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Internet use for family carers of people with intellectual disabilities: A literature review and thematic synthesis

Sue Caton (1), Emma-Reetta Koivunen (2), Callum Allison (3)

Corresponding Author: Dr Sue Caton, Research Fellow, Faculty of Health, Psychology and Social Care, Manchester Metropolitan University, Brooks Building, Birley Campus, Manchester, M15 6GX
s.caton@mmu.ac.uk

(2) Dr Emma-Reetta Koivunen, Research Associate, Department of Nursing, Faculty of Health, Psychology and Social Care, Manchester Metropolitan University, 53 Bonsall Street, Manchester, M15 6GX. Email: e.koivunen@mmu.ac.uk

(3) Mr Callum Allison, callumrhysallison@gmail.com

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Abstract

Being a family carer can be rewarding, but can also lead to mental and physical exhaustion as well as feelings of social exclusion and isolation. Research has shown that use of the internet and online forums can provide an immediate place to find information and reassurance and that forum use can be an empathetic place to share experiences and seek emotional support. This paper details a systematic literature search of research on carers of people with intellectual disabilities and /or autism using the internet. A thematic synthesis of the resulting papers identified that online forums gives carers a sense of agency by providing a place to go for informational support that may not be elsewhere. Carers also enjoyed the safe community of solidarity and emotional support that online forums provide. An important finding is the lack of published papers in this area with the inclusion of just eight papers.

Introduction

This paper reviews the published literature exploring how use of the internet can help in navigating the experience of being a carer of a person with intellectual disabilities. The introduction begins with a short overview on the experience of being a carer, moving on to how using the internet has been shown to be able to provide support to people experiencing a range of life experiences. Finally, the introduction briefly explores how use of the internet may be beneficial for carers.

Being a Family Carer

A carer is defined as "anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support" (Carers Trust, 2018). Worldwide data shows that for people with intellectual disabilities, it is families that continue to be the primary providers of care (Braddock et al, 2013; Cummins, 2001; Mansell, 2010). Being a carer can be gratifying and allows the construction of bonds between the two individuals to become strong (Baum, 2004; Sullivan and Miller, 2015). Cohen et al. (2002) found that carers felt a sense of companionship, that caring was rewarding, and an enjoyable activity rather than a chore.

However, research that has explored the experience of being a carer for people across a range of health, disability and mental health needs has primarily focused on the burden on quality of life for carers. Caregiver burden harbours a number of negative sub-concepts such as grief, mental and physical exhaustion and social isolation (Miller et al., 2017). Social support can become neglected when giving care to others; the intensive nature of caring may lead carers to feel socially isolated. Caring can sometimes cause resentment towards the cared for (Woodford et al., 2018) and can prevent carers from enjoying free time and often they will give up employment (Brodaty and Donkin, 2009). Del-Pino-Cosado et al. (2018) highlight that there was a negative relationship between perceived social support and subjective caregiver burden. Family carers often make financial sacrifices in order to fund the care of a relative (Lai, 2012). Employment can be difficult due to having to attend multiple appointments, unusual time demands and necessary childcare (Ryan and Runswick-Cole, 2008; Shearn and Todd, 2000) and without employment, carers do not benefit from added entitlements associated with employment such as paid leave (Schulz and Eden, 2016). Those carers that do work, often do so in part-time, poorly paid work of low status, or in full-time work which can lead to stress from the dual demands of home and work (Shearn and Todd, 2000). Emotions are profoundly affected when caring; distress can be caused by problematic encounters with professionals (Todd and Jones, 2003) and the severity of the symptoms of the person they care for (van der Lee et al., 2015). The mental health of the carer can often be affected due to the situational factors of caring such as decreased social time and less time for hobbies.

Parents of children with intellectual disabilities and autistic spectrum disorder (ASD) have been shown to be significantly economically disadvantaged (Emerson, 2003) and experience higher levels of stress than parents of other children (Meaden et al 2010; Sivberg, 2002; White and Hastings, 2004). Mothers of children with intellectual disabilities experience a social and psychological impact (Emerson, 2003) and Baker et al, (2003) have suggested that the presence of higher levels of child behaviour problems amongst children with developmental delay is related to increased parental stress.

White and Hastings (2004) found that parents' (of adolescents with severe intellectual disabilities) perceptions of the helpfulness of informal sources of support have the most consistent associations with parental well-being. Carer support groups (offline) are popular; according to one study, two-thirds of families of children with autism have participated in support groups (Mandell and Salzer, 2007). Support groups can provide carers of people with autism with additional help that they may not receive elsewhere and can be an important source of instrumental, informational and emotional support for parents, siblings and other family members (Meaden et al, 2010). Support groups run by parents of disabled children have been shown to increase both a sense of power and a sense of belonging for parents (Law et al, 2001). Smith et al. (1994) explored reasons why parents of children with special needs might use support groups and found a preference for the emotional support aspects rather than information sharing and teaching. However, despite these benefits, childcare and transport can be barriers to accessing groups (Ryan and Runswick-Cole, 2008; Smith et al. 1994), as can lack of time (Loane and D'Alessandro, 2013) which suggests why online support groups might be preferred by some carers. The next section explores the use of the internet for both support and convenience with everyday activities.

Online Communities as Peer Support

The development of online communities first stated as mailing lists or message boards but now include social media (for example Facebook, Twitter) and online forums (such as national news forums, parenting forums such as Babycenter and Mumsnet and travel forums such as Tripadvisor). These communities are used by wide-ranging groups of people in areas as diverse as discussions on sport, gaming, travel information and advice, health information and advice and a for a variety of long-term chronic conditions.

People use online forums for information, education (Ryan, Haroon and Melvin, 2015) and for emotional support (Mo and Coulson, 2014; Moore and Ayers, 2016; Bar-Lev, 2008). In terms of health, Lewis et al (2010) found that people with obesity search online materials for solutions to being overweight as well as using a support forum to share their experiences. Likewise, Mo and Coulson (2014) found that those with HIV/AIDs appreciated online support groups because they provide first hand experiences and reassurance that other people have experienced similar issues.

The anonymity of online forums have been found to be attractive to people with mental health problems (Chan et al., 2015) and male infertility (Hanna and Gough, 2016) as is the immediacy of support to both those with mental health problems (Chan et al, 2016) and those who lost friend or relative due to suicide (Bailey et al, 2017). The convenience of access from home can mean that for some support such as for weight loss, online forums can provide better support than face-to-face help (Hwang et al, 2011). For those living in rural areas, gaining online connections is beneficial as it may be otherwise difficult to find (Griffiths et al, 2017). Chan et al (2015) found that forum use can help participants understand and empathise with others in their positions or to help deal with rejection that they felt from people in real life (Bailey et al, 2017).

Despite these advantages, online communities can also have drawbacks. Lack of quality control, lack of trust and reduced applicability of general information to specific circumstances have all been identified as reasons for parents of children with ASD to avoid the internet (Gibson et al, 2017). Sharing of misinformation can be problematic (Bailey et al. 2017; Nasland et al, 2016). Indeed, a cycle of misinformation can build in an online community as suggested by Terbeck and Chesterman (2012) who found when parents wanted feedback following being told by specialists that their child does not have ADHD, 87.6% of the responses that the parents received from other members of an online forum reinforced the negative attitude towards the professional’s judgement. However, the evidence for the benefits on online peer support appear to outweigh the potential risks (Nasland et al, 2016).

Internet Use for Carers

Focussing specifically on internet use for carers, it has been shown that that forums are used for information and education as an adjunct to information given at a clinic for parents of children with ADHD (Ryan, Haroon & Melvin, 2015). Use of the internet by carers of older people, including those living with dementia, has been studied widely. For example, in Topo’s (2009) review the studies focused on benefits from ICT-mediated services on the well-being of carers, including “the social, emotional, and information support received and changes in caregiver burden”. Similarly, Boots et al. (2013) in their review found that internet based interventions can improve carer well-being.

Among carers of people who have dementia, many had limited awareness of the illness, its progression and symptoms (Boots et al 2015; Kim, 2015). Wasilewski et al. (2017) studied adult children who were carers of people with dementia and found that information sharing through online forums was a useful way to access information carers were lacking otherwise.

Use of online forums can provide support through connection with other carers, as well as a different source of information. Andréasson, Andréasson, and Hanson (2017) found that online forums can be a form of 'recognition' with other carers. They described accessing online forums as a relief and a way to establish new social relationships and a feeling of 'stepping outside of the shadows' and being ‘seen’ not just as a carer but also as a person (Andréasson et al. 2017). Similarly as others using online communities, their research participants also felt the benefit of flexibility of the online support group, and saw it as complementary to traditional support groups.

Aim and research questions

There has been several reviews about internet use by carers, particularly focusing on carers of older people, especially those with dementia (for example, Topo, 2009). Research about internet use by carers of people with intellectual disabilities has been more limited. The aim of this review is to examine what evidence exists about:

1) How does the use of internet fit into the lives of carers of people with intellectual disabilities?
2) What benefits do carers of people with intellectual disabilities get from using the internet?
3) What problems are carers of people with intellectual disabilities experiencing with internet use?

Method

A database search was conducted in July 2018 using Scopus, Web of Knowledge, PsycINFO, CINAHL and Google Scholar. The search terms used were:

> “learning disabil*” OR “intellectual disabil*” OR “autism” AND internet OR online OR website OR “social media” AND “carer” OR “caregiver” OR “social support”

Citation tracking was used on papers shortlisted for inclusion alongside checking of references included in those papers.

Inclusion and Exclusion Criteria

There were no restrictions regarding research design nor date of publication. The specific inclusion and exclusion criteria were as follows:

Inclusion criteria:

- Papers that empirically explored the online experiences of carers of people with intellectual disabilities.
- Only studies written in English.
- The focus of the search was on intellectual disabilities. However, according to the UK's National Autistic Society (2018), between 44% - 52% of autistic people may have intellectual disabilities and around a third of people with intellectual disabilities may also be autistic. With this in mind, our search included the keyword 'autism' as it is likely that many family carers of a person with an intellectual disability will be seeking information or support on websites and forums aimed at carers of people with autism.

Exclusion criteria:

- Reviews or discussion pieces were excluded.
- Papers that did not explore online experiences were excluded.

- Papers were excluded if they detailed that the children of the family members consisted of fewer than 25% of children with intellectual disabilities (this was the case with the paper written by Clifford and Minnes, 2013).

An initial screen of the titles and abstracts of the studies identified by the database searches was carried out by the third author to determine eligibility. The first author then independently evaluated the full texts of relevant and unclear papers. Decisions about whether to include the unclear papers were made by discussion between authors one and two and reassessment of the exclusion criteria. A flowchart detailing the process of the review is shown in Figure One.

Figure One Here

Quality Assessment

A review of existing literature benefits from using a tool such as the Crowe Critical Appraisal Tool (CCAT) or the CASP Qualitative Checklist to assess the quality of each study prior to inclusion in a review. However, it was clear early on in the search that there was very little research in this area so a decision was taken not to exclude studies based on quality. This approach has been used previously in reviews of areas of research with a small literature base (for example Hutchinson and Bodicoat, 2015). Despite taking this decision, the inclusion criteria ensured that all included papers provided empirical evidence that focussed on the experiences of carers of people with intellectual disabilities.

Analysis

A thematic analysis and thematic synthesis was carried out. An adapted version of the methods described by Thomas and Harden (2008) were used to bring together and integrate the findings of the papers. Thomas and Harding (2008) recommend a three-stage process. The first stage involved coding of the data. Each study was read, codes were attributed to findings and a bank of codes was created as each study was read. This process resulted in a total 19 initial codes (for example 'focus on children', 'emotional support'). The second stage involves the development of 'descriptive themes'. Thomas and Harden's (2008) approach draws on techniques commonly described as thematic analysis. The authors looked for similarities and differences between the codes in order to start grouping them into the initial descriptive themes. For this stage, Webster and Watson's (2002) 'concept matrix' was used to provide structure, clarify concepts and record emerging themes. A draft summary of the findings across the studies organised by the four descriptive themes was then written by Author One. Author Two commented and contributed to the descriptive summary and a final version was agreed. The third stage was the generation of 'analytical themes'. According to Thomas and Harden (2008), the development of descriptive themes remains close to the primary studies while the development of analytical themes represent a stage of interpretation whereby the reviewers go beyond the primary studies and generate new interpretive constructs or explanations. This process is dependent on the judgement and insights of the reviewers and discussion using 'researcher judgement' (Braun and Clarke, 2006) took place between authors one and two to finalise the two overarching analytical themes.

Results

Characteristics of the papers

Eight studies fulfilled the review inclusion criteria; an overview of the studies is provided in Table One.

Table One Here.

The papers were published within a 16-year time-frame, between 2001-2017. Leonard et al (2004)'s research was a quantitative survey-based study, the remainder were qualitative investigations (details of methods are seen in Table One).

The main focal points of the eight studies that were included were:

- use of a social media support group (Cole et al., 2017);
- use of self-published websites (Fleischmann, 2005);
- exploring reasons for using the internet (Gundersen, 2011);
- exploring the functions of an email group (Huws et al., 2001)
- exploring communications on a discussion group (Jones and Lewis, 2001);
- determining the value of an e-mail listserv for parents (Leonard et al., 2004);
- the state and benefits of social support of Facebook support groups (Mohd Roffeei et al., 2015);
- examining how mothers make sense of their experiences online emotional and informational support (Reinke and Solheim, 2015).

Although there was a small number of relevant papers, the context in which the research took place was broad and therefore contains data of worldwide relevance (albeit with a bias towards societies where the internet is easily available in the majority of households). Table One shows the context in which the research studies took place. In three of the papers the geographical location was clear; participants were based in South Africa (Cole et al, 2017), Norway (Gundersen, 2011), and the USA (Reinke and Solheim, 2015). However, in the remaining five papers, the geographical location was less clear as the research was either entirely web-based (Fleischmann, 2005; Huws, 2001) or the study location was implied rather than made explicit for example Jones et al. (2001) was a web-based study but reference was made to participants posting messages outside of working hours implying that they were UK based (the geographical location of the authors). Similarly, Mohd Roffeei's study used national (Malaysia) Facebook Groups suggesting participants were based in Malaysia. The context of the studies is made more complex because while participants may be geographically located in one country, they may have been using online resources that are predominately used by users from a different country. For example, this was the case in the Gundersen (2011) study where participants were geographically located in Norway but made reference to the use of US forums.

The overall number of participants was not possible to record as some studies used messages posted on chat forums (thousands) while other papers used small numbers of interview participants. Details of participants in the included studies are detailed below (also included in Table One):

- mothers of children with ASD (Cole et al, 2017; Reinke and Solheim, 2015
- parents of children with autism (Fleischmann, 2005; Huws et al., 2001);
- parents of children with rare genetic disorders (Gundersen, 2011);
- parents of people with Down Syndrome (Jones and Lewis, 2001);

- parents and carers of people with Rett Syndrome (Leonard et al, 2004);
- members of two Facebook groups for parents of people with autism (Mohd Roffeei et al, 2015);

As explained above the decision was taken to include papers that focussed on carers of people with ASD because of the likelihood of the presence of intellectual disabilities. However, the fact that five of the eight papers focussed specifically on carers of people with ASD highlights the paucity of research that solely focussed on the experiences of carers of people with intellectual disabilities.

Following Thomas and Harden's (2008) method of analysis, the findings are presented as a thematic synthesis with four descriptive themes and two analytical themes.

Descriptive Themes

Webster and Watson's (2002) 'concept matrix' was used as a tool in the development of the 'descriptive themes' (Thomas and Harden, 2008) to clarify concepts that featured in the included studies; shown in Table Two. The descriptive themes are: *Informational Support (8 papers), Emotional Support (8 papers), Filling the Gaps (8 papers),* and *Problems (5 papers)*

Table Two Here

Informational Support

All eight papers confirmed that the internet provides informational support for carers of people with intellectual disabilities. One parent in Gundersen's (2011) study said the internet was her number one asset as it gives all the information and knowledge she needs to cope. Furthermore, Leonard et al (2004) found that parents joined an online support group primarily for seeking information (82%) and Mohd Roffeei et al (2015) found that the highest percentage of messages in the two Facebook support groups they examined dealt with informational support.

Carers used the internet to find general information about a condition (Fleischmann, 2005) including causes and cures (Huws et al, 2001) and also more specifically information about how to support the person they cared for in terms of communication, behaviour, feeding (Cole et al, 2017), the child's management and education (Leonard et al, 2004) advice, referral to experts, (Mohd Roffeei et al, 2015) and about medication and comparing symptoms (Cole et al, 2017; Leonard et al, 2004).

Reinke and Solheim (2015)'s participants explained that information seeking is an ongoing part of their lives; as their circumstances change, there are more ideas to search for. Indeed, as Gundersen's (2011) study suggests, as parents adjust, so do the frequency and purpose of their internet searches. Using online informational support can mean that carers become knowledgeable about the condition and/or expectations of the person they care for which leads to a gradual comprehension and management of a situation that can initially seem unmanageable (Gundersen, 2011; Huws et al 2001).

In one study (Cole et al, 2017), a speech and language therapist was part of the online support group and this was welcomed by participants who considered that a professional was able to give informational support and could validate other people's information (Cole et al, 2017).

Emotional Support

Emotional support found from other carers online was a theme in all eight of the papers reviewed. After information seeking, Leonard et al (2004) found that the second most common reason that parents joined an online support group was to share experiences with others, followed by emotional support, making friends with other parents or carers and to share feelings. Mohd Roffeei et al's (2015) study also found that the second highest percentage of messages in the Facebook groups they examined were related to emotional support. When asked for reasons for recommending the online service to other parents, the most common reason given by users was emotional support (Leonard et al 2004). Similarly, Cole et al (2017)'s participants referred to emotional support as a core function of the group.

Reinke and Solheim (2014) looked at how parents of a child with ASD would search and look for online support to assist them. Through the online platform, nearly all participants expressed how being connected with other parents of children with ASD was deeply valuable and offered them a safe space where other people would fully understand them. The closed groups were described as being a comfort zone, a place to share, be honest and not be judged. Gundersen (2011) found that other parents immediately understood what each carer had to deal with and that they found it helpful to have a place to share thoughts and vent emotions without risking negative reactions. Indeed, the group in Jones and Lewis (2001)'s research was often described as a family and seemed to share many of the functions of such a close relationship. In the research by Huws et al (2001), carers demonstrated concern and were caring towards each other with shared understandings and reciprocating concerns. Parents used the list as a place to come to terms with a diagnosis, for emotional support, encouragement and to share experiences.

The studies also found that carers helped others by sharing personal experiences. Participants both received and provided support (Reinke and Solheim, 2015). In both Huws et al (2001)'s and Fleischmann (2005)'s studies, coping with and making sense of autism was a central theme. In Fleischmann's (2005) study, the parents who had come to terms with their situation were willing to reach out and help others and this was sometimes the rationale for building a website in order to reach out to the community and support parents of children with autism who are still in the early stages of coping.

As well as providing emotional solidarity around the difficulties of caring for a child with intellectual disabilities, Jones and Lewis (2001) also identified a theme of celebration and positive affirmation (for example, new members were congratulated on the birth of their child), where the child was seen before the disability and there was a sense of hope and optimism amongst members.

Filling the Gaps

A theme across all eight papers reviewed was that internet use was filling the gaps that 'real life' was leaving for carers of people with intellectual disabilities.

Research participants liked to use the internet because it was a positive experience; it was convenient (Cole et al, 2017; Jones and Lewis, 2001; Leonard et al, 2004; Reinke and Solheim, 2015) and has the benefits of instant contact (Cole et al, 2017; Jones and Lewis, 2017; Reinke and Solheim, 2015) and information being available at any time, day or night (Huws et al, 2001). Moreover, Jones and Lewis (2001) found that in a Down Syndrome support group, 73% of the 77 messages asking for help were posted outside working hours (i.e. when it would have been difficult to get other help from professionals). The convenience of using the internet was also supported by the research by Leonard et al (2004) who found that those not in the workforce and those living in rural areas spent more time accessing the online support group. Likewise, Reinke and Solheim (2015) found that limited resources, limited time and geography can sometimes prevent real life connections of people with similar experiences so the online community filled that gap.

Participants from the studies used the groups for extra support aside from that given ‘in real life’ from both friends, families and health professionals (Fleischmann, 2005; Cole et al., 2017). This was raised in the papers as happening both in terms of the informational and emotional support already discussed.

In terms of informational support, Huws et al (2001) found that parents often face difficulties obtaining the help they need. By using the online community to exchange up-to-date information, the inadequacies of receiving help elsewhere are overcome. For some parents or carers, a reason for using online resources was that when their children have a rare disorder; they commonly sensed that doctors had limited information to share, providing the motivation to search online (Gundersen, 2011).

In terms of emotional support, the rapid availability of connections (Jones and Lewis, 2001) is a key way in which the internet use was filling the gaps left open in real life. Huws et al (2001) found that the email group provided opportunities for parents to write about the experiences they faced and how they understand, interpret, transform and live with these experiences. Huws et al (2001) concluded that “parents appear to be motivated by the need to share their stores, or to utter their thoughts aloud without addressing any person in particular.” (P.580). Huws et al (2001) found that many parents were encountering difficulties with real life family and friends who were not always supportive and Reinke and

Solheim (2015)'s participants talked about how mothers online were said to understand more about their lives than their child's treatment team.

Cole et al (2017) found that the use of a social media group provided ongoing support to parents of children with ASD. They suggested that the group may have clinical significance for use by practitioners as well as the creation of similar groups on other platforms, to help fill some of the gaps in real life.

Problems

The final theme, 'problems' was identified in five of the eight included studies. The studies, as a group, primarily focussed on the benefits that using the internet can bring to carers (there was an emphasis on support hence why some papers did not feature the 'problems' theme), however problems with using the internet and/or online communities for carers was raised a number of times.

It is self-evident that participants found that there was an overwhelming amount of information on the internet (Reinke and Solheim, 2015) and that it can be both challenging and time-consuming (Leonard et al , 2004; Reinke and Solheim, 2015) for carers to find information that applied to their specific situation (Reinke and Solheim, 2015). Carers felt that they could never finish looking for information online (Reinke and Solheim, 2015). For those participants who took part in online communities, the communication could overload their email account (Leonard et al, 2004) and misinformation from other members of the community could be problematic (Leonard et al, 2004).

Gundersen (2011)'s participants revealed that seeking information online can risk exposing oneself to potentially frightening information about the condition of the person they care for which can increase rather than ease emotional distress. Similarly, Cole et al (2017) found that participants referred to occasional negative discussions that meant there was no escape from negativity. Jones and Lewis (2001) also reported that although internet use was mostly positive, sometimes arguments develop resulting in negative feelings from parents. Reinke and Solheim (2015) describe how sometimes there was tension between parents with more negative attitude and those with more positive attitudes; this could mean that it became difficult to post positive messages about children meeting milestones and accomplishments because they did not want to boast to other parents who might be struggling.

Analytical Themes

Following Thomas and Harden's (2008) method of thematic synthesis, the descriptive themes have been further synthesised to develop two analytical themes or interpretive explanations of the included papers. The two analytical themes are 'agency' and 'solidarity'.

Agency

Carers of people with intellectual disabilities are confronted with an unknown destiny (Gundersen, 2011) and as such it is important that informational support was mentioned as the most common kind of online support sought by participants by both the Leonard at al (2004) and Roffeei (2015) studies. Using the internet for informational support was reported to allow carers to be active participants in providing support to their family member. The internet was referred to as both a time-saver and source of agency and empowerment which enabled access to information to make informed decisions (Leonard et al 2004) and help prepare carers for advocating for their child in meetings with professionals. In this respect, knowledge gained through online informational support gave carers a sense of power (Reinke and Solheim, 2015). This was also an important finding in Gundersen's (2011) research who referred to a parent who armed himself with information prior to meeting healthcare professionals, "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" (Gundersen, 2011 p. 89). Furthermore, in Gundersen's (2011) study, parents used the internet to search for information and a diagnosis. Once a diagnosis was received, the internet was used again to search for more information when it was felt they had not received enough. This active information seeking rather than passive waiting for medical information in the traditional ways was considered beneficial by participants.

Both Gundersen (2011) and Huws et al (2011) demonstrate that this acquisition of information can be a gradual process that makes the situation manageable. Searching the internet, finding the information that other carers have shared around medical advice, training for parents and on the organisation of social events for caregivers (Cole et al) meant that agency was a crucial element to the benefits of internet use for carers of people with intellectual disabilities.

Solidarity

At its core, the descriptive theme of emotional support was primarily about emotional solidarity. The reviewed papers have shown that parents want emotional support in a safe space from people who understand. The shared identity is important and the 'filing the gaps' theme demonstrated that extra support is often sought aside from that which real life friends and family are able to give (Cole et al, 2017; Huws et al, 2001; Fleischmann, 2005).

Taking the theme of 'solidarity' further, the Jones et al (2017) study highlighted that the pathological model that carers are often initially presented with is not always considered appropriate and can be offensive to a lot of carers. Online spaces can be a place where carers meet like-minded carers and can enable activism. Additionally, the pathological or medical models do not always have room for optimism and the studies have shown that online communities can be a place where carers find positivity and a sense of celebration. The online communities were shown to be spaces where stories were told, experiences were shared, virtual hugs and kisses were sent (Fleischmann, 2005; Huws et al, 2001; Mohd Roffeei, 2015).

Discussion

The findings have shown that for family carers of people with intellectual disabilities the convenience of being able to seek support online at any time can be both important and incredibly valuable. The studies demonstrate that online sources of information and emotional support are often filling gaps that carers are not able to get elsewhere.

The value of being able to find informational support online was a universal finding. Family carers appreciated the ability to consult with like-minded parents about their knowledge. The ability to find information online was also considered to be essential in a parents ongoing need to be prepared before meetings with the many professionals they encounter. Ryan and Runswick-Cole (2008) refer to the necessity of having to fight and advocate for rights of a disabled child and the findings from the papers in this review suggest that using the internet to gain knowledge and therefore power (Reinke and Solheim, 2015) was an important factor in motivation for internet use. Parents did not want to be passive in waiting for information and saw information-seeking as an ongoing part of their lives with a child with intellectual disabilities.

The idea that using online forums gives participants power alongside a freedom to use that resource at their convenience is how the analytical theme of agency developed in this synthesis. Bandura (1989) states that “among the mechanisms of personal agency, none is more central or pervasive than people’s beliefs about their capabilities to exercise control over events that affect their lives” (p.1175). The accessibility of information and support enables carers to exercise control over potential threats (Bandura, 1989). In turn, the increased information and agency can lead to improved outcomes for the people being cared for (Bader and Braude, 1998).

The studies also explored the importance of emotional solidarity that is to be gained online. Close relationships are formed in safe spaces with other people who understand their situation and experiences and where they will not be judged. The studies identified that carers enjoy both giving and receiving emotional support which helped with their journey in coming to terms with their situation. The role and importance of solidarity embraced the findings of the papers reviewed and was hence used as the second analytical theme. Since the publication of the most recent papers reviewed here, online solidarity and activism amongst carers of people with intellectual disabilities and/or autism has increased significantly. In the UK, the avoidable death of 18 year-old Connor Sparrowhawk in 2013 led to a swelling of solidarity and the growth of a social media campaign #JusticeforLB (Ryan, 2017). Since then, social media has been used regularly to campaign for social justice (for example in the UK, following the death of Danny Tozer and 'Bethany's Dad' campaigning for better treatment of his daughter).

This small pool of evidence suggests that carers of people with intellectual disabilities are gaining informational and emotional support that is filling the gaps from 'real life'. Leonard et al (2004) raised the point that online communication by carers warrants attention from health professionals. Reinke and Solheim (2015) suggested that the findings can be used to inform ways clinicians and healthcare professionals can improve their own online support services and resources.

A striking finding of this review is that the majority of the included papers (five out of eight) focussed on carers of people with autism. As stated in the 'inclusion criteria', it is estimated that around half autistic people may have intellectual disabilities and around a third of people with intellectual disabilities may also be autistic (NAS, 2018), so it was important not to exclude these papers from the review. However, the focus on intellectual disabilities is currently missing from published evidence and it would be interesting for future research to explore this further. In addition, most of the papers focussed on parents of children (aged under 18). There is a lack of evidence on the online lives of carers who are caring for adults with intellectual disabilities and/or autism and also about the experiences of carers who are not parents. Meaden et al (2010) found that (offline) support groups are a useful resource for families, parents and siblings but how carers of people with intellectual disabilities other than parents use online communities has not been explored to date.

While most of the research covered in this review has been related to how online communities can benefit carers, the review of the literature presented here also intended to cover wider internet use. The internet has made a difference to the lives of carers with the advent of online shopping, instant access to information from websites, online banking and services. However, research on these topics is limited. Blackburn and Read (2010) discuss findings from a survey with parents of children with disabilities, and among the uses of internet they listed shopping, leisure and entertainment (in addition to caring related internet use). More in-depth understanding of the importance of this for carers would be beneficial. Another benefit of carers engaging with online resources is that by improving their own internet skills and awareness, carers can also better support internet use by the person they care for (authors, in submission).

There has been a great deal of research exploring experiences of carers using the internet, in particular online forums. However one of the most important findings from this review was the lack of research in the area of carers of people with intellectual disabilities. It could be argued that the experiences of carers of people with intellectual disabilities is likely to be similar to that of other carers, in particular those caring for people with conditions such as dementia where they might be providing ongoing support and attention to the people they care for. For those caring for people with intellectual disabilities, the length of time of being a carer is likely to be longer than it is for carers of people with other conditions. Access to information over the years of caring as situations and needs change is important (Reinke and Solheim, 2015; Gundersen, 2011) and this may be a different experience to other groups of carers. Whether the experiences are similar can currently only be judged with the knowledge from these eight papers. In addition, some of the findings presented in the introduction suggest that the anonymity of online forums is important for users (Chan et al., 2015; Hanna and Gough, 2016), but this was not an issue that was documented in the findings from the papers reviewed and this deserves further consideration. Additionally, some of the evidence presented in this review, although valuable in terms of benefits gained, is becoming dated in terms of ways that carers might be seeking online support (such as email support groups) and it would be of interest to further explore social media such as Twitter which has a strong community of carers.

The eight papers included in this review all use data relating to active internet users. Gibson et al (2017) studied information source preferences of parents of people with ASD and found that parents were “ambivalent about the internet and wavered among appreciation, distrust and overload when describing information seeking on the web” (p. 2199). The findings from Gibson et al’s (2017) research suggests that parents may prefer locally-oriented internet sources such as Facebook groups for local organisations but that national organisation websites were the most frequently selected information source. This suggests that parents may not be getting what they seek from online support and could be an area that needs to be explored with further research.

A possible drawback when considering online communities for carers is that despite the convenience of home access, carers are still restricted in time availability. This can mean that their time available to commit to investing in an online community is limited but as the findings from Reifegerste et al. (2017) demonstrate, the amount to which people engage with an online forum influenced overall perceptions of available emotional and informational support. This suggests a ‘the more you put into it, the more you get out of it’ dynamic that may not lead to positive experiences for those with caring responsibilities.

This review aimed to address three research questions. Firstly, ‘How does the use of internet fit into the lives of carers of people with intellectual disabilities?’ The evidence presented that answers this question reveals the essence of why online support can be so valuable to carers. Its convenience, easy accessibility and instant contact with support were key features that fit in with the lives of time-poor carers. Secondly, the review examined what evidence there was around ‘What benefits do carers of people with intellectual disabilities get from using the internet?’ The papers reviewed provide evidence that the internet acts as an exceptionally important resource for those caring for people with intellectual disabilities. This offers carers a different kind of support that is offered via friends, families and healthcare professionals. Online forums and social support websites allow personal experiences to be shared and understood so that parents or family carers can share information, develop a sense of agency and experience a solidarity with people they interact with online as they adjust to their role as a carer. The final research question was examining what evidence there was around ‘What problems are carers of people with intellectual disabilities experiencing with internet use?’ There was less evidence around this research question. The time-consuming nature of finding relevant information, misinformation, emotional distress and tension between carers with different approaches were raised as problems but the overwhelming findings from the studies were about positive online experiences rather than a focus on problems.

Conclusion

This review of published research on internet use for family carers of people with intellectual disabilities has focussed on just eight papers that met the inclusion criteria. The thematic synthesis of the findings from these papers has revealed that the research has primarily focussed on online communities or forum use for parents of young people with ASD and intellectual disabilities. The forum users have been shown, by the included research, to benefit from the agency that stems from the informational support that is not available to them elsewhere. Additionally, the emotional support and resulting community of solidarity plays an important role in the benefits of internet use for carers.

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Table One: Details of Studies Included in the Review

Full Reference	Participants and who they care for	Aims of the Study	Methods	Context	Findings
Cole, L., Kharwa, Y., Khumalo, N., Reinke, J. and Karrim, S. (2017) Caregivers of School-aged Children with Autism: Social Media as a Source of Support. *Journal of Child and Family Studies*, 26(12) pp.3464-3475.	6 mothers with a child with autistic spectrum disorder.	Aimed to explore the use of a social media support group on WhatsApp to provide support to parents of children with ASD between the age of 5-12.	Semi Structured Interviews	Participants based in South Africa	Managing behavioural difficulties and emotional support for caregivers were the core functions of the group and having a professional on the group served as a valuable resource. The use of a social media group provided ongoing support to parents of children with ASD implying that the group may have clinical significance for use by practitioner as well as the creation of similar groups on other platforms.
Fleischmann, A. (2005) The hero's story and autism: Grounded theory study of websites for parents of children with autism. *Autism*, 9(3) pp.299-316.	33 websites self-published by parents of children with autism.	Aimed to examine the experience of having a child with autism and narratives of distress.	Grounded theory analysis of published web content.	No details given regarding nationality / geographical location of website owners.	Coping with autism was a central theme in all of the websites demonstrating a process of moving from devastation regrading diagnosis to being able to help others online. Parents gained knowledge including from surfing the internet – seeking the assistance of other parents in chats and websites established by other parents of children

					with autism. The rationale for building a website was to reach out to the community and to the parents of children with autism who are still in the early stages of coping. The study suggests that the Internet allows stressed parents of children with autism to forge ties among themselves and extricate themselves from their isolation.
Gundersen, T. (2011) ‘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. *Sociology of Health and Illness*, 33, 1, pp 81-95	10 parents of children with rare genetic disorders (9 had an associated intellectual disability)	Aimed to explore parents’ reasons for using the internet and the ways it functioned for them.	Qualitative interviews	Participants were Norwegian but data refer to some participants being members of US forums.	Internet use centered around worries about the child and coping with their own emotions. Parents used the internet to search for information and a diagnosis. Once a diagnosis was received the internet was used again to search for more information when it was felt they hadn’t received enough. Time reduced information seeking but still used when necessary. Finding other parents in a similar situation was comforting. Involvement in online social interactions changed as the parents adapted to their situations. It was helpful for parents to have a place to share thoughts and

					vent emotions without risking negative reactions. The 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.
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, 569-584	Parents of children with autism (6142 messages from 374 email addresses).	Aimed to explore the functions of an email group used by parents of children with autism.	Grounded theory analysis of 6142 messages posted to an international email discussion list.	International email discussion list for parents of children with autism. No details provided as to where most originated.	Parents used the discussion list as a means of making sense of autism. Shared understandings and reciprocating concerns amongst parents was identified as important. The list was used as a place to come to terms with a diagnosis. Emotional support, encouragement and sharing experiences were main functions of the group. The email group provided opportunities for parents to write about the experience they face and how they understand, interpret, transform and live with these experiences.
Jones, R. S. P. and Lewis, H. (2001) Debunking the pathological	Parents of people with Down Syndrome.	Aimed to explore the communications occurring on a 'Down	Content analysis of the daily discussions over a 5	No details given regarding geographical location	73% of the 'help' messages were posted outside working hours demonstrating the

model – the functions of an Internet discussion group. *Down Syndrome Research and Practice*, 6, 3, 123-127		Syndrome Discussion Group'.	month period and over a 2 week follow up period 6 months later.	of participants. However, reference to messages being posted outside of working hours implies an assumption that participants were UK based.	value of the rapid ability to obtain help is a feature of the discussion group. The analysis revealed themes of celebration (positive affirmation), seeing the child before seeing the handicap, hope and optimism, a sense of purpose in life and being like a family within the group. Using the group was mostly a positive experience but sometimes arguments develop resulting in negative feelings from parents.
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, 902-907	Parents of children with Rett Syndrome (N = 199).	Aimed to determine the value of an e-mail listserv (Rettnet) for parents of children with Rett Syndrome.	Survey – closed and open questions on a web based survey.	Worldwide - email listserv established by the International Rett Syndrome Association. However, participants referred to lack of relevance outside of the USA, so majority of participants probably from USA.	The principal motivation for joining Rettnet in 82% was to seek information, while 53% joined to share their experiences with others; 46% for emotional support; 53% to make friends with other parents or carers and 31% to share feelings. Most (81.5%) of the participants felt that Rettnet provided advice concerning the child's management. They also indicated that Rettnet was useful in dealing with their child's education & emotional support. Disadvantages were time taken up, repetition of topics, overloading their

					email account, and misinformation.
Mohd Roffeei, S., Abdullah, N. and Basar, S. (2015) Seeking social support on Facebook for children with Autism Spectrum Disorders (ASDs). *International Journal of Medical Informatics*, 84(5) pp.375-385.	Parents of children with Autism Spectrum Disorders who use 2 online support communities (381 postings).	Aimed to explore the current state and potential benefits of social support within Facebook groups for parents and/or caregivers of children with ASDs.	Deductive content analysis.	Facebook groups – Autism Malaysia and Autism Children Club (nb it is not stated if the Autism Children Club is also connected to Malaysia).	Results indicated that the highest percentage of messages offered dealt with informational support, followed by emotional support. Informational support included posts for advice, referral to experts, situation appraisal, reassurance – often with new information, teaching and announcements with new information and postings to share information about personal experiences. Emotional Support included relational support (relationships), physical/virtual affection (words and symbols for hugs and kisses), sympathy, empathy/understanding, encouragement, prayer, consoling, gratitude, and congratulation. Concluded that health professionals could use information from FB support groups to

					improve their approaches.
Reinke, J. S. and Solheim, C. A. (2015) Online Social Support Experiences of Mothers of Children with Autism Spectrum Disorder. *Journal of Child and Family Studies*, 24: 2364-2373	14 mothers of children with ASD.	Aimed to examine how mothers of children with ASD make sense of their experiences of looking for and subsequenttly finding online emotional and informational support.	Semi Structured Interviews	Participants based in the USA.	Parents are never done information-seeking. It is challenging and time consuming to find information that applied to their situation. Convenient and instant access to the internet for informational support. Being an active participant – the internet as a time-saver and source of empowerment – able to access informational support to help prepare for advocating for their child. Nearly all participants expressed the importance of being connected with other parents of children with ASD. The closed groups were described as being a comfort zone, a place to share, be honest and not be judged. Findings suggest the internet serves as an important source of both emotional and informational support.

Table Two: Concept Matrix

Articles:	Informational Support	Emotional Support	Filling the Gaps	Problems
Cole L, Kharwa Y, Khumalo N, Reinke J and Karrim S (2017)	x	x	x	x
Fleischmann A (2005)	x	x	x	
Gundersen T (2011) ‘	x	x	x	x
Huws JC, Jones RSP and Ingledew DK (2001)	x	x	x	
Jones, R. S. P. and Lewis, H. (2001)	x	x	x	x
Leonard H, Slack-Smith, L, Phillips, T, Richardson, S, D’Orsogna L and Mulroy S (2004)	x	x	x	x
Mohd Roffeei S, Abdullah N and Basar S (2015)	x	x	x	
Reinke and Solheim (2015)	x	x	x	x

Figure 1: Literature Search Flow Diagram