obvious improvement. At this point, others began to suggest that she should ask for further assessment:

> Maybe he is impacted higher up, I think I would bring him back to GP as they really should scan him to check.

> I would ask your GP to arrange for you to be seen at your local children’s dept today. It has gone on for too long now, for both of you. [...] Maybe he needs to be assessed by a paediatrician again.

The discussion continued over the following ten days, with the opening poster updating on progress but remaining worried that the problem was not resolving. At this stage the advice to seek access to more specialist help was stronger:

> I think you need to bring him back again to hospital, they need to find the reason for this[...] Bring him to hospital and demand they do a scan and investigate this further.

> I’d just go and sit in a&e with him, refuse to move till he’s been scanned and they can help make him more comfortable.

> There should be a constipation and soiling service in your area, and he needs assessing by them. I think he may need assessing by a paediatrician, if you do need to go back to A/E, then ask to see a paed.

The opening poster was ambivalent about this advice:

> God! Do you all really think so?? At this rate he’ll be traumatised by doctors. We’d be hours waiting too. Might ring nhs direct and see what they say. Will be OOH again though, it always is with a child. Our OOH is in the hospital. Last time saw nurse practitioner only. Could insist on seeing a doctor I suppose. [...] A&E though? Really?
Again one parent reinforced their advice to persist in seeking care based on experience:

My daughters both grew out of it but both had very bad phases, [eldest daughter] was under the hospital for it and it lasted about 2yrs, [younger daughter] was just under the doctor as I was much more forceful with them and had experience and hers lasted 8mths.

This suggestion here that being ‘forceful’ resulted in a better outcome for a child supports the idea that being persistent in seeking care is the right thing to do. In the context of internet use in parental decision making, Burrows and Nettleton have suggested that:

Parents are not prepared to accept uncritically the views and advice of health professionals or the results of studies which are published in learned scientific journals. They are keen to seek advice from a range of sources and listen to the views of other non-professionals whose observations are based on experiential “evidence” (Burrows & Nettleton 2002: 262).

A readiness to challenge professional expertise on the basis of experiential knowledge is apparent on Mumsnet.

Advice to self-care

‘Self-care’ is a term that has not been clearly defined in theoretical literature (Wilkinson & Whitehead 2009). It is most commonly used in relation to the management of chronic illness, but here it is used to mean taking measures to treat symptoms at home without seeking a medical consultation. A study by Porteous and colleagues (2006) found that self-care was respondents' preferred method of managing minor illness, and it is well-recognised that the majority of symptoms do not lead to a medical consultation (Hannay 1979).

The longest thread in the sample of discussions was started by a mother who asked for advice on how to ease the itch of chicken pox. It was generally recognised by those who responded that this was not something for which parents should seek medical attention; in fact parents actively discouraged each other from going to GP waiting rooms where there may be vulnerable or immune-suppressed patients. Instead, parents shared tips on how to manage the illness at home, including the best creams and lotions to use:

Pharmacist recommended Eurax to [husband] but don't know if it's any good cos [daughter] wouldn't stand still long enough to apply it! So back out for poxclin it's miracle stuff smeared on in seconds all over body bit longer to soak in. [Daughter] said it wasn't too bad never one to admit mummy knows what she is doing. No itching though and no screaming about it stinging like with the calamine and Eurax. She also managed some sleep which is good.

However, in this thread there was quite a lot of discussion about the ineffectiveness of some pharmaceutical remedies, and while many parents did advocate the use of particular creams and lotions, there was also considerable sharing of non-medical tips and remedies for dealing with the illness. As in previous examples, parents drew largely on their own experience in advising others.

I was advised to use virasoothe by the pharmacist but it didn't help at all. On day 3 she was so itchy and uncomfortable even after a dose of piriton I decided to try Lanes tea tree and witch hazel cream on each spot (I had some left over from treating my son's Molluscum Contagiosum) put some tea tree face wash in her bath. Worked instantly!

Porridge oats in the bath worked great for us. Put them inside an old pair of tights. You can then use it to bathe them too.
Get loads of tubs of bicarb also brilliant in the bath. When [daughter] had it terribly we spent a few nearly whole days with her in the bath watching dvds on the laptop.

Of the threads looked at in this study, this is the discussion which most resembled a ‘support group’ as it continued for over a month, and many parents whose children were suffering from chicken pox joined in, updating each other on progress, advising each other about what symptoms to watch out for and sharing what treatments and distraction techniques were working well for them.

However, even this discussion was not completely free from mentions of risk, and it was clear that some parents didn’t feel confident in diagnosing and treating the illness themselves. One mother whose daughter had been quite unwell and feverish with chicken pox wrote:

I read a terrifying article about a little boy who died from chicken pox because the parents thought he would get better and were fobbed off repeatedly by their GP's receptionist and he developed pneumonia. It was too late by the time he was treated in hospital.'

Others responded to the mother advising her to call her GP or NHS Direct if she was worried, and not to Google any more stories about chicken pox.

Discussion: Parental decision making and online support

Decision-making around caring for a sick child is not straightforward and many parents go through a range of actions such as home care, using over the counter remedies and seeking peer advice before accessing formal health care, as has been discussed by Cunningham-Burley and Irvine (1987) and Houston and Pickering (2000). In those studies, mothers were keen to take responsibility for their children’s health themselves and the decision to call a doctor was not taken lightly. They learned from experience of previous illnesses and generally recognised themselves as experts in their children’s health. However, Houston and Pickering noted the impact of fear on decision making when dealing with a sick child and how parents’ usual confidence and coping abilities could be undermined, leading them to worry about whether they were ‘doing the right thing’. This indecision and worry can be seen in some of the discussions on Mumsnet, along with concerns about burdening health services, and an awareness that by seeking medical advice one may be labelled as an ‘over-sensitive mother’. A further consideration when deciding to seek care is a concern not to submit children to unnecessary medical attention, as expressed by the mother of the constipated toddler who she feared would be ‘traumatised by doctors’. Houston and Pickering also recognised ‘the social isolation of looking after a sick child’ (Houston & Pickering 2000:239) and the importance of support from family, friends and neighbours. The parents posting in the thread about chicken pox frequently commented on how grateful they were for the support available on Mumsnet, especially as many of them were reluctant to go out in public or to see friends and family while their children were contagious.

It is clear from reading discussions on Mumsnet that for some parents it is the first port of call for advice when making decisions about their children’s health. This raises an interesting question as to why this might be. Although there are healthcare professionals who are members and occasionally post advice in a professional as well as peer capacity, the majority of users are not medically trained. It has been suggested that the nature of the internet blurs the boundaries between lay and professional audiences, and that the unregulated space of the internet allows diversity in the models of health about which information is available (Hardey 1999). A site like Mumsnet allows space for the sharing of lay knowledge about self-care and alternatives to medical treatment, as well as first-hand
experience of medical care, including specialist care. The parents who offer advice are drawing on an attractively diverse range of knowledge; personal and professional, derived from their own experiences and those of others. The way that an online forum allows people to access a broad range of opinion is similar to that described by Borkman in relation to face-to-face support groups:

*By pooling the experience of a number of people, the common elements of the problem and attempts to cope with it emerge, while simultaneously highlighting the uniqueness of each individual’s situation. Consequently, the individual learns how his [sic] problem is both similar to and different from that of others, which forces him to utilize the knowledge selectively to fit his situation. Similarly, the group is protected against inapplicable knowledge that is too idiosyncratic or peculiar because a number of people rather than just one or two persons are pooling their knowledge (Borkman 1976: 450-51).*

Hine has suggested that, in the Mumsnet discussions she analysed, ‘personal experience was evaluated on a par with, and often favoured over, formal scientific knowledge’ (Hine 2012:15). Mumsnet is a female dominated community, and a feminist critique of medicine holds that ‘women’s own experience is devalued by comparison with that of doctors’ expert ‘knowledge” (Doyal 1994:145). Significantly, Madge and O’Connor have argued that the virtual space of online communities allows women to ‘bypass dominant health discourses and power relations’ (Madge & O’Connor 2006:210). In addition, the advice offered on Mumsnet is frequently very specific, actionable advice. Pedersen and Smithson (2013) link this ‘straight-talking’ style to the middle-class demographic on the site and suggest that this is more important to Mumsnet users than the sort of ‘mere sympathy’ offered by other parenting networks.

In research by Nettleton and colleagues, respondents stated that they would not seek or trust information from chat rooms as ‘it’s only an opinion’ (Nettleton et al 2005: 983). However, as the authors point out, this ‘does not reveal any underlying truth’ but is an example of how people construct themselves as ‘careful, discriminating’ and ‘sensible rather than opinionated and misguided’ (Nettleton et al 2005:983). On Mumsnet, parents do occasionally acknowledge the fact that they are seeking advice from potentially unreliable sources, for example the mother of the constipated toddler explained her decision to seek help from ‘complete strangers’ on the forum as being due to ‘sleep deprivation’, which suggests that it is somehow out of character. However, the fact that other users are ‘strangers’ maybe a considerable attraction, as it allows parents to ask questions and seek help without fear of being judged or typecast (O’Connor and Madge 2004). Research into the use of parenting information accessed via online communities has highlighted that parents seek advice from a range of sources, both on and offline, and make decisions based on an evaluation of information from all sources (O’Connor & Madge 2004). The diversity of responses allows parents to exercise choice over what advice to follow, and although discussions can take place in real-time, they are often asynchronous, allowing parents time to weigh up advice and discuss it rather than being told what to do in a hurried appointment. Poor advice can be challenged by others, offering further protection and potentially enhancing the degree to which people may feel they can trust what they are told.

**CONCLUSION**

Parents can easily seek the advice of healthcare professionals from a wide range of reliable sources including NHS 111 (previously NHS Direct) or NHS 24, and so it seems evident that they are looking for something else when they choose to seek advice online. I suggest here that it is the experiential knowledge and the support offered by their peers that they look for.
and value. It has been proposed that this attribution of worth to experiential knowledge may be in part a reaction to the specialisation and expropriation of knowledge in modern scientific systems (Williams & Calnan 1996: 1616). It may be that online forums offer a way for people to reassert control over knowledge and over how it is used in everyday life. In addition, advice may be more acceptable to people when it is ‘personalized to the individual’ and ‘appears to come from and be directed to similar individuals (i.e. those with a shared social identity)’ (Sillence et al 2006: 699). On Mumsnet, there is a high degree of personalisation of advice and there is a strong sense of a shared social identity primarily through the common experience of parenthood, but also perhaps due to the relative homogeneity of the membership as discussed above. Previous research using Mumsnet has noted that the website was a ‘friendly non-judgemental space’ (Skea et al 2008: 1388), though this view has been to some extent challenged by others (Pedersen & Smithson 2013). Nevertheless, personal relationships can develop online ‘that are absolutely real and meaningful even in the absence of physical, touchable matter’ (Pacagnella 1997: Page N/A, original emphasis). There is no suggestion that these online relationships are a replacement for face-to-face support networks (O’Connor & Madge 2004), however it is clear that significant online support is being sought by, and offered to, parents when making decisions about their children’s health and that these networks are a source of valued experiential knowledge. Online networks can operate in a similar manner to offline lay referral networks in both urging and sanctioning help-seeking behaviour when parents are making decisions about their children’s health.
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