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The role of online groups for autistic people in users' autism information journeys

ABSTRACT

Purpose

The numbers of people with both diagnosed and suspected autism have risen exponentially worldwide over the last few decades. Autistic individuals face significant health and social disparities, including higher rates of poor health, early mortality, and limited access to essential services. Understanding autistic people's information needs and information journeys is therefore crucial.

Methodology

The research was qualitative and consisted of two consecutive studies. First, a sample of posts from an online autism group, made by group users who described themselves as autistic, was generated and analysed using Reflexive Thematic Analysis. Fifteen semi-structured interviews were then undertaken with adults who used online groups for autistic people and stated that they had received a professional diagnosis of autism or were awaiting an autism assessment. Interview transcripts were analysed using thematic analysis.

Findings

The results identified some distinctive information behaviours connected to autism. A descriptive model was developed to represent the information journeys of people with autism. The model shows how people who have been diagnosed with autism, or who are awaiting professional assessment, seek and encounter online information about autism, and the role of online groups for autistic people within users' information journeys.

Originality

This research is the first attempt within the literature to describe and model the information journeys of people who are autistic, or likely to be autistic, and who use online groups to find and share information. This is also the first study focusing specifically on the information behaviours of autistic adults.

Keywords: information behaviour; information needs; information journeys; autism; autistic; neurodivergent; sense-making; online groups.

INTRODUCTION

This paper presents findings from a research project investigating the role of informational support within UK based online groups for people on the autism spectrum. The results described within this paper focus on the role of such groups within the information journeys of a sample of group users, and in meeting the group users' perceived information needs. This project aims to increase knowledge about the information behaviours of adults who are autistic or likely to be autistic, rather than those of non-autistic carers, family members, or professionals who form part of the autism community. This paper includes a novel descriptive model of the information journeys of people who stated that they had been professionally diagnosed as autistic, or were awaiting assessment and likely to be autistic, and who used online autism groups to find and share information. The paper also builds on existing theories of information behaviour to incorporate the social model of disability and demonstrate how differences in communication and social behaviour may influence information behaviour.

BACKGROUND

Within the UK, the National Health Service (NHS) describes autism as a condition where, "… your brain works in a different way from other people…" (NHS, 2022). The term autism, or autism spectrum, is used to describe a range of differences in social communication and interaction, combined with a tendency towards repetitive or rigid behaviours and interests. Sensory differences, such as hypersensitivity, are also known to be associated with autism (MacLennan *et al.*, 2022; Manning *et al.*, 2023; Sibeoni *et al.*, 2022). Autism is a broad spectrum and may sometimes be accompanied by additional language or learning disabilities, and other conditions, whilst Asperger's Syndrome is now considered to be autism, and is no longer used as a separate diagnostic label (Bent *et al.*, 2017; Happé, 2011). In the UK, there has been a shift away from the use of person-first terminology for autism, for example, 'people with autism', towards identity-first terminology, e.g. 'autistic people', following evidence that most autistic people prefer identity-first language (Botha *et al.*, 2023; Kenny *et al.*, 2016). Individual support needs may be classified as 'requires support', which may be 'substantial' or 'very substantial' (Happé, 2011): these definitions have replaced previous functioning labels, such as 'high-functioning', which have been deemed controversial and are no longer part of diagnostic terminology, as individual support needs may vary from low to high, between individuals, and across time and different situations (Alvares *et al.*, 2020; Happé, 2011; Kenny *et al.*, 2016). The numbers of people diagnosed with autism worldwide have increased exponentially over the past 20 years, with some research suggesting a 787% increase in the recorded incidence of autism diagnoses between 1998 and 2018 within the UK (Russell *et al.*, 2022). A marked increase in diagnoses has been documented in many countries, including Sweden, the United States, Denmark, France, Finland, and Iceland (Blenner and Augustyn, 2014; Delobel-Ayoub *et al.*, 2020; Lundström *et al.*, 2015). In addition to the increase in recorded diagnoses, evidence suggests that many more people meet the criteria for a diagnosis of autism, whose autism has gone unrecognised (Lai and Baron-Cohen, 2015; O'Nions *et al.*, 2023).

Autistic people experience very high levels of social isolation, health and social inequalities, suicidality, and premature mortality (Cassidy *et al.*, 2014; Hirvikoski *et al.*, 2016; Veenstra-VanderWeele, 2018; Zahid and Upthegrove, 2017). Autistic people with average, or above average, cognitive ability are more likely to experience mental health problems and suicidality than both the general population, and autistic people with additional learning disabilities (Casten et al., 2023; Hirvikoski et al., 2016; Segers & Rawana, 2014). The risk of suicidality is higher amongst those with a late diagnosis of autism, i.e. in adulthood (Cassidy *et al.*, 2022), and undiagnosed people with autistic traits are significantly overrepresented within suicide death statistics (Cassidy *et al.*, 2022; Mantenuto *et al.*, 2023; Newell *et al.*, 2023; Pelton and Cassidy, 2017). The difficulties experienced by diagnosed autistic people may therefore extend to those who are likely to be autistic but undiagnosed.

There is compelling evidence that autistic people are socially marginalised and excluded in the areas of employment, housing, and living circumstances (Office for National Statistics, 2019, 2022). Within the UK, an ongoing capacity crisis within the services responsible for providing autism assessments for both adults and children has left many people waiting for several years, or unable to access an autism assessment (O'Nions *et al.*, 2023; Rutter *et al.*, 2024). Professional assessment and support services for autistic children and adults have become overwhelmed to the point of national crisis (NHS England, 2023; Rutter *et al.*, 2024) and specialised support services for autistic people following diagnosis are insufficient, or unavailable (Beresford *et al.*, 2020; Brede *et al.*, 2022; Camm-Crosbie *et al.*, 2019; Scattoni *et al.*, 2021).

It is therefore important to research the support needs of autistic people who are sometimes assumed to have low support needs (often referred to as 'high-functioning'), and those of people who are likely to be autistic, even if a diagnosis has not been made. The important role of social support (defined as support provided by non-professional people, within the context of a social relationship or interaction (Gottlieb and Bergen, 2010)) in reducing social isolation, and in improving individuals' health and social wellbeing has been well-documented (Cohen and Wills, 1985; Mezuk *et al.*, 2010; Uchino, 2009). Many autistic people wish for, and benefit from, social support but are also less likely than non-autistic people to receive it (Camm-Crosbie *et al.*, 2019; Hirvikoski *et al.*, 2016; Moseley *et al.*, 2021). Tobin et al. (2014)'s systematic review of autistic adults' social participation, and the links between social support, social functioning, and quality of life, concluded that many autistic adults experienced loneliness and isolation, that informal social support played an important role in improving their quality of life, and that many autistic people wished for more social support and social interaction with others. Hickey et al. (2017) reported that, amongst older autistic adults,

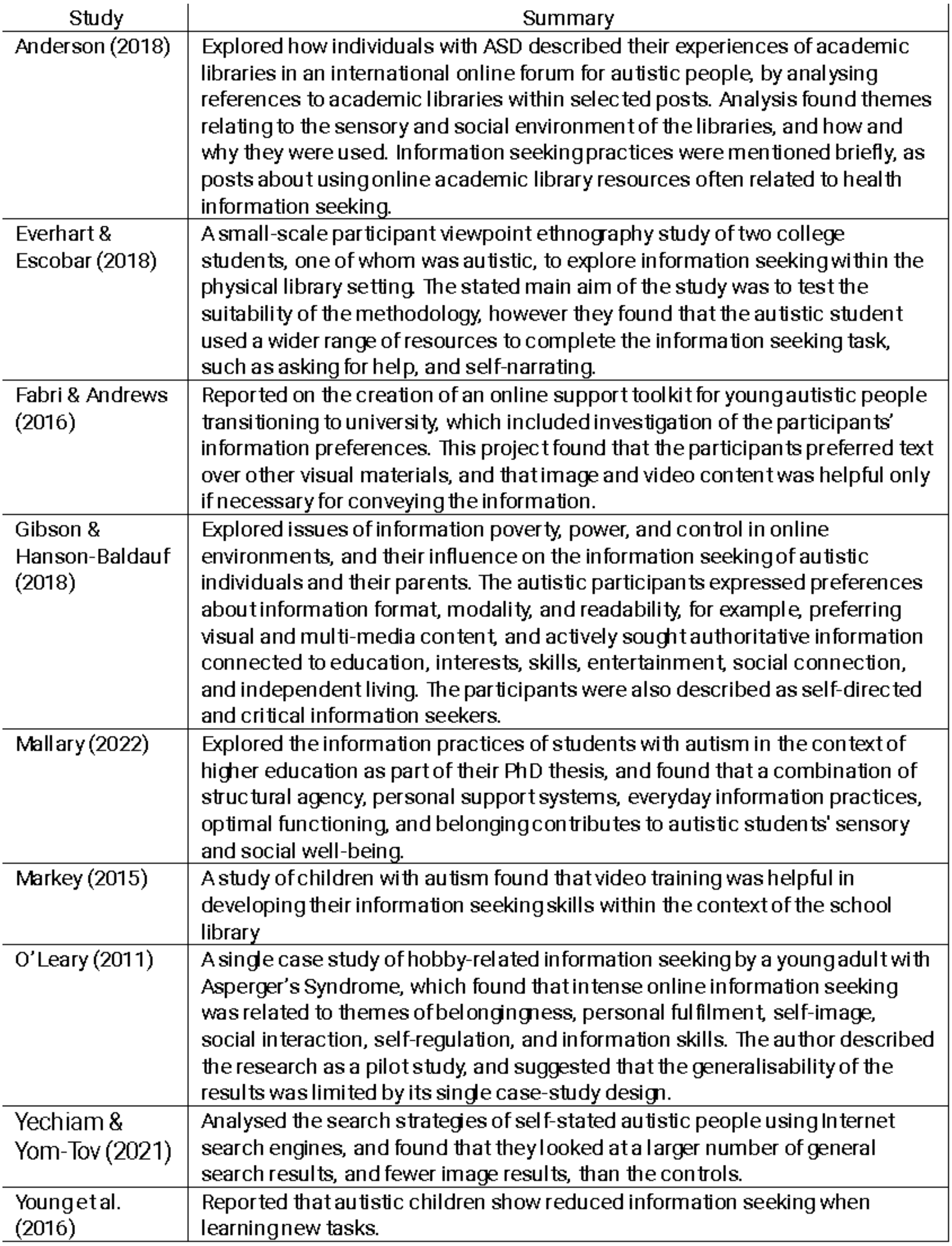
> "Loneliness, isolation and yearning for interpersonal connection were ubiquitous and longstanding. Autism support and social groups were highly valued, offering opportunities for belonging, acceptance and social comparison." (Hickey *et al.*, 2017, p. 357)

Autistic people use the Internet for the purposes of social networking with each other, and the Internet is often a preferred means of communicating for autistic people, (Bertilsdotter Rosqvist *et al.*, 2013; Davidson, 2008; Koteyko *et al.*, 2022; Parsloe, 2015). Skafle et al. (2024) explored autistic people's use of social media in Denmark and found that their study participants used social media to seek information and interact with other autistic people. They reported that peer interactions on social media helped autistic people to develop their perceptions of autism, and provided information that was not available from elsewhere, although such information was not necessarily seen as reliable, and the social media groups did not always foster a sense of community.

Informational support, an important component of social support alongside emotional and social networking support, refers to the sharing of information by non-professional people within supportive social interactions. Informational support may increase feelings of empowerment and confidence for people managing health conditions (Bartlett and Coulson, 2011; Oh *et al.*, 2013; Oh and Lee, 2012). As described above, autistic people use online settings for social networking support (Carter and Wilson, 2006; Parsloe, 2015), and online settings can be more accessible for autistic people than face-to-face settings in meeting the needs of group users (Benford and Standen, 2009; Davidson, 2008; Gillespie-Lynch *et al.*, 2014). However, very little is known about autistic people's use of online settings for receiving, or providing, informational support.

Theories of informational support and information behaviour are closely linked, as information behaviour includes activities related to obtaining or providing informational support to meet information needs. Previous studies have explored the information behaviour of people who are living with health conditions and/or social inequalities (Buchanan *et al.*, 2019; Savolainen, 2005). Peer-to-peer information seeking and sharing activities form an important part of online support/health group use, and numerous studies have demonstrated the benefits, and limitations, of information sharing within such groups for helping people to manage and live with their health conditions (Hargreaves *et al.*, 2018; Zhao *et al.*, 2013). Health conditions and impairments may have some impact on information behaviour (Berget *et al.*, 2021). Some studies have explored the information needs of parents/carers of autistic people, including their use of online autism groups (Nguyen *et al.*, 2014; Zhao *et al.*, 2019). Larnyo et al. (2024) investigated health information needs expressed within an online autism community consisting of autistic people and nonautistic carers and found that the online members discussed a diverse range of health-related concerns. However, the analysis focused on the autism community as a whole and did not distinguish the contributions of autistic people from non-autistic carers. Similarly, Lorence (2007) studied an online Asperger's Syndrome community to assess whether grounded theory could be used to investigate health information in this context and found that health issues were frequently discussed. However, the results suggested that many of the group users were non-autistic carers of autistic children. Autistic people's views and priorities may differ from those of non-autistic carers (Pellicano *et al.*, 2014). Additionally, the defining characteristics of autism relate to differences in social communication; since communication and information are intricately linked (Wilson, 1999), it is highly likely that autistic people's information behaviour may differ in some ways from those of non-autistic people, and this is therefore an important area to investigate. However, relatively few information science studies have focused specifically, and in detail, on the information needs of autistic people, differentiated from those of non-autistic carers.

Previous studies reporting specifically on autistic peoples' information needs and behaviour are summarised in Table 1:



Study	Summary
Anderson (2018)	Explored how individuals with ASD described their experiences of academic libraries in an international online forum for autistic people, by analysing references to academic libraries within selected posts. Analysis found themes relating to the sensory and social environment of the libraries, and how and why they were used. Information seeking practices were mentioned briefly, as posts about using online academic library resources often related to health information seeking.
Everhart & Escobar (2018)	A small-scale participant viewpoint ethnography study of two college students, one of whom was autistic, to explore information seeking within the physical library setting. The stated main aim of the study was to test the suitability of the methodology, however they found that the autistic student used a wider range of resources to complete the information seeking task, such as asking for help, and self-narrating.
Fabri & Andrews (2016)	Reported on the creation of an online support toolkit for young autistic people transitioning to university, which included investigation of the participants' information preferences. This project found that the participants preferred text over other visual materials, and that image and video content was helpful only if necessary for conveying the information.
Gibson & Hanson-Baldauf (2018)	Explored issues of information poverty, power, and control in online environments, and their influence on the information seeking of autistic individuals and their parents. The autistic participants expressed preferences about information format, modality, and readability, for example, preferring visual and multi-media content, and actively sought authoritative information connected to education, interests, skills, entertainment, social connection, and independent living. The participants were also described as self-directed and critical information seekers.
Mallary (2022)	Explored the information practices of students with autism in the context of higher education as part of their PhD thesis, and found that a combination of structural agency, personal support systems, everyday information practices, optimal functioning, and belonging contributes to autistic students' sensory and social well-being.
Markey (2015)	A study of children with autism found that video training was helpful in developing their information seeking skills within the context of the school library
O'Leary (2011)	A single case study of hobby-related information seeking by a young adult with Asperger's Syndrome, which found that intense online information seeking was related to themes of belongingness, personal fulfilment, self-image, social interaction, self-regulation, and information skills. The author described the research as a pilot study, and suggested that the generalisability of the results was limited by its single case-study design.
Yechiam & Yom-Tov (2021)	Analysed the search strategies of self-stated autistic people using Internet search engines, and found that they looked at a larger number of general search results, and fewer image results, than the controls.
Young et al. (2016)	Reported that autistic children show reduced information seeking when learning new tasks.

Table 1: Literature summary

Two studies in Table 1 investigated the information processing of young autistic children in school settings (Markey, 2015; Young *et al.*, 2016) and it is not clear how applicable the results may be for adults. Two other studies were each based on the experiences of one autistic adult, primarily to test methodologies, and the results may not be transferrable to other contexts (Everhart and Escobar, 2018; O'Leary, 2011). The studies focused on the experiences of autistic university students accessing academic library facilities (Anderson, 2018; Fabri and Andrews, 2016; Mallary, 2022) found evidence of the impact of informational environments on autistic students' wellbeing and learning, including the effects of social and sensory stimuli. Gibson and Hanson-Baldauf (2018) found that autistic people preferred using the Internet to find out information about a wide range of topics, and that they sought reliable, high-quality information. Yechiam and Yom-Tov (2021) found that autistic people looked at more search results, and fewer images, than non-autistic controls. Outside the field of information science, research exploring autistic people's information processing from a neuropsychological perspective provides evidence of atypical information processing skills (Ewing *et al.*, 2018; Hetzroni and Shalahevich, 2018; Miller *et al.*, 2014). Murray et al. (2005) suggested that autistic people's cognitive style is characterised by monotropism and a tendency to focus on details.

Overall, the existing research on autistic people's use of the Internet for social networking purposes, and information-related behaviours, suggests that the Internet may be an important source of informational support for autistic people, and may play an important role in autistic people's information activities. There is evidence that autistic people process information differently and may use different information search strategies. However, many gaps remain in what is known about how autism may influence information needs, and the barriers that autistic people experience in relation to information, in both online and offline settings. The aim of the research project was therefore to develop knowledge and understanding of informational support within online groups for people on the autism spectrum, and the context in which it occurs. The following research questions were posed:

- What is the role of informational support in online groups for autistic people?
- How might autism influence the informational support needs and information behaviour of adults who use online groups for people on the autism spectrum?

This paper describes the research carried out to address these questions, and how informational support plays an important role within online groups for people on the autism spectrum, forming an important part of the users' autism information journeys, and contributing towards meeting the users' information needs. The results are discussed in relation to existing theories of information behaviour, and the social model of disability, which is concerned with the ways in which societies create barriers for people with disabilities.

For this paper, a broad concept of information behaviours is used, encompassing information needs, information behaviours, and information-related needs and behaviours, defined by Wilson (2000) as:

> '… the totality of human behaviour in relation to sources and channels of information, including both active and passive information seeking, and information use' (Wilson, 2000, p. 49).

An information journey is defined, for the purposes of this paper, as an iterative process of recognising or encountering information needs and engaging in information behaviours related to these needs. This definition is based on that of Blandford and Attfield (2010), who use the term 'information journey' to describe how people iteratively "recognise a need for information, find information, interpret and evaluate that information in the context of their goals, and use the interpretation to support their broader activities. People's information needs may be explicit and clearly articulated but, conversely, may be tacit, exploratory and evolving." (Blandford and Attfield, 2010, p. vi).

METHODOLOGY

The overarching aim of the research project was to explore informational support within online groups for people on the autism spectrum. Autism is a complex and evolving topic, with conflicting views as to its exact nature (Kenny *et al.*, 2016; Milton, 2012; Nicolaidis, 2012), and social construction is a feature of many concepts related to information behaviours, such as sense-making (Dervin, 1992). The project was therefore designed from a constructivist paradigm with a qualitative and inductive approach to the research questions.

The study design was multimethod with two consecutive parts, selected to gain a range of perspectives on the topic and triangulate data from different sources:

1. Analysis of posts on an online forum for autistic people
2. Semi-structured interviews with people who used a range of online autism groups and stated that they were autistic

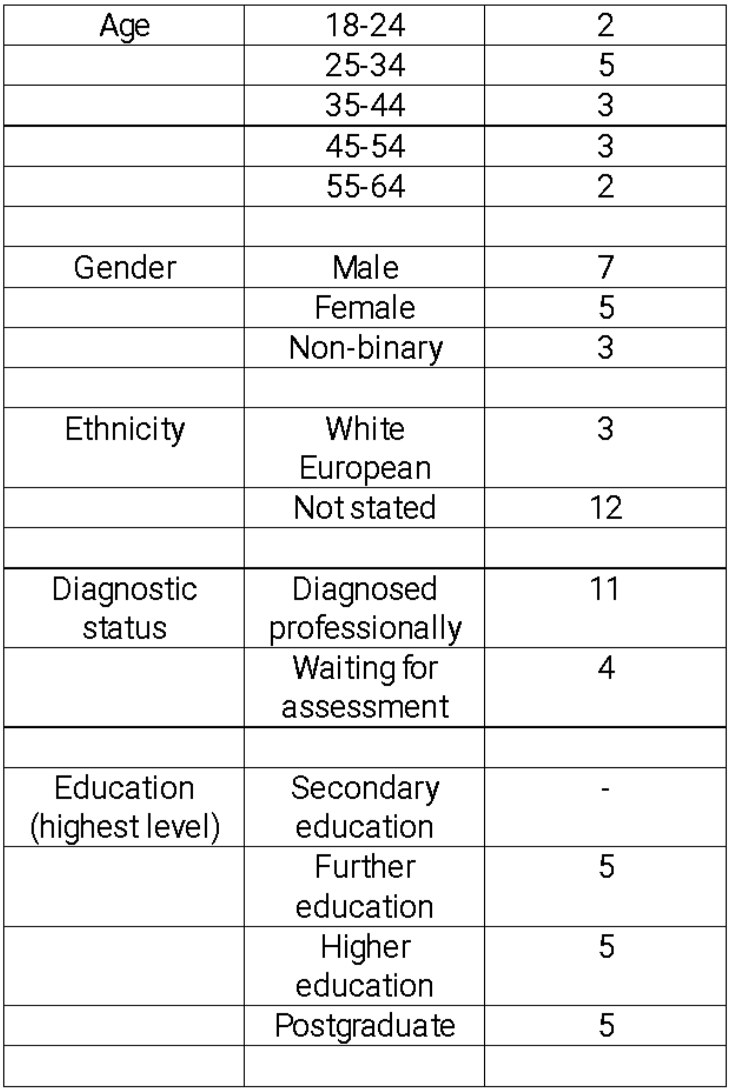
Online posts analysis

A purposive sample of posts made to a frequently used, UK-based online forum for autistic people (unnamed to protect the privacy of users) was collected with the permission of the forum manager and analysed using Reflective Thematic Analysis. I64 threads were collected, consisting of 2012 posts in total, made by 220 unique users. Posts made by users who described themselves as non-autistic were excluded from analysis.

The material was anonymised before analysis, with any identifying details removed. The results of the thematic analysis were then used to inform the design of interviews. For example, the online forum users described using a wide range of social media platforms, including Discord, Reddit, Facebook, and Twitter, for supportive information sharing. The original study focus, which had been on informational support within traditional-style online forums and support groups for autistic people, was then widened to include users of social media platforms where groups of autistic people exchanged or sought information.

Interviews

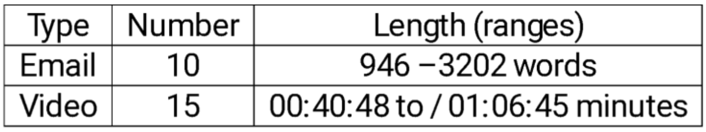
The second part of the study consisted of 15 semi-structured interviews with adults who used a range of online forum / social media groups for people on the autism spectrum (actively or passively), and who had either received an autism diagnosis (n=11) or were awaiting an autism assessment (n=4). Interviewees were recruited by posting study information on a range of online autism group message boards. The interviews were carried out via face-to-face video conferencing (n=5), or by asynchronous email exchanges (n=10), according to the preferences of the interviewees, before being transcribed and analysed using Reflective Thematic Analysis. Interviewee characteristics are summarised in Table 2.



Age	18-24	2
	25-34	5
	35-44	3
	45-54	3
	55-64	2
Gender	Male	7
	Female	5
	Non-binary	3
Ethnicity	White European	3
	Not stated	12
Diagnostic status	Diagnosed professionally	11
	Waiting for assessment	4
Education (highest level)	Secondary education	-
	Further education	5
	Higher education	5
	Postgraduate	5

Table 2: Interviewee characteristics

Email interviewing has been used successfully in previous qualitative studies (Amri *et al.*, 2021; Fritz and Vandermause, 2018) and with autistic people (Benford and Standen, 2011; Gowen *et al.*, 2019). The email interviews were shorter than the video interviews in terms of word counts but generated similarly rich data in terms of codes generated during analysis. The interview questions focused on participants' experiences of using online autism groups, their history and patterns of use, how using the groups compared to other settings, the positive and negative aspects of the groups, and if/how they felt autism influenced their information needs. Interview data are shown in Table 3.



Type	Number	Length (ranges)
Email	10	946 –3202 words
Video	15	00:40:48 to / 01:06:45 minutes

Table 3: Interview characteristics

Ethics

The main ethical concerns were to protect the privacy of participants, and to use inclusive methods for participation. Published guidelines for working with autistic people were incorporated (Chown *et al.*, 2017; National Autistic Society, 2021; Pellicano *et al.*, 2014), in addition to general research ethics guidelines (British Psychological Society, 2009, 2017) and institutional policies (XXX).

Interviewees were asked for their preferred autism terminology and choice of interview format when they agreed to take part, and the study materials and communications were then individualised according to their preferences. A majority chose the email option. The participants who chose to take part in synchronous video interviews were asked if they wished to have the main interview questions in advance, and all chose this option. All collected data were carefully anonymised, and all names used within this paper are pseudonyms. Any quotations from online forum posts have been carefully reworded to preserve their meaning whilst avoiding identification of individual posts and posters via search engines, in line with the published and institutional ethics guidelines cited above.

Analysis

Reflexive thematic analysis (Braun and Clarke, 2006, 2019) was data-driven and carried out inductively, following the stages of:

1. Familiarisation
2. Coding
3. Generating initial themes
4. Reviewing and developing themes
5. Refining, defining, and naming themes
6. Writing up

Measures taken to ensure the quality of the research analysis focused on the framework for trustworthiness in qualitative research developed by Lincoln and Guba (1985) and incorporated the guidelines of Braun and Clarke (2019, 2021). For example, data extracts, codes, and themes were discussed in detail by the authors of this paper throughout the analysis period, to explore any areas of ambiguity or alternative interpretations. During each interview, the interviewer summarised what they had understood from the answers, and asked the interviewees if that matched their intended meaning.

The themes generated from both the forum posts and the interviews were compared and triangulated, and a final single map of themes representing all the data was developed. This led to the development of a model illustrating the participants' autism information journeys.

RESULTS

Preliminary analysis of the forum posts and interviews showed that the online group users were seeking and sharing information in the following areas:

Topics	Autism	Life as an autistic person	Non-autism related topics
	– what it is – autism in adulthood – comparisons with related conditions – diagnosis – gender issues	– being an autistic parent – coping strategies – Department for Work and Pensions (DWP) and benefits – eating habits – education – humour – living independently – mental health – relationships – sensory issues – special interests – stimming – struggles and worries – support – systemic and institutional issues – traits of autism – ways of understanding the world – work issues	– pop culture – LGBTQ+ – Humour – hobbies

Table 4: Topics discussed

Themes

Thematic analysis suggested that online autistic groups were an important information resource for their users. Five main themes contributed to this overarching message:

- The world is a hostile environment for autistic people
- Making sense of autism
- Distinctive autistic information needs
- Online groups as a valuable resource for autistic people
- Balancing benefits with the risks and downsides of the groups

These themes reflect the participants' views of how and why they used online autistic groups, and their experiences when they attempted to engage in information-related activities both online, and in the physical world. The participants also described ways in which they felt autism influenced their information needs. Table 3 provides examples of quotes for each of the themes.

Theme	Example quotes	
The outside world is a hostile environment for autistic people	*Being able to access information online means I get to feel in control, calm and safe – I can be myself without fear of attack. [Jen]*	*When I have to enter a building with overwhelming sensory stimuli then I try to brace myself and hold everything together until I can let the suffering out at home. [John]*
Making sense of autism	*I spent a long time thinking I was a defective neurotypical person when actually I am simply autistic. [Jude]*	*… talking about autism and talking about being autistic … we can't disentangle it really from the politics of autism, and the politics of being autistic … the activist component of the neurodiversity movement is very important to me… [James]*
Distinctive autistic information needs	*Autism has a significant influence in the amount and detail of information and instructions I need, both in order to understand but also to not feel stressed… [Louise]*	*I also find that I need more information about a thing before it happens than most people do, because it helps me understand what's going to happen, manage expectations and just generally reduces surprises… [Matt]*
Online autistic groups are a valuable resource	*A sense of community through shared experience, the knowledge that you're not alone in your experiences of life. [Beth]*	*They just know what it's like more. On a non-autism group people might ask more questions to try and understand you, whereas if someone has autism they know why with fewer questions. [Hannah]*
Balancing benefits with the risks and downsides	*The same artefacts of online culture- trolling, misinformation, information, internet slang, memes, etc- seem to exist pretty comparably across the board … [Luke]*	*I stopped posting following a lot of hassle (and bullying) from a very small group of people … [John]*

Table 5: Example quotes

The themes are illustrated along with their subthemes in Figure 1.

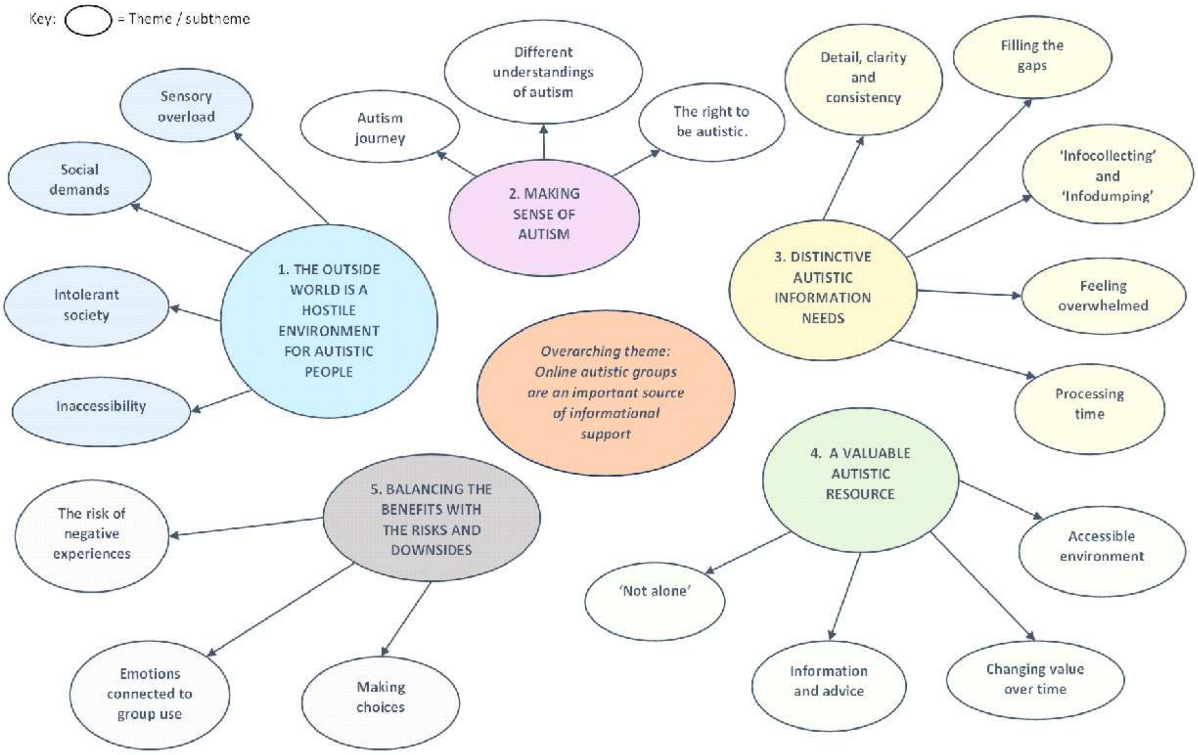


Figure 1: Map of themes (Source: Authors own work)

This paper is focused on the theme of "distinctive information needs". A detailed description and discussion of all the themes and subthemes is provided by XXXX (2024).

Information needs

Distinctive autistic information needs were identified by the study participants when discussing how they felt autism influenced their seeking and sharing of information, and why they used the online autism groups. In addition to online autistic groups, which were the focus of the study, the participants referred to other information sources, including physical resources (such as books, leaflets and health professionals), the NHS website, research journals, unnamed health and charity websites, autistic people's blogs, and podcasts. The interviewees reported that they had difficulties in finding autism information that met their needs, including:

- sufficiently detailed offline information
- expert information that used accessible, familiar language
- detailed explanations of autistic traits and diagnostic criteria from reputable health websites, with relatable examples

An example of struggling to find useful autism information offline was provided by Luke, who reported how difficult it had been to find suitable autism information from physical world sources, including from health professionals he had seen:

> *I have found it extremely difficult, bordering on impossible, to access offline information or support about autism… No one has ever … told me anything about autism, and I had to be*

> *extremely insistent to get my gp to even discuss it as a possibility with me… they told me nothing themselves about what autism was. [Luke]*

Luke went on to say,

> *The Google skills needed to investigate autism are a lot higher than for other subjects I've tried to research… exacerbated by the absence of offline support meaning you have to undertake that search without guidance … for a lot of clinical information online from nhs-like organisations, you need to already know the terminology of autism to even be able to find it, as well as needing to already know or suspect that you are autistic in the first place… [Luke]*

Luke's comments suggest that the lack of offline support he had experienced, including a lack of autism information from health professionals, made the task of finding suitable information online even more difficult. Several other interviewees commented that searching for suitable autism information required particular effort or persistence on their part:

> *… accessing something online is … matter of persistence in googling it up … [Alex]*

> *I would say that I have managed to find any information I needed online, though never in one place which is fine as I am quite good at looking for info. [Beth]*

Although Beth stated that she had managed to find information, this was online rather than offline, and was spread between different sources, meaning that she had needed to rely on having good information seeking skills.

The study participants were aware of the risks of online misinformation:

> *I … seek out wherever possible … whatever I consider to be given the context a reliable source of information… I'll try and balance … personal and academic sources… and be very careful about like unpicking like inferences … [James]*

> *I read a lot on many websites about autism, I found [a] few websites telling lies as well, or at least carefully redacted truth. [Alex]*

> *… moderation in any kind of group like that or information sharing service [is required] because incorrect information is just as bad as no information or worse even. [Richard]*

However, information from reputable resources, such as the NHS website, was felt to be too brief, and lacking in important areas, such as autism in adults, autism in women, and being an autistic parent:

> *For example, the info on the NHS autism page is pretty basic, and if I were only using their "signs of autism in adults" list/page I would not feel I had enough information from that… [Beth]*

> *I was looking for more information about autism and how it affects women [Jen]*

> *… clinical sources like the NHS devote the majority of their resources and online space to talking about autism in children, with comparatively few resources for those diagnosed in adulthood [Luke]*

> *… to talk to other mums who are autistic… which is not something you get from sort of official sites, you know. You realise that it's not particularly unusual. There are quite a lot of autistic mums out there. [Rowann]*

In addition, the participants suggested that the language used by health websites and professional literature could be ‘clinical’ and difficult to relate to. For some participants, the online autism groups served as a bridge to professional information sources. This suggests that the online groups may have a ‘translation’ function, linking group users’ informal experiential descriptions to professional terminology, which made professional information sources more accessible:

> *I find the information from online groups and YouTube in particular a lot more relatable and digestible than “official” clinical sources like the NHS. [Luke]*
>
> *I have loads of books … but the lived experiences online translate that.… it was a massive translation basically of textual information… [from] quite dry textual information that you get online, to … real life experience. [Rowann]*
>
> *My path was first googling my layman's description of elements of that experience … quite a clumsy and vague search - and that led me to the proper terms … Once I started using the proper terms to search… the 'hits' I got came from more actually medical/factual sources of information and therefore were, I felt, actually reliable and could be trusted as they weren’t just people's opinions…[Beth]*

Participants also reported that they needed more detailed information in general:

> *Autism has a significant influence in the amount and detail of information and instructions I need, both in order to understand but also to not feel stressed... [Louise]*
>
> *I also find that I need more information about a thing before it happens than most people do, because it helps me understand what’s going to happen, manage expectations and just generally reduces surprises… [Matt]*

Another need identified by participants was processing time:

> *There is such a huge amount of information to process and make sense of when talking to people, from exactly what is being said to how it's said as well as trying to interpret body language. I often find that it takes days to process all the information from interactions with one or more people, while reading and writing require fewer forms of information processing. [Jen]*
>
> *I prefer written information because it allows me to process the information in my own time and to refer to it as and when required. [John]*
>
> *… written and visual information is helpful for me to make sense of information and if I don’t understand to be able to look back at the information. I find processing auditory information hard and so often choose to have subtitles on video. [Louise]*

The overall value of the information found within the online groups was summarised by Richard:

> *… the access to information is beyond helpful… if I had had access to this kind of information in the early 2000s and sort of late ‘90s it would have been a different world … things I've done all my life without relating to the word stimming, I didn't even know that was a thing…I had to live my whole life not knowing, knowing I do something strange, but not knowing there's a name for it. [Richard]*

For Richard, the groups provided information that he had not found elsewhere, and that might have had a life-changing effect.

Identified information needs therefore included:

- Information about specific aspects of autism which had not been provided by professionals, such as autism in women, and being an autistic parent
- More detailed information than that usually provided
- More varied and relatable examples of autistic traits, based on lived experience
- Autism information using more familiar, and less clinical, language
- More information processing time

Relationship between the themes and information behaviours

The five themes were linked in several ways. The sense of the world in general being a hostile environment was pervasive throughout the interviews and the forum posts, and was alluded to by the interviewees, when asked how they came to be using the groups. Experiencing the world as hostile was seen by the interviewees as the start of their journeys. They described their need to understand why the world was so difficult for them, and sought information about the issues they experienced, and to make sense of autism, once they became aware that they were, or might be, autistic. The participants also described how the difficulties they experienced in the outside world directly influenced their information needs and how they sought information. Public environments, and some methods of communication, were described as difficult or impossible to engage with, and were often avoided which, in turn, led to reduced access to, and encountering of, information. The participants also described how they felt autism influenced their information behaviours, for example, by influencing the places from which they sought information, the amount and type of information they needed, and the modes of communication used to obtain or share information. These distinctive information needs and information behaviours contributed to the participants' need to make sense of autism. The need to make sense of autism can itself be viewed as a distinctive autistic information need. These relationships are displayed in Figure 2 below.

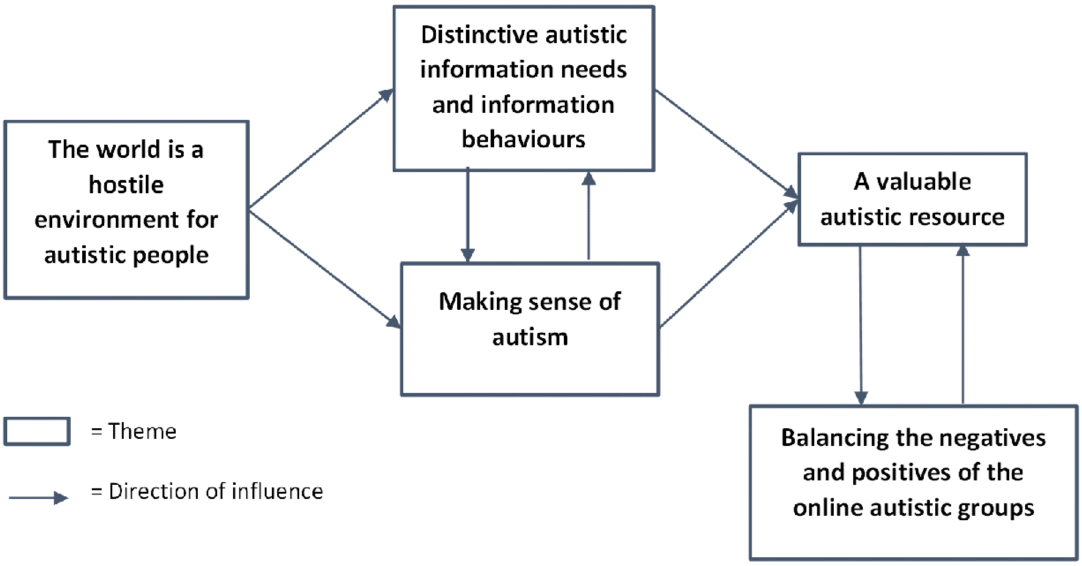


Figure 2: Relationships between the themes. (Source: Authors own work)

As illustrated in Figure 2, the participants described how experiencing the world as a hostile environment directly influenced their information behaviours, whilst contributing to their need to make sense of autism, with these two facets also influencing each other. These needs led them to use online autistic groups, which they found to be an accessible environment, and a helpful resource that provided information and social support from other group users. However, despite these important benefits, the online groups had negative aspects too. The participants described how they encountered difficulties and risks, and how they had to make choices about how they used the groups, restricting their usage in various ways, to minimise the dangers.

The connections between the themes show how a combination of social barriers and autism itself may influence autistic people's information behaviours, and how the online autistic groups can be an accessible and important resource for some users. At the same time, the groups can be a source of risks as well as benefits, and were seen as an imperfect, and incomplete, source of information for some users. These relationships between the themes also suggest a sense of progression from one point to another, indicating how using the groups forms part of the participants' autism information journeys, including the journeys of those contemplating the likelihood that they might be autistic, and those with a diagnosis.

Discussion

Many of the information behaviours described by the participants are those commonly included in existing models of information behaviour, such as seeking, finding, sharing, encountering, avoiding, and evaluating information. For example, information encountering/accidental information acquisition (Erdelez, 1999; Williamson, 1998) was demonstrated when the participants described seeking information about one thing and encountering information about something else that was significant to them. Luke and Beth described encountering information about autism while seeking information about interests and mental health concerns respectively, and realising that they might themselves be autistic:

> *I was watching a video essay about one of my interests on YouTube, and one of the presenters went on a tangent about their autism, and the way they experience things, and everything they said sounded very, very familiar- I want to emphasise how intensely it felt like an epiphany …I had never previously considered that I might be autistic … [Luke]*
>
> *I'd been searching symptoms related to my mental health and noticed that autism/ the spectrum appeared quite often in these searches. [Beth]*

Rowann described how seeking autism information about her child, via online autism groups, led to a feeling of similarity and connection with the autistic group members:

> *I knew so little about autism generally really. I just thought I was a bit rubbish at life… I suddenly fitted in for the first time in my life … it was life changing, that moment was just life changing [Rowann]*

These quotes express the profound effect of encountering or finding autism information had for the participants, and the role of the groups in addressing their information needs.

The participants described other information-related needs and behaviours that they linked to autism, such as needing and seeking particularly detailed and precise information to alleviate uncertainty and anxieties about unfamiliar events:

> *I want to know all the details of what will happen all the way through from start to finish, as I'm very anxious… [Kelly, forum post]*

> *I've memorised where everything is in the supermarket and I've made myself a map with a route to follow… together with a list of all the items I need in the same order as my route - but it's terrible when they've moved things around. [Mike, forum post]*

Uncertainty and unpredictability are known causes of anxiety for autistic people (Jenkinson *et al.*, 2020), and the quotes above demonstrate the role of information in reducing or increasing anxiety. Other examples of information behaviour linked to autism are collecting and sharing large amounts of information for enjoyment ('infocollecting' and 'infodumping'), as referenced in the following quotes:

> *I also tend to "collect" information like random trivia that doesn't seem to interest anybody else! This is something I have to be conscious of when posting comments as lots of people don't care about obscure facts that I find interesting and I might get told that my comments are unwanted. [Jude]*

> *I like a lot of information, I like a lot of it very quickly… there's information I gather because it's just what I do… I will usually be fixated on something, and then just consuming all the information I can on it… I'm pretty indiscriminate in that case, just anything I can get my hands on… [James]*

Interviewees observed that autistic people were more tolerant and accepting of infodumping, and discussing unusual interests, viewing this more positively than non-autistic people:

> *Also infodumping about special subjects is more tolerated within the groups. [Hannah]*

> *… in an online space that [infodumping] doesn't matter at all. Especially in like an autism specific group it's kind of I would say even encouraged and celebrated that people do that … for me that exchange of information is the socialising … hanging around non autistic people in real life they don't necessarily [get that] … [James]*

These information behaviours have not, to the authors' knowledge, been previously described in information behaviour literature. Similarly, the study participants described how they avoided certain situations and environments due to feeling overwhelmed by sensory or social information as evidenced by the quotes below:

> *I don't go outside much… the outside world is just often – it's too loud and chaotic and scary…it can get physically painful… [Matt]*

> *I struggle in environments that are very loud and/or have lots of echoes. Shopping centres are a big challenge for me because light and sound bounces off all of the surfaces and I can end up feeling really overwhelmed. [Jude]*

> *I went to group where a light was flickering lightly and it took all my focus, it was in a cinema lobby and that also meant that I felt overloaded and distracted due to people walking around and noise. [Louise]*

This could be viewed as 'information avoidance' (Case *et al.*, 2005; Golman *et al.*, 2017; Howell and Shepperd, 2013; Sweeny *et al.*, 2010). However, although feeling overwhelmed by sensory and/or social information is a familiar concept within autism literature, as described in the background literature review, it has not been previously described in information behaviour literature. The following quote suggests how social and sensory differences characteristic of autism may directly influence information behaviour:

> *In day-to-day interaction, I find turn-taking difficult, so physical conversations can be more difficult. It also takes me a while to process information, so when I'm also focusing on the other*

> *aspects of conversation (eye contact, body position, gestures, facial expressions, as well as other things going on around me) it makes it more difficult to process and respond to information in a way that someone without autism could. [Drew]*

The quotes above also suggest why the participants found the online environment to be particularly useful for informational purposes, as it allowed them greater control over the sensory and social aspects of information.

Finally, as the participants described their use of online autistic groups for informational support, elements of an iterative autism information journey were apparent alongside their reported information behaviours.

PROPOSED MODEL OF THE GROUP USERS' AUTISM INFORMATION JOURNEYS

A descriptive model of the group users' autism information journeys was developed based on the study results. The model was then compared to existing models of information behaviours, sense-making, and the social model of disability. This section will firstly outline the new proposed model, before discussing how it compares to other models.

Figure 3 presents a model of autism information journeys derived from the analyses of the forum posts and the interviews. For succinctness, the box captions summarise the comments of multiple participants. The model was developed until every interviewee's autism information journey was incorporated and could be traced within it.

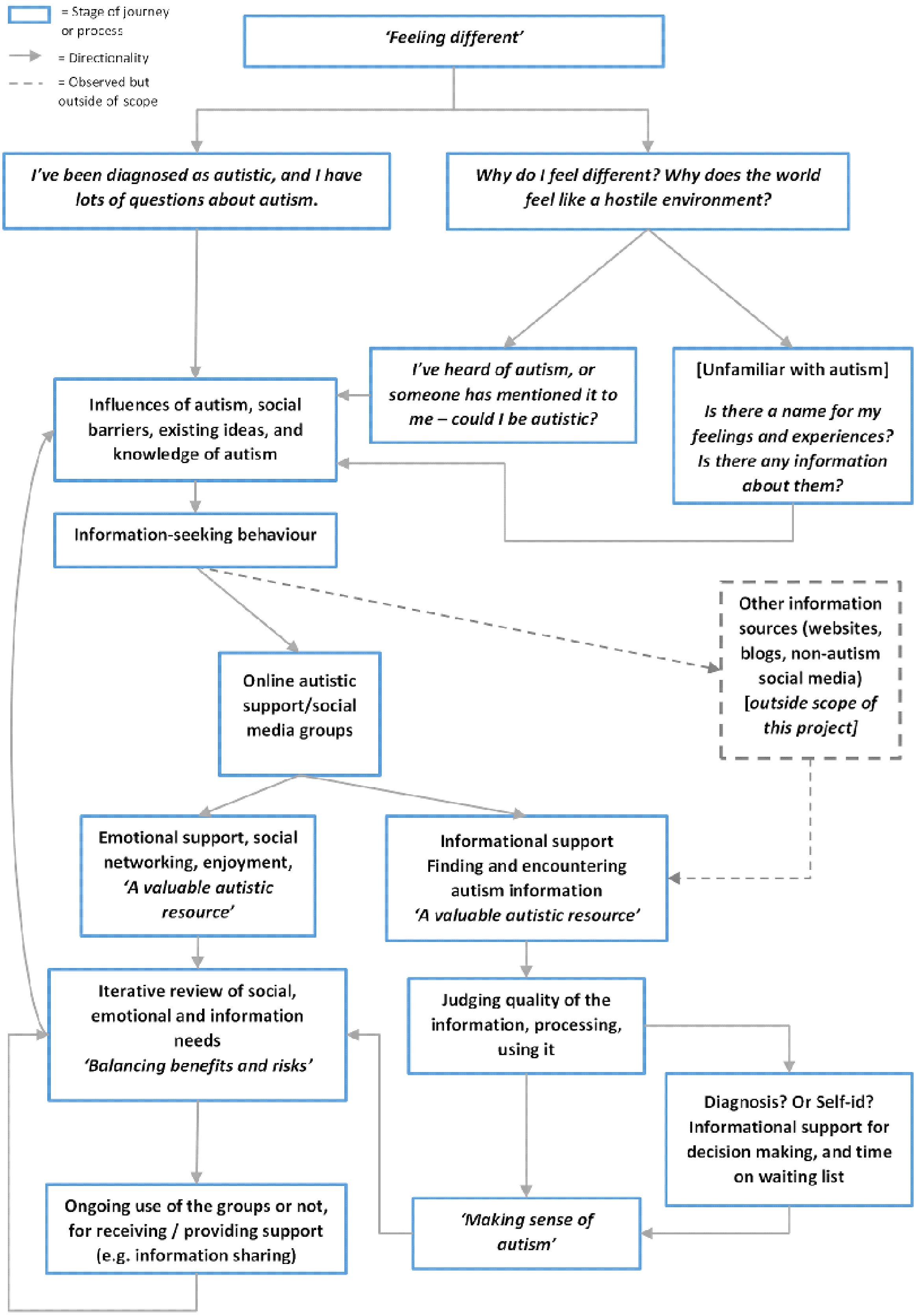


Figure 3: Proposed model of autism information journeys. (Source: Authors own work)

Every interviewee, and many of the online forum posts, described feeling different to other people, often from a very early age, and this was often reported as the starting point for how they came to be using the online autism groups. This feeling of ‘difference’, often related to experiencing the outside world as a hostile place due to overwhelming social and sensory demands, formed part of the context for participants finding and using the online groups.

> *… most of my life … since sort of being an early teenager, being acutely aware of like differences between me and other people. [James]*
>
> *… many people throughout my life have felt it appropriate and necessary to comment on something about me being strange or different. [Luke]*
>
> *I'd always known from maybe about four or five I wasn't like the other kids… [Richard]*

On the model, this is summarised as ‘Feeling different’. This awareness of ‘difference’ led the participants to question the reasons for this, and why life felt so difficult for them. The participants varied as to when they became aware of autism, at a knowledge level and as a possible explanation for their own personal experiences. A few participants reported that it was after they had been diagnosed that they began to seek information about autism:

> *I didn’t really start using them until after I was diagnosed … I started looking up, you know, some more things about it, I joined a couple of the subreddits to see how much some of the things chimed. [Matt]*

Some discovered autism indirectly when seeking information about certain characteristics and feelings (e.g., Beth and Luke, quoted earlier).

Others reported that they began to look for information about autism, as they had heard of it, and wondered whether it might explain their experiences. For some, autism had been suggested to them by other people:

> *A friend suggested it 5 years ago, I went to my GP to be referred 4 years ago, I self-identified 11 months ago shortly after joining the forum, and I was diagnosed 3 months ago. [Alex]*

The participants’ information seeking was therefore influenced by their existing ideas and knowledge of autism, as well as by autism itself, alongside other factors known to influence information seeking, e.g. personal characteristics (Al-Samarraie *et al.*, 2017; Tidwell and Sias, 2005) and demographic and socio-cultural factors (Eneya and Mostert, 2020; Wilson, 1997). Those who knew that they might be autistic could search directly for autism information, whereas those who were unaware of autism described broad searches using vague terms (e.g. Beth and Luke).

These differences are reflected in the different pathways through the model towards information seeking behaviour:

‘I’ve been diagnosed as autistic, and I have questions about autism’

‘Why do I feel different? Why does the world feel like a hostile place?’

‘I’ve heard of autism, or someone has mentioned it to me – could I be autistic?’

‘Is there a name for my feelings and experiences? Is there any information about them?’

All the participants described or displayed some information-seeking behaviours. Information was sought from various sources, including physical world settings and other Internet sites, in addition to the online autistic groups, with varying degrees of success. This was expressed by Luke (quoted earlier) and others:

> *I pretty much never attempt to access information *in person* in real life. I have given up the effort. [Roz]*

This is noted in the model:

> *'Online autistic support/social media groups'*
>
> *'Other information sources (websites, blogs, non-autism social media) [outside scope of this project]'*

Having found the groups, the participants found different aspects of value, including informational support, emotional support, and enjoyment of social interaction with other group users. Some found that emotional support was very rewarding, while all identified informational support as a major benefit of using the groups.

> *I don't know any openly autistic people my age in real life, and so I don't feel that there is anyone who understands and relates to my experiences. [Drew]*
>
> *… the first time realising there's other people who had had similar experiences…that was very crucial for me in understanding and coming to terms with being autistic, and kind of still is… from … dealing with difficulties through to sort of understanding things [James]*

For some, informational support was more important than emotional support. Others reported that they valued the opportunity to provide emotional and informational support to other group users.

The value of the online autistic groups as a source of social support is shown in the model as:

> *'Emotional support, social networking, enjoyment, 'A valuable autistic resource''*
>
> *'Informational support, Finding and encountering autism information, 'A valuable autistic resource''*

The participants who sought and found informational support within the groups described how they evaluated, processed, and used the information. Those who had an autism diagnosis valued learning more about autism, finding useful strategies to manage the difficulties they experienced, and sharing ideas and advice with other group users. Some participants used the information to make decisions about pursuing an assessment for their autism. Those who were on long waiting lists for assessment used the groups while they waited, to build their knowledge and understanding of autism, and to prepare themselves for the autism assessment process:

> *I am still very new to the belief that I am very probably autistic, and am still waiting for an assessment and diagnosis… I read most posts, to try and build my understanding of what autism is and how it may be affecting me. [Luke]*

Processing and using the information in these ways contributed to the participants' efforts to make sense of autism. These parts of the journey are described in the model as:

'Judging quality of the information, processing, using it'

'Diagnosis? Or Self-id? Informational support for decision making, and time on waiting list'

'Making sense of autism'

The participants also described how they evaluated their use of the groups and reviewed their own needs as their knowledge and understanding of autism developed.

> *… when I first joined … I was sort of collecting data … trying to understand people's experiences and relate them to my own, see if there was any sort of correlation in my own. Since being diagnosed … I don't have such a need to sort of collect data in that way. [James]*

For some, there was a shift in focus between different types of social support, for example, seeking more emotional support as their need to make sense of autism was fulfilled, or feeling more confident to provide support to others.

> *Since forum helped me get back on my feet, I try to pay my due so to say and answer at least one looking for help post daily. [Alex]*

Others, particularly those recently diagnosed or still awaiting diagnosis, felt that they had more to learn about autism, and remained focused on informational support as the main benefit from the groups. Another feature of the journey was how the participants responded to the negative aspects of the groups they encountered. For some, this meant continuing to use the groups whilst changing how they used them; for others, a change of group was the solution. A few of the participants suggested that they would probably not continue using the groups in the future. The participants' use of the groups evolved over time, reflecting their changing needs, changes within the groups themselves, and the ongoing process of reviewing and balancing the benefits and risks. This is shown on the model as follows:

'Iterative review of social, emotional and information needs; 'Balancing benefits and risks''

'Ongoing use of the groups or not, for receiving / providing support (e.g. information sharing)'

Finally, the participants' accounts suggested that, as they used the groups, and their needs, knowledge, and ways of using the groups developed over time, the influences on their information behaviours also evolved, leading them to review their information needs, forming a natural loop. The following quotes demonstrate two participant's changing information needs over time, as they progressed through their information journeys, and their use of online groups changed:

> *… when I first got diagnosed … I needed to learn more about this and what makes me tick. And that led to a whole learning experience for a few years. I learned what I thought was useful and what I thought was relevant to me, and [then] I backed off a bit because I thought, well there's not really much more that I can get ... [Richard]*
>
> *At first, I was only reading, it takes a while to overcome shyness, or feeling like an imposter before official diagnosis. Then I started asking questions, and talking to a friend I made there using private chat. After diagnosis I started giving advice in comments as well, on those rare occasions I feel like my experiences qualifies me to do so. [Alex]*

This is summarised in the model as:

'Influences of autism, social barriers, existing ideas, and knowledge of autism'

Finally, it is important to note that for most of the participants, online groups only partially met their information needs, as expressed by Luke and James:

> *I think the offline information needs to be much, much better… I think it is impossible for online resources to substitute for this adequately… there is a language and knowledge barrier to even finding it [online autism support] without better offline support. [Luke]*
>
> *… the truth lies in a sort of murky grey area … the core sets of diagnostic criteria are not the complete picture of what autism is. But similarly, the exhaustive lists of every experience that every autistic person has ever had which you find online are also very over inclusive, are going to lead to a lot of confirmation bias… [James]*

Discussion of the model

The participants' need to make sense of autism, and how this was linked to their information behaviours, and online group use, suggested that models incorporating sense-making theory and information behaviours would be the most helpful to consider for comparison. The following models of information behaviour and sense-making were identified as particularly relevant:

- Wilson (1999) model of information seeking
- Dervin (1998) sense-making framework
- Eneya and Mostert (2020) model combining the social model of disability and Wilson's model of information behaviour

Wilson's model incorporates contextual, psychological, and environmental factors influencing information behaviour. The 'context of information need / person-in-context' corresponds to the participants' feelings of being different, and struggling with the outside world, as autistic people (or people who are likely to be autistic) in a non-autistic world, whether they are initially aware of autism or not. Their questions about why they feel this way, and need to make sense of themselves and their experiences, constitute the 'activating mechanism' for the participants to begin seeking information. The 'intervening variables' in this case may include the influences of autism, social barriers, existing ideas, and knowledge of autism, as part of Wilson's psychological, demographic, environmental, interpersonal, and source variables. The 'risk-reward' and 'social learning' theories referred to as the ongoing activating mechanism could be applied to the participants' needing to balance the positive and negative aspects to use the online groups. The study participants described information-seeking behaviours that included those suggested in Wilson's model, i.e. active searching, passive searching (encountering information), and ongoing searching. 'Information processing and use' correlates with the participants' descriptions of processing and judging the quality of information, and using it to make sense of autism, and to make decisions regarding diagnosis. The ongoing nature of the processes is indicated on both models as loops.

There are some differences between the Figure 3 model and Wilson's 1999 model. Figure 3 breaks down some of the journey / process components in detail, such as different types of support received from the online groups, and refers to a specific context, whereas Wilson's model is a general representation to be applied to various contexts. This is reflected in the slightly different loops, where Wilson's loop returns to the beginning context, and the loop identified in this study returns to the iterative review of using the groups, and to the influencing factors/intervening variables stage. This is because the study model is signifying a specific context, rather than a general context, and focuses on one area of information need.

Overall, the two models are compatible, with some similarities and consistency. The autism journey model provides a more detailed and specific view of the participants' information journeys and incorporates the distinctive autistic information needs and behaviours discussed earlier in this paper.

The Dervin (1992) sense-making theory framework has 5 components, which are applied to the proposed model as follows:

Situation: participants feel different to other people and experience many challenges, and seek to understand their experiences and find support. This links to themes of 'the outside world is a hostile environment' and 'making sense of autism'. The 'Situation' component corresponds with the context of information need in Wilson's model, and the 'Feeling different' context in the study model.

Gap: for the participants, the identified gap is knowledge and understanding of autism, and where and how to find support and help. This relates to the themes of 'distinctive autistic information behaviours' and 'making sense of autism'. The Gap component refers to, "questions, confusions, muddles, riddles, angst", which is similar to the participants' 'Why do I feel different?' and 'lots of questions about autism', and also to Wilson's 'activating mechanism'.

The Bridge: the concept of the 'Bridge' is the role of the person's knowledge, emotions, socialisation, and experiences in negotiating the 'Gap'. The 'Bridge' corresponds closely to Wilson's 'intervening variables', and to the study model's 'Influences of autism, social barriers, existing ideas, and knowledge of autism'.

Verbings: the concept of 'Verbings' emphasises the active role of the person in making sense of things. 'Verbings' may include information behaviours, such as information seeking, information searching and information evaluating. In the model, this corresponds to the participants' information seeking, and their processing, appraising, and using information.

Outcome [desired]: in this case, the desired outcome is making sense of autism, and life experiences, finding out how to access support and professional help effectively, learning self-help strategies, and feeling supported. This relates to the themes of 'a valued autistic resource', 'making sense of autism', and 'balancing the benefits with the risks and downsides.'

Outcomes [actual]: may include bridging the gap and / or not bridging the gap. The 'Outcomes' relate to the iterative reviews of information needs in Wilson's model and the study model.

Overall, although the components between the models do not match exactly, they share core concepts and are compatible with each other. The ways in which all three correspond together are shown in Figure 6 below, which combines the proposed autism information journey model with elements of Wilson's and Dervin's models to create a composite model of the autism information journeys observed in the study.

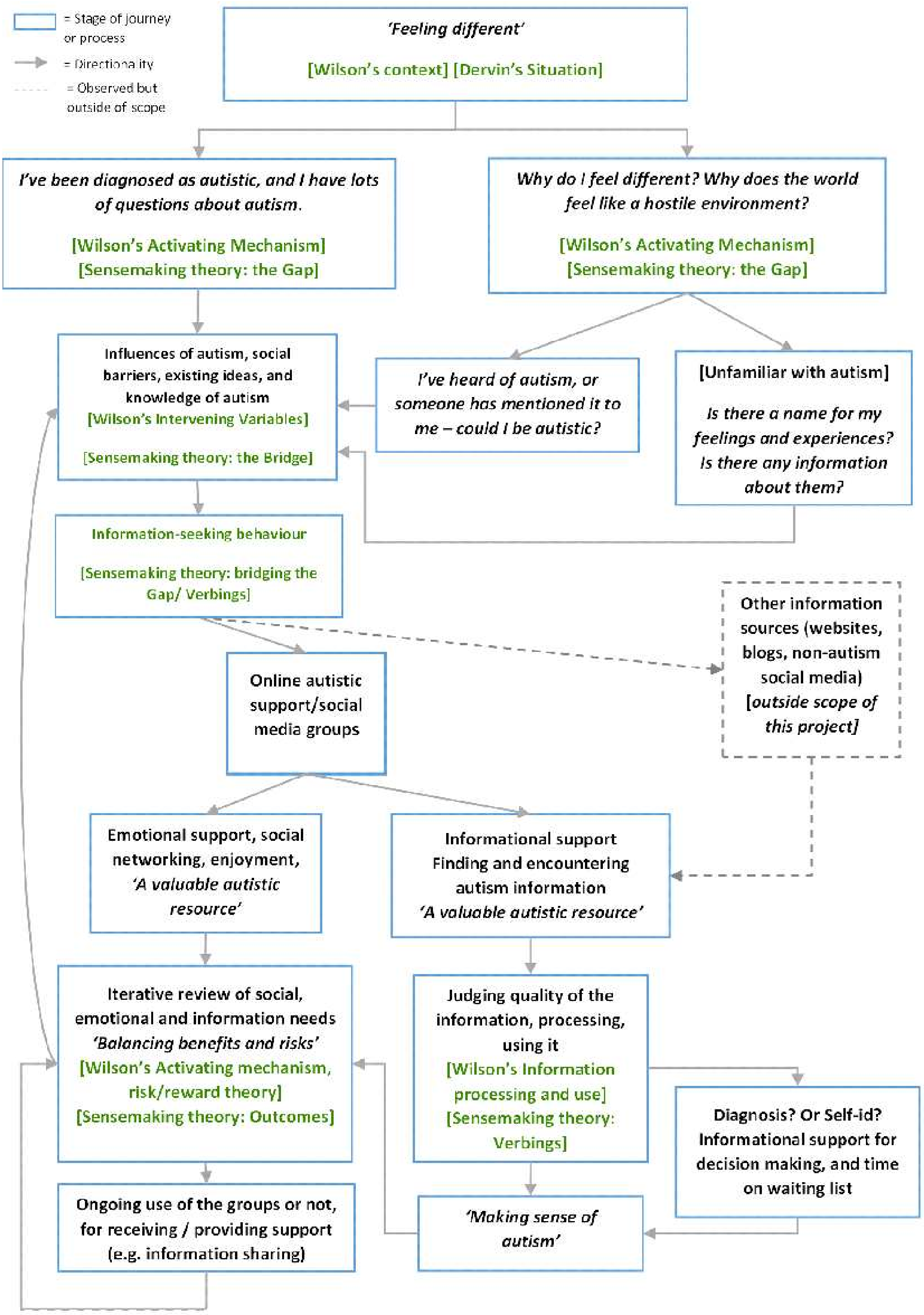


Figure 6: Composite model of participants' autism information journeys. (Source: Authors own work)

This composite model therefore accommodates aspects of existing models, whilst focusing and expanding on important elements of the participants' autism information journeys.

Social model of disability

Finally, the proposed autism information journey model incorporates principles of the social model of disability, which focuses on social barriers in relation to disabilities. This has been referenced previously within information science literature (Anderson, 2018; Ellcessor, 2010; Eneya and Mostert, 2020). The model includes social barriers reported by the participants, such as experiencing the world as a hostile environment, and the influence of social barriers on the participants' information seeking. Some of the information barriers reported by the participants included:

- access to information being dependent on social interaction
- the environment e.g. sensory overload
- geographical location e.g. no local sources of support
- inconsistent or unreliable information
- social demands
- knowing the right language or terminology

PRACTICAL IMPLICATIONS

The study identified some areas that may be of interest to health and social care professionals working with autistic people. The study participants identified the following topics as information needs:

- Autism in girls and women
- Autism in adults
- Descriptions of autism that are detailed, relatable, and use less clinical or academic language
- Everyday life as an autistic person (e.g. parenting, working, studying, living independently)

Other information-related needs identified by participants included:

- More processing time
- Environments with fewer sensory and social demands
- Accommodation of autistic traits and different styles of interacting during information exchanges (such as choice of format or communication method)
- Opportunities for information to be repeated e.g. via recordings and visual formats
- Information that is detailed, unambiguous, and consistent

At a methodological level, the study demonstrated that email interviews can be used successfully alongside face-to-face interviews to collect rich data suitable for thematic analysis.

STUDY LIMITATIONS AND SUGGESTIONS FOR FURTHER RESEARCH

This study focused on the role of online groups for autistic people in users' information journeys. Investigation of other sources of information and informational support for autistic people, including health websites and physical world settings, was outside the scope of this project, but would allow for further expansion of the model. This would help to develop a fuller understanding of autistic people's information needs and overarching autism information journeys. The study participants were all regular Internet users, and their experiences may not reflect those of autistic people who do not use the Internet, through digital exclusion or preference. Additionally, as this was a qualitative study using purposive sampling to explore the experiences of autistic, and likely-to-be-autistic, people using online autistic groups for informational purposes, only basic demographic information was collected. An important aim for future research in this area is therefore to investigate the needs and experiences of autistic people from ethnically and socially diverse backgrounds.

The issue of verifying the autistic status of participants is complex. A known risk is that some people may identify that they are autistic when they are not actually have a clinical diagnosis. However, our research was interested in people who use online forums aimed at people with diagnosis: these can be used by people who self-identify as being on the autism spectrum irrespective of whether they have a clinical diagnosis. This is important because there is evidence that underdiagnosis of autism in adults is a greater problem than overdiagnosis; it has been shown that many undiagnosed adults with autistic traits meet the criteria for an autism diagnosis (O'Nions *et al.*, 2023; Ruzich *et al.*, 2015), and that access to diagnosis is fraught with gender, ethnic, and socioeconomic inequalities (Gould, 2017; Lewis, 2017; Roman-Urrestarazu *et al.*, 2022). Restricting participation to diagnosed autistic people therefore risks excluding people who are autistic but who have faced greater barriers to accessing a diagnosis, thereby perpetuating inequalities. Additionally, people with late-diagnosed autism, and probable undiagnosed autism, are more likely to experience poor mental health and suicide, as mentioned in the literature review. This, coupled with the known inequalities in access to diagnosis, means that it is important to investigate the support needs and journeys of those who are undiagnosed but likely to be autistic, some of whom may be *en route* to diagnosis. In summary, our study examined the role of online groups for people with autism, irrespective of whether those people had a clinical diagnosis or self-identified as being on the autistic spectrum.

The participants' descriptions of how autism influences their ability to find and access information suggest that there may be distinctive information behaviours, which have not been previously referred to within the existing information behaviour literature, such as enjoyment of, and feeling a need for, collecting information ('infocollecting'), and sharing large amounts of information with other people, ('infodumping'). Theories of embodied knowledge and information (Cox, 2018), and of information environments (Veinot and Pierce, 2019) might be helpful in developing greater understanding of features such as feeling overwhelmed by sensory information. Autistic people's information needs could also be explored further in relation to the concept of incognizance (St. Jean, 2017). The concept of there being distinctive autistic information behaviours, and the implications of this for reducing social barriers, could therefore be explored further within information science. The descriptive model of the study participants' autism information journeys presented in this paper could be refined and developed further in future studies focusing on different contexts, such as offline information, or specific topics.

CONCLUSION

This paper has described the autism information journeys of a sample of adults who use online autism groups and report being diagnosed autistic or awaiting assessment. The findings suggest that online autism groups can be a very important, but flawed, source of informational support for group users. Experiencing the physical world as an inhospitable or distressing environment, and having specific information needs related to autism, mean that the importance of online settings is heightened for some autistic people. Despite the risks reported by the study participants, which include misinformation, social conflict, and hostility from other group users, the groups provide experiential and practical information that group users have not been able to find, or access, elsewhere. For some, the informational support found in the groups has been life changing in its significance, whereas for others, it has been viewed as a helpful and useful addition to their information journeys. The proposed descriptive model of group users' information journeys incorporates the social model of disability, and illustrates issues experienced by people who are autistic, or who are likely to be autistic, in relation to information and information-related behaviours. The proposed model is compatible with existing theories of information behaviours, and sensemaking, and could be further developed in future research. Email interviewing proved to be successful in terms of collecting rich qualitative data from people who may not have participated in face-to-face interview methods.

These findings may be of interest to health and social care professionals whose work involves information provision or services for people on the autism spectrum, within a range of contexts, including healthcare, education, and online services. Information gaps identified by the study participants included autism in women and gender differences, advice about being an autistic parent, careers advice for autistic people, and independent living skills for autistic adults, in addition to needs for greater information clarity, detail, and processing time, and environments with reduced sensory and social demands.

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