

ABSTRACT

Background: Autism is a complex and life-long neurodevelopmental disorder. In recent years, there has been an increase in the use of complementary and alternative medicines (CAMs) and dietary interventions in people with autism. However, there is a paucity of quality information surrounding the use of these treatments in autism. Hence there is a need for a resource to be developed to guide healthcare professionals (HCPs) and caregivers in evidence based selection of these treatments. In the development of the resource, it is important that the information needs of caregivers of children with autism are determined to ensure that the resource identifies the key issues surrounding autism and CAMs/dietary interventions that are relevant to this group. **Aims:** To examine the information needs of caregivers of people with autism surrounding the use of CAMs and dietary interventions and to explore the experiences of these caregivers when seeking information regarding CAMs and dietary interventions or deciding whether to implement these treatments. **Methods:** A total of 16 parents participated in the focus groups and were recruited via advertisements placed in a quarterly newsletter sent to members of Autism SA. Data was analyzed using NVivo qualitative software to identify themes regarding the caregivers' information needs and experiences. **Results:** The themes that emerged regarding the information needs of caregivers of people with autism were classified as essential information (including evidence, safety, dosage and frequency, access to product and credentials) and desirable information (including cost, rationale, interaction and practical measures to administer CAMs/dietary interventions). Themes that emerged around experiences were challenges faced (including the lack of information and difficulty in deciphering available information) and the importance of the therapeutic relationship between HCPs and caregivers. Views surrounding the format of the resource included a multi-modal presentation and information presented at two levels; one for caregivers and another for HCPs. The information needs identified in the focus groups were combined with information from guidelines for producing consumer health information to produce a draft resource about CAMs and dietary interventions in autism. **Conclusion:** This study identified the information needs of caregivers of people with autism surrounding CAMs/dietary interventions. The information has been used to assist the development of the first draft of an information resource.