

# Information behaviours within an online support group for people on the autism spectrum

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## Keywords

Asperger's syndrome, autism spectrum, information behaviours, information needs, online support groups

## 1. Introduction

Many studies indicate that people on the autism spectrum (including Asperger's Syndrome) experience significantly higher rates of physical and mental ill-health, early mortality and social exclusion compared to non-autistic people [1–3]. Previous research indicates that information needs and behaviours play an important role in individuals' management of their health [4], and also that online support groups (OSGs) may be beneficial for people living with various health conditions [5]. Very little literature currently exists on the information needs and behaviours of autistic people. Studies investigating Internet use of people on the autism spectrum suggest that online settings and computer-mediated communication may be particularly accessible [3,6,7].

This study forms part of an ongoing doctoral research project aiming to explore the information needs and behaviours of autistic people, focusing on those who are using online settings to seek and share information. In this poster, we present preliminary findings from the study.

## 2. Methods

For this inductive study, a qualitative methodology was adopted, involving the analysis of public posts gathered from an OSG forum for autistic adults. The UK-based forum is well established and popular, with a large volume of posts by users who are predominantly located in the UK. Permission was given by the provider organisation to analyse public posts from the forums. A total of 164 forum threads (2012 posts in total, by 220 forum users), were analysed using Thematic Analysis [8,9]. The analysis focused on the characteristics of the information shared, the information seeking and sharing processes and behaviours, and motivations for using the forum.

## 3. Results

The preliminary findings are that the OSG provides a combination of informational, social and emotional support for users, and that information needs, seeking and sharing play an important role within this. Users seek and share information relating to mental and physical health, understandings of autism, autism assessment and diagnosis, employment, and social relationships.

The themes suggest that the forum users' information behaviours are influenced by shared experiences of social isolation, and by having specific needs relating to autism that are poorly met in a world designed for non-autistic people. Awareness of other people's stigmatising views of autism was a prominent feature, including those of health professionals.

The OSG provides valued access to experiential information from peers, in addition to social and emotional support, via an online space and medium that the forum users find particularly accessible.

## 4. Conclusions

The work carried out so far indicates that autism influences information needs and behaviours in several ways, including the topics that are discussed, the accessibility/inaccessibility of different information environments and mediums, and the presence of significant social barriers to information seeking and sharing in the wider world.

The next stage of the research will be to carry out individual interviews with autistic people who use the OSG, to gain a deeper understanding of their perspectives of information seeking, use and sharing, and their OSG experiences. It is hoped that the findings from this study will lead to recommendations for organisations hosting forums for people on the autism spectrum.

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