Seeking social support on Facebook for children with Autism Spectrum Disorders (ASDs)

Siti Hajar, R. Noorhidawati, A. and Siti Khairatul Razifah, B.
Department of Library & Information Science
Faculty of Computer Science & Information Technology,
University of Malaya, Kuala Lumpur Malaysia
E-mail: noorhidawati@um.edu.my

Abstract

Purpose: This study examined the types of social support messages exchanged between parents and/or caregivers of children with Autism Spectrum Disorders (ASDs) who communicate via Facebook (FB); it studies two autism support groups: Autism Malaysia (AM) and Autism Children Club (ACA).

Method: A total of 3,637 messages including both postings (381) and comments (3,256) were gathered from August to November 2013. The study employed a deductive content-analysis approach. The qualitative data were analysed for social support themes adapted from the Social Support Behavior Code (SSBC). Before collecting the data, email was sent to the FB groups’ moderators to gain formal consent from the members.

Result: The finding indicated that the highest percentage of messages offered dealt with Informational support (30.7%) followed by Emotional support (27.8%). Network and Esteem support messages were responsible for 20.97% and 20.2%, respectively. Tangible Assistance was the least frequent category (0.4%). A majority of these messages discussed and addressed challenges and difficulties associated with caring and raising ASD children, as well as issues such as children’s social lives and self-care routines.

Conclusion: Understandings of how FB is used to seek social support could impact supporting and maintaining effective communication among parents and/or caregivers of children with ASDs. This information could also improve approaches used by health professionals in developing, improving and evaluating social support systems for parents/caregivers.

Keywords: Social support, Support group, Facebook, Autism, ASD

1.0 Introduction

At present, online support groups play an important role in helping individuals cope with health-related issues by providing them with indispensable information via multitudes of social support networks [1]. A number of websites offer interactive features to facilitate online support groups for a variety of chronic illnesses and conditions. These online communities have evolved from mailing lists and asynchronous and synchronous message boards to newer types of social networking sites (SNSs) such as blogs, wikis and Facebook (FB). Vitak, et al.[2], suggesting that FB is a suitable means of communication providing ‘methods’ for passively gathering information while actively engaging its members by enabling them to create profiles and exchange comments or narratives to incorporate various forms of support that subsequently may develop unique bonds within the communities. Kang, et al. [3], discovered that a support group may be a unique source of encouragement as well as emotional and informational support for those coping with health-related problems. Wong [4] also agreed that FB has become a platform for social interactions involving dynamic social network exchange by community members seeking help by efficiently disseminating information.
The literature describes considerable research covering the use of online support groups, including studies on Huntington’s disease [1], HIV/AIDS patients [5], alcohol abusers [6], the weight-loss community [7], breast cancer survivors [8], lung patients, and women with fertility problems [9]. However, insufficient specific information has been reported on the usage of social support by parents and/or caregivers of children with Autism Spectrum Disorders (ASDs). Parents and/or caregivers of ASD children are struggling in their daily lives, mainly because these children require constant support and attention while performing routine chores and self-care activities. This situation is particularly prevalent in Malaysia where public awareness of autism is still low [10] and there is discrimination toward ASD children and their families [11]. Evidence for this is shown by scarcity of research regarding ASD in Malaysia (particularly on clinical interventions), definitions and recognitions of autistic behaviours and recommended treatments [12], teachers’ perceptions and inclusive education in pre-school [13], parents’ motivations and quality of life [14], depression among autistic individuals [15], and means of reducing isolation among ASD individuals [16]. This study is therefore focused on exploring the current state and potential benefits of social support with regard to parents and/or caregivers of children with ASDs by examining messages (postings and comments) exchanged within two FB-based ASD support groups.

2. Literature Review
2.1. Autism Spectrum Disorders (ASDs)
According to www.autism.org.uk, autism is a lifelong developmental disability that affects how a person communicates with and relates to others. Experts believe that autism occurs during the first three years of a person’s life as a result of a neurological disorder that affects brain functions and the means by which these functions make sense of the world. Individuals with autism syndrome share certain difficulties that may affect them in different ways such as experiencing learning disabilities that require special types of support. Some ASD sufferers may experience hyper or hyposensitive reactions to sounds, tastes, smells, brightness and/or colours. ASD occurrences are reported to be higher among males than among females by a ratio of 4 to 1, and they exist across all racial and ethnic groups [12, 14].

Three major difficulties faced by ASD individuals are associated with social communication, social integration, and social imagination. ASD individuals often encounter challenges when it comes to non-verbal communication, and a wide range of ASD incidences involve social interactions and activities that include some elements of play and/or banter. Individuals with ASD tend to maintain a set of behaviours as fixed routines and may resist either small or major changes in their activities. Such inclinations present daily challenges for parents and/or caregivers of children with ASDs. These children also require constant special care and attention, possibly leading to physical and psychological distress among their parents and/or caregivers. These parents and/or caregivers were reported to experience physical pain, stress, extreme anxieties, anger, depression, and frustration, as reported by Sian & Tan, [14]. According to Bromley, et al. [17], parents of ASD children are more likely to suffer psychological distress than parents of children with other types of developmental disability. Mothers in particular are at significant risk of experiencing acute distress associated with heightened child (autistic) misbehaviour and a scant degree of informal support from other family members.

In the Malaysian context, Sian & Tan [14] reported an increase of ASD cases, with an estimated 12,800 autism occurrences as corroborated by Razali, et al. [13]. These findings have confirmed ASDs as the fastest growing disorder in Malaysia, causing the Malaysian Health Ministry to change its diagnostic
2.2. Online Social Support Group
Social support includes information, encouragement, motivation, feedback, emotional support, tangible support, and network support exchanged among peers [1,6,7,18]. Social support groups have evolved from face-to-face groups to computer-mediated groups to online communities that started as mailing lists and online message boards and more recently have evolved through SNSs such as FB, blogs, and wikis.

Advantages of such support groups include 24-hour access, availability of information, access to a group of people or a community who can personally relate to what an individual is going through, and useful sources of health information and support from others across geographical boundaries [1,3,19]. Members of a FB group can choose alternative methods of communication such as wall posts, inbox messages, chats, and status updates [2] using text notes, photos, videos or any combination of these media [4]; these support anonymity not afforded by face-to-face groups [1,3].

One instance of such an online support group is Computer-Mediated Self-Help (CMSG) for patients with HIV/AIDS that encourages individuals with similar and shared interests to communicate regularly by exchanging social support with and for each other [5]. The Internet acts as a venue for these exchanges in which informational and emotional support is frequently both given and received among participants. The anonymity offered by CMSG group benefits individuals with possibly stigmatizing diseases (such as breast cancer, AIDS, and prostate cancer) when discussing topics and issues that may be sensitive and potentially embarrassing.

Additionally, the Computer-Mediated Social Support (CMSS) group is a unique source of encouragement as well as emotional and informational support while coping with health-related problems. Kang, et al. [3], reported that affection may develop within a social support group as a direct result of sharing intense experiences, and the fact that others share similar problems may help members feel less isolated. Group cohesiveness is an important factor in creating positive psychosocial health outcomes associated with participating in a support group. Enhanced bonding processes, stress management, and dealing with health problems can definitely have positive impacts on coping strategies. Hwang, et al. [7], also reported online social support within the weight-loss community. Their findings indicated that the online platform provided unique characteristics of Internet-mediated support, mainly through anonymous and non-judgmental interactions that play an essential role in participants’ weight-loss efforts.

A study by Vitak, et al. [2], on SNSs and social connections, observed that FB pages benefit especially from interpersonal relationships at both individual and collective levels due to the reciprocating nature of the messages in which an individual would post questions and/or thoughts and other members would comment, validate, or offer responses to the original posts. The findings from Vitak, et al. [2], supported the idea that FB could play a supplemental role in providing a channel for maintaining relationships and promoting strong ties among members so that communications can happen even when face-to-face interactions are either not possible or regarded as being too complex.
Similarly, many sites of disease-specific groups have emerged on FB, providing important sources of informational support and patient engagement. Thoren, et al. [20], used a qualitative research method to evaluate the content of interactions within FB communities dedicated to preterm infant-related issues, stated in this report that some FB groups have become popular tools for raising funds and awareness in addition to sharing personal experiences, asking questions, and receiving direct feedback. Oh, et al. [18], further investigated the use of SNSs for health purposes by examining the impacts of perceptions regarding social support and individual health self-efficacy. The findings connoted that individuals having health concerns search for information at health-related social support sites; that study confirmed that individuals benefit from SNSs by seeking social support for health-related matters. Wentzer & Bygholm [9] additionally studied online support groups of lung patients and women with fertility problems. Their findings demonstrated that online communities empower patients in managing their ailment through collaboration with co-patients and guidance of professional health care.

3. Methods
3.1 Research questions
The main objective of this study is to investigate the nature and potential benefits of social support for parents/caregivers of children with ASD using a content-analysis approach to information exchanged via postings and comments within FB autism groups. The specific research questions are:
1. What types of support are exchanged within FB groups of parents/caregivers with ASD children?
2. What types of support are being offered and requested within the groups?

3.2 Data Collection
Data for this study were obtained from two FB autism support group pages, namely: Autism Malaysia (AM) and Autism Children Club (ACA). Both groups are online support communities established to support and increase public awareness about ASD children. In addition, they provide platforms for parents and caregivers to use in sharing knowledge about their experience in raising children with autism, and about development of such children; they frequently share images and videos about ASD children and their current activities. At the time of data collection for this research, the memberships of the two FB groups were 3,972 for AM and 4,094 for ACA, respectively.

These two groups were selected because of their active interaction through exchange of posts and comments with other group members, presenting a sizeable dataset of a total 381 postings (128 from AM and 253 from ACA) and a total of 3,256 comments (1,118 for AM and 2,138 for ACA) for analysis. Data were gathered from August to November 2013. In general, the two groups included mostly parents (approximately 80%) and the remaining 20% were teachers in special education, suppliers of ASD-related products and services, health professionals (including ASD-trained therapists and medical specialists), academic researchers (including students who conduct studies related to autism), and other individuals directly/indirectly affiliated with ASD children. Although messages on the FB pages are publicly posted and displayed, they are not subject to human participation constraints, so ethical approvals from individuals are not necessary, according to Coulson, et al. [1]. However, during the data collection process, emails were written to groups’ moderators to formally request consent from the members to collect exchanged messages from the FB pages. The members gave their consent and the groups were made aware of the purpose of the study.

3.3 Data analysis
The fundamental units of the data analysis were the postings (messages posted by members of the groups) and the comments (messages replying to the postings). “Message” is a generic term used to
describe both postings and comments. Posting normally represents messages that pose questions, or a start of a chain, while a comment is a response or feedback given by a group member to the related posting [21].

The qualitative data were analysed using deductive content analysis in which all messages were coded into several themes based on the Social Support Behavior Code (SSBC) originally developed by Cutrona & Suhr [22] and adapted by Coulson, et al. [1], and Coursaris & Liu [5]. The data were tabulated to generate frequency of occurrence for descriptive analysis purposes. The units of data (narrative messages) treated as qualitative data were coded into five main themes (Information Support, Esteem Support, Network Support, Emotional Support, and Tangible Assistance), and 26 sub-themes, as shown in Table 2.

3.4. Intercoder agreement method
Two intercoders were responsible for coding the data into the themes. The percentage of intercoder agreement was calculated by dividing the number of times they agreed by the total number of units of analysis [23]. The initial percent of agreement was 45.7%, a low percentage indicating a need to further refine the sub-themes to correct vague definitions and remove redundant sub-themes. The sub-themes were therefore revised and, as a result, several new sub-themes were included, irrelevant sub-themes were removed, and redundant sub-themes were removed or merged as follows:

- Messages that included posting certain depictions of a child or an event in the child’s life were coded as ‘Sharing’ [1, 7]
- Messages including information on personal experiences were coded as ‘Personal Experience’ [5, 6]
- Announcements regarding events organized for autistic children and families (community as a whole) and requests to seek participants for face-to-face or online surveys/interviews were coded as ‘Announcement’
- Comments about members’ opinions or thoughts expressed regarding certain situations were coded as ‘Feedback/Opinion’ [6]
- Messages about a particular accomplishment with regards to autistic children (usually generating positive reactions from the communities) were coded as ‘Congratulation’ and ‘Gratitude’ [5]
- Messages allaying sorrow/grief of parents of newly-diagnosed autistics children were coded as ‘Consoling’
- Three sub-themes, ‘Confidentiality’, ‘Listening’, and ‘Loan’ introduced by Coulson, et al. [1], were removed due to the way the messages were openly posted online for others to read, rendering them irrelevant
- ‘Listening’ referred to a behavior that occurred while writing and/or reading posts/comments and impossible to convey via mediated communications
- ‘Loan’, referred to messages containing offers for lending objects in material or monetary form
- Two sub-themes, ‘Perform direct task’ and ‘perform indirect task’ were merged into ‘Performing Task’.

Subsequently, after the second round of data analysis, the intercoders’ agreement increased to 83.7%. The small occurrence of disagreement was resolved by assigning messages to the most appropriate theme as mutually agreed by both intercoders.

For further analysis, messages in the Informational Support theme were additionally coded into two types of interactions: ‘Offered’ and ‘Requested’ [6] to provide answers for the second research question. Offered support refers to informational messages that provide options or solutions related to a
situation/problem, while requested support refers to “the type of support sought”, usually asking for detailed explanation or recommendations pertaining to a specific event/problem. The frequencies and percentages of postings and comments classified into these two main themes were tabulated and calculated. Verbatim statements from both FB groups’ members were included as evidence. The process described earlier was used to generate a final intercoder agreement of 80.6%. The small occurrence of disagreement again was resolved by assigning the messages to the most appropriate theme, as mutually agreed by both intercoders.

4. Findings

4.1. Types of support exchanged within FB groups of parents and/or caregivers with ASD children

Table 1 shows results from all 3,637 support messages within the two FB pages that consisted of 381 postings (128 from AM and 253 from ACA) and 3,256 comments (1,118 for AM and 2,138 for ACA), based on different user roles. The findings indicate messages communicated exclusively by parents with a total of 3,600 (99%) messages (361 postings and 3,239 comments). This includes all five support-message themes: Informational, Emotional, Network, Esteem, and Assistance. Aside from those, only about 1% of the total number of messages involved other types of users. There were 14 messages (0.4%) from the FB administration, 8 (0.2%) from researchers, 7 (0.2%) from health professionals, 6 (0.2%) from childcare/school personnel/administrators, and 2 (0.1%) from interested individuals (a swimming coach and a product supplier).

Table 1: Distribution of overall social support messages based on the FB group members’ roles

<table>
<thead>
<tr>
<th>Role of User</th>
<th>Informational</th>
<th>Emotional</th>
<th>Network</th>
<th>Esteem</th>
<th>Tangible Assistance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>P</td>
<td>C</td>
<td>P</td>
<td>C</td>
<td>P</td>
</tr>
<tr>
<td>Parents (including relatives)</td>
<td>AM</td>
<td>63</td>
<td>311</td>
<td>32</td>
<td>351</td>
</tr>
<tr>
<td></td>
<td>ACA</td>
<td>143</td>
<td>572</td>
<td>31</td>
<td>594</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>3,600</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Academic researchers (including students)</td>
<td>AM</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>ACA</td>
<td>1</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health professionals (doctor, physiotherapists, nurses)</td>
<td>AM</td>
<td></td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>ACA</td>
<td>4</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FB admin</td>
<td>AM</td>
<td>5</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>ACA</td>
<td>2</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>14</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Childcare/school personnel/administrator (related to autism)</td>
<td>AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>ACA</td>
<td>1</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others (product)</td>
<td>AM</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(FINAL DRAFT)

Citation Information:
Examples of the postings include:

Parents:
“Thank goodness, mummy is very proud of you ... although you are in a PPKI class (a special class for ASDs children) but you managed to get the first place in the class ranking, hope this is only the beginning of many more to come my dear Felix..” (P35-ECR)

Researcher:
“I would need some advice... I am planning to do a research on ‘Teaching Children with Autism in Inclusive Educational Settings’ but I am still unable to finalise the niche area and the research questions. Please share with me your ideas, or any other potential research area about autism children. Your help is much appreciated...thank you very much.” (P27-AD)

FB admin:
Attention! Autism Malaysia’s Family Day (together with annual meeting) will be held on 7th & 8th December 2013 at Nur Laman Bestari & Eco Resort, Ulu Yam Baru, Batu Caves, Selangor. Information on the fees and participation would be available soonest possible. Get ready to join us..” (P8-ANC)

Physiotherapist (Service Provider):
“..... By the end of September, AnNahlu Therakids will begin its operation in Taman Pahlawan, Sungai Udang, Melaka. Among available services are: Individual Occupational Therapy (OT), Group Therapy and Social Skill group, after-school programme, school readiness programme, school holiday camps, and parents support group (including sharing, talks and trainings)...” (P194-ANC)

Table 2 gives an analysis of the frequencies and percentages of messages when grouped into five main themes and 26 sub-themes. The most frequently recorded theme was Informational support with 58.5% postings (n=223) and 27.5% comments (n=895). The second most frequent theme was Emotional support, with 16.8% postings (n=64) and 29.1% comments (n=946). Messages associated with the third most frequent theme fell under Network support, with 16.3% postings (n=62) and 21.5% comments (n=699), followed by Esteem support with 7.1% postings (n=27) and 21.7% comments (n=706). Tangible Assistance was the least frequently occurring with 1.3% postings (n=5) and 0.3% comments (n=10).

<table>
<thead>
<tr>
<th>Themes</th>
<th>Frequency of postings (%)</th>
<th>Frequency of comments (%)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informational</td>
<td>223 (58.5)</td>
<td>895 (27.5)</td>
<td>1,118 (30.7)</td>
</tr>
<tr>
<td>Advice/guidance</td>
<td>64 (16.8)</td>
<td>396 (12.2)</td>
<td>460 (12.6)</td>
</tr>
<tr>
<td>Referral to experts</td>
<td>23 (6.0)</td>
<td>86 (2.6)</td>
<td>109 (3.0)</td>
</tr>
<tr>
<td>Situation appraisal</td>
<td>14 (3.7)</td>
<td>165 (5.1)</td>
<td>179 (4.9)</td>
</tr>
</tbody>
</table>
(FINAL DRAFT)

Citation Information:

<table>
<thead>
<tr>
<th></th>
<th>Teaching</th>
<th>Announcement</th>
<th>Personal Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional</td>
<td>11 (2.9)</td>
<td>147 (4.5)</td>
<td>158 (4.3)</td>
</tr>
<tr>
<td>RS Relationship</td>
<td>6 (1.6)</td>
<td>26 (0.8)</td>
<td>32 (0.9)</td>
</tr>
<tr>
<td>AFF Physical/virtual affection</td>
<td>0 (0.0)</td>
<td>17 (0.5)</td>
<td>17 (0.5)</td>
</tr>
<tr>
<td>SYM Sympathy</td>
<td>7 (1.8)</td>
<td>31 (1.0)</td>
<td>38 (1.0)</td>
</tr>
<tr>
<td>EMP Empathy/understanding</td>
<td>3 (0.8)</td>
<td>182 (5.6)</td>
<td>185 (5.1)</td>
</tr>
<tr>
<td>ECR Encouragement</td>
<td>23 (6.0)</td>
<td>316 (9.7)</td>
<td>339 (9.3)</td>
</tr>
<tr>
<td>PRY Prayer</td>
<td>5 (1.3)</td>
<td>89 (2.7)</td>
<td>94 (2.6)</td>
</tr>
<tr>
<td>CNS Consoling</td>
<td>0 (0.0)</td>
<td>21 (0.6)</td>
<td>21 (0.6)</td>
</tr>
<tr>
<td>GRT Expression of gratitude</td>
<td>18 (4.7)</td>
<td>138 (4.2)</td>
<td>156 (4.3)</td>
</tr>
<tr>
<td>CNG Congratulation</td>
<td>2 (0.5)</td>
<td>126 (3.9)</td>
<td>128 (3.5)</td>
</tr>
<tr>
<td>Network</td>
<td>64 (16.8)</td>
<td>946 (29.1)</td>
<td>1,010 (27.8)</td>
</tr>
<tr>
<td>ACC Access</td>
<td>6 (1.6)</td>
<td>79 (2.4)</td>
<td>85 (2.3)</td>
</tr>
<tr>
<td>PRS Presence</td>
<td>4 (1.0)</td>
<td>22 (0.7)</td>
<td>26 (0.7)</td>
</tr>
<tr>
<td>CMP Companionship</td>
<td>1 (0.3)</td>
<td>41 (1.3)</td>
<td>42 (1.2)</td>
</tr>
<tr>
<td>SHR Sharing Stories</td>
<td>51 (13.4)</td>
<td>557 (17.1)</td>
<td>608 (16.7)</td>
</tr>
<tr>
<td>Esteem</td>
<td>27 (7.1)</td>
<td>706 (21.7)</td>
<td>733 (20.2)</td>
</tr>
<tr>
<td>CPL Compliment</td>
<td>18 (4.7)</td>
<td>266 (8.2)</td>
<td>284 (7.8)</td>
</tr>
<tr>
<td>VLD Validation</td>
<td>0 (0.0)</td>
<td>349 (10.7)</td>
<td>349 (9.6)</td>
</tr>
<tr>
<td>RTB Relief of blame</td>
<td>0 (0.0)</td>
<td>6 (0.2)</td>
<td>6 (0.2)</td>
</tr>
<tr>
<td>FO Feedback/Opinion</td>
<td>9 (2.4)</td>
<td>85 (2.6)</td>
<td>94 (2.6)</td>
</tr>
<tr>
<td>Tangible assistance</td>
<td>5 (1.3)</td>
<td>10 (0.3)</td>
<td>15 (0.4)</td>
</tr>
<tr>
<td>DIT Perform task</td>
<td>3 (0.8)</td>
<td>6 (0.2)</td>
<td>9 (0.2)</td>
</tr>
<tr>
<td>ACT Active participation</td>
<td>2 (0.5)</td>
<td>2 (0.1)</td>
<td>4 (0.1)</td>
</tr>
<tr>
<td>WLL Express willingness</td>
<td>0 (0.0)</td>
<td>2 (0.1)</td>
<td>2 (0.1)</td>
</tr>
<tr>
<td>Grand Total</td>
<td>381 (100.0)</td>
<td>3,256 (100.0)</td>
<td>3,637 (100.0)</td>
</tr>
</tbody>
</table>

4.1.1. Informational Support

Messages within this theme were observed and divided into six sub-themes: Advice, Referral to Experts and Resources, Situation Appraisal, Teaching, Announcement, and Personal Experience. Advice postings usually include specific questions concerning ASD and seeking advice and suggestions from community members. In response to postings, comments contain advice and offer suggestions as guides to managing challenges faced by autistic individuals, parents, and family members.

For example, one posting offered the following advice when asked about a particular sedative:

“For me, being aggressive and hyperactive are different matters... hyperactivity can usually be controlled through regimented diet and by increasing physical activity... while long-term medication is not encouraged... typically aggressive behaviour have its trigger, so if the trigger is identified, it is easy for us to regulate/train... intensive therapy can benefit them because I did observe severe autism behaviour (harming others) was able to be subdued via intensive therapy...” (P142, C4 - AD)
Referral to experts includes direction of questions to specific institutions, sources of expertise, specialists, websites and other online or offline resources. Websites and links were normally recommended as reading sources, while a number of medical centers and institutions were frequently referred to as venues for various tests and therapy sessions. Members of the group also named a few specialists and professionals working in this area.

Situation appraisal includes messages to help “reassure, redefine, and reassess circumstances, often in manners which help create optimism or reveal new information that might be helpful” [24]. One example is:

“I think you should not quit... you are considered lucky the kindergarten willing to accept your child... ever since we moved to a new place not one kindergarten wants to take in Eriq once knowing he is an autism children... not even a single opportunity is given to him... we are not hoping to much at the moment. As long as Eriq is accepted and able to communicate with his peers, we are grateful…” (P177, C1 - APR)

Teaching messages provide factual or technical information about various aspects of ASDs and the behaviours and skills needed to deal with certain circumstances. Announcement on the other hand includes messages that inform certain events organised for ASDs children and families (community as a whole) as well as requests seeking participants for online or face-to-face surveys/interviews. Information on new government schemes were made available for parents and ASDs individuals were also included under this sub-theme. For example, parents with ASDs children were eligible to apply for special car stickers under a new school program scheme.

Postings to share information about Personal experiences were the most commonly observed in this theme. These differed from teaching messages in that the messages conveyed personal encounters or descriptions of specific events related to ASD children. As an example of such posting:

“huhuhu... this was our second time went to speech therapy without any results.... I feel like crying already! Minny refused to do anything, we did our best to persuade her with toys, but it did not work... she ignored us and put on her stone face... when the therapist invited her to perform activities, she started making fake noises as if she wanted to throw-up or spit... when we asked her to do more, she would scream and cry ... I feel helpless, I really do not know how to handle Minny... but it is fine, I don’t really want to think about it anymore right now, I just want to drive back to Raub ... huhuhu…” (P83 - PE).

4.1.2. Emotional Support

Emotional support messages are related to sharing and describing emotional and psychological encounters that normally represent seeking comfort. The nine sub-themes include Relational Support (Relationship), Physical/Virtual Affection, Sympathy, Empathy/Understanding, Encouragement, Prayer, Consoling, Gratitude, and Congratulation. Relational support includes friendships and companionship within the communities. For example, one message describes a close contact between one parent and another with an autistic child during a festive season:
“We met due to AM... thanks to Lynn and family for making the effort to come over and celebrate Eid with us while doing some shopping at the same time :). It is fun to get the chance chatting with Phil... Do visit our home again in the future”. (P137 - RS)

Others showed direct support using Physical Affection gestures with words or icons like “hugs” and “kisses”. Sharing another’s emotions, especially those of sorrows or anguish, pity, and compassion, falls under the sub-theme of Sympathy. Empathy was shown through understanding and demonstrating an ability to identify and respond to others’ situations, sentiments, and motives for actions taken. For example, a mother shared a message about her daughter’s experiences while travelling to their hometown during a festive season, while another mother empathized and replied by describing her own experiences:

“Yeeaah, we are ready to go back to our home sweet home tomorrow ... I am so tired to handle Kathy’s continuous “hoop haap” along the journey from Perlis to Temerloh. At least when at home, Kathy will get her freedom, we only have to keep her away for dangerous object. She would want to open the fridge a hundred times a day, I will let her be... mummy is fine with it…” (P145 - SHR)

“I thought my child is the only one who likes to open the fridge ... I do not know what they see inside the fridge. But the unpleasant experience is when we visited others and my child opens the host’s fridge as well, that is why I am reluctant to go out. It is better to just stay at home…” (P145, C4 - EMP)

Encouragement messages offer members of a group reassurance, faith, and support. Parents of autistic children normally face common challenges and somewhat similar situations. Some messages appeared to be highly devastating, especially when emotions were strongly communicated through messages and posts. Most feedback messages offered prayers for the recipients and wishes toward wellbeing of the family hoping they could endure. Some messages appeared to offer Consolation to allay grief and despair. Expression of Gratitude was implied when messages offered useful tips or compliments. Congratulation messages were also posted to those sharing distinct accomplishments involving ASD individuals.

4.1.3. Network Support
This theme supports community connections. Access messages welcome members to participate in discussions or group activities by joining the groups, e.g.:

“Once I moved there... we will get together, yes”. (P75, C6 - ACC)

Presence messages remind communities that members should never have to struggle alone in difficult times. Companionship messages emphasized availability of members with similar interests and experiences, and to show friendship; for example:

“It is hard and difficult to educate people who do not understand the true meaning of autism... stay strong ... you are not alone... I am here with you…” (P115, C29 - CMP)

Sharing messages were mostly posted by parents about a particular child development, behavior, or activity in their daily life, e.g.:

“I will be year two in 2014”... “can I get some gifts then?”... (P64 - SHR)
4.1.4. Esteem Support
This type of message validates members’ perspectives with respect to a situation in terms of beliefs, actions, thoughts, or emotions (Validation). For example:

“You did well 😊 explaining to kids... sometimes we need to do some reverse psychology too (even when anger occurs)...” (P115, C16 - VLD)

Some offered praises (Compliments) for positive comments made about personality or improved ability of ASDs children. Relief of Blame messages simply alleviated others’ feelings of guilt. For example, a mother shared a link for information related to risks concerning induced birth and autism, while another mother assured her that the current situation matters most:

“The odds about a significant increase of autism cases in children were probably because of induced or augmented labor. a study of more than 600,000 births has reported this” (P130) – [Induced Labor Linked to Higher Autism Risk from www.medpagetoday.com]

“Not all, but no need to feel so bad. The child is already out, just do the best to help...” (P130, C4 - RTB)

Feedback/Opinion is views or judgments formed about a topic not necessarily based on any facts or knowledge [6]. These messages are more often views about a situation rather than suggestions for action.

“I do not know either, all I know is that the medication will slow down the ASD children. If the children are not consuming it, they will become aggressive, somewhat hyperactive... my sister said the medication is useful to keep the children calm and control their aggressive behaviour...” (P142, C3 - FO)

4.1.5 Tangible Assistance
Messages coded within Tangible Assistance offer to provide necessary help to others. One example might be offering help in Performing a Task (online or offline), including volunteering to do online research or offering to accompany a person to consult a specialist for the first time. For example, a parent wrote:

“When we attend our next session, I can prepare some papers and color pencils for Harry to scribble as he likes.” (P221, C22 - DIT)

Active Participation was illustrated by messages such as, “We will do this together, okay! :)” . Some messages implied a Willingness to help without specifying the exact nature of offered assistance; for example:

“I will pray that Lucy will always have perseverance. If you need anything please pm me...” (P68, C21 - WLL)

4.2. Exchanges of Offered and Requested Informational Support
Table 3 shows further analysis of Informational Support exchanged to examine the types of offered and requested information being exchanged in the FB autism groups. 74% of the overall postings offered while 26% requested information. Out of the total number of postings, 40.4% offered information about
Citation Information:

Personal Experiences and the most frequent request for postings (22.4%) asked for Advice. For comments, 79.9% offered while 20.1% requested information. From the overall informational comments, 25.4% offered advice, 18.2% offered Situation Appraisal, and 16.4% offered Teaching or Factual Info. Only 18.9% requested Advice.

Table 3: Details of Informational support in Offered and Requested

<table>
<thead>
<tr>
<th>Posts</th>
<th>Offered</th>
<th>Requested</th>
<th>Offered</th>
<th>Requested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advice</td>
<td>6.3% (14)</td>
<td>22.4% (50)</td>
<td>25.4% (227)</td>
<td>18.9% (169)</td>
</tr>
<tr>
<td>Announcement</td>
<td>5.8% (13)</td>
<td>1.3% (3)</td>
<td>0.1% (1)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Situation Appraisal</td>
<td>6.3% (14)</td>
<td>0% (0)</td>
<td>18.2% (163)</td>
<td>0.2% (2)</td>
</tr>
<tr>
<td>Referral to Expertise</td>
<td>10.3% (23)</td>
<td>0% (0)</td>
<td>9.3% (83)</td>
<td>0.3% (3)</td>
</tr>
<tr>
<td>Personal Experience</td>
<td>40.4% (90)</td>
<td>2.2% (5)</td>
<td>10.5% (94)</td>
<td>0.7% (6)</td>
</tr>
<tr>
<td>Teaching/Factual Info</td>
<td>4.9% (11)</td>
<td>0% (0)</td>
<td>16.4% (147)</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Total</td>
<td>74.0% (165)</td>
<td>26.0% (58)</td>
<td>79.9% (715)</td>
<td>20.1% (180)</td>
</tr>
</tbody>
</table>

Some examples of the highest requested and offered messages (in postings and comments) are:

Postings: Offering Personal Experiences (40.4%):
“This morning Jacob had his OT at IIUM. As a result of a comprehensive discussion during the OT session, the therapist made a comment that Jacob is able to read and write (although selectively) besides having an ‘immature grip’ of pen and pencil. He needs to keep stimulates muscles on his fingers through training” (P4 - PE, OFR)

“Adam seems comfortable lying on the floor under the table at the restaurant. Pulling him off the floor or scolding him might cause a tantrum. Then nobody will be able to have dinner in peace. We just let him be. Although all the waiters were throwing us weird looks... we (Adam’s mummy and daddy) just ignored them…” (P232 - PE, OFR)

“Noah has been really active today, so I had to swaddle him for a bit.” (P80 - PE, OFR)

Postings: Requesting Advice (22.4%):
“My child is above 3 years old and still cannot talk, I have observed some symptoms of autism. I was concerned so I brought him to see a child specialist at a private facility. The doctor said that my child is not autistic, but my child was out of focus when doing things that make me worry. What should I do?” (P12 - AD, RQT)

“ Asking for opinion from AM especially SLPs and parents with older kids. Can a low functioning autistic child with 'severe communicative impairment' (but verbal), ever learn to communicate well? With/without AAC? Any experience? Could cognitive ability determine their communication progress? (besides sensory, audio-processing and speech). Tq very much AM.” (P152 - AD, RQT)

“Hi all... I am asking for opinions... which supplement or vitamin is suitable for children with autism? (: ” (P251 - AD, RQT)

Comments: Offering Advice (25.4%):
“If we keep thinking about what others was saying, and we will be in agonize. We need to learn to turn a deaf ear, open our minds and hearts as well as our thoughts.” (P232, C10 - AD, OFR)

“My suggestion is to visit a child psychiatrist and do a prognosis to identify areas where attention is needed... you do not need to wait for confirmation whether the child is autistic or otherwise...” (P140, C13 - AD, OFR)

“At a government-funded hospital, allergy test is done by the dermatology department or skin specialist... Usually an allergy test is recommended to identify any serious reactions such as whole body itch or breathing difficulty or for other allergy reactions such as swollen eyes. It is advisable for the parents to do a preliminary observation on such condition” (P208, C5 - AD, OFR)

Comments: Requesting Advice (18.9%):
“What autistic symptoms does your child have?” (P140, C5 - AD, RQT)

“What is the name of the medication?” (P142, C2 - AD, RQT)

“If he is hyperactive, did he eat anything out of the ordinary?” (P197, C3 - AD, RQT)

“Hurm... How to apply GL for blood test? How to justify that the blood test is necessary? Do I get a referral letter from the doctor?” (P208, C21 - AD, RQT)

5. Discussion
This study reports types of social support messages exchanged between parents and/or caregivers of children with Autism Spectrum Disorders (ASDs) who communicate via FB pages. Two autism support groups: Autism Malaysia (AM) and Autism Children Club (ACA) were included in the study. The findings indicate that Informational and Emotional support postings were the most frequently offered and sought among members of the communities. This is in agreement with previous studies conducted by Braithwaite, et al. [24], Coulson, et al. [1], Coursaris & Liu, [5] and Chuang & Yang, [6]. Support postings relating to Network and Esteem were exchanged at similar frequencies, while Tangible support was the least-frequent among the five main themes. This could be attributed to the online nature of the interactions where the group’s members live at different states across dispersed geographical areas, reducing their capability for exchanging anything tangible or responding to offers of physical assistance. Nevertheless, the FB group members were observed as being connected and ‘knowing’ each other well enough to allow them to organize meetings for particular events.

To address the first research question, the findings reported that messages falling under the Informational theme comprised more than 30% of overall postings and comments (n=3,637). The related sub-themes additionally support the results of other related studies. It was also found that FB community members sharing Personal Experiences engaged in discussions about just what is ASD and which Early Intervention Programme (EIP) would be the best for their children. Group members also shared their problems in handling autistic children in public places and engaged in sub-themes on Advice/Guidance to share information related to schools in which ASDs children should enroll. Some details on highly technical and factual information related to ASD education were coded under the Teaching sub-theme that often includes conversations about school subjects, therapy courses
associated to phycology development, toilet-training methods, communication skills, and reading abilities.

The second most frequently exchanged messages fell into the *Emotional* theme, also consistent with previous studies [1, 5]. The study noted that *Emotional* messages were most frequently conveyed within comments rather than via postings. This is logical because postings carrying emotional messages often receive lengthy comments that show *Empathy*. *Prayer, Sympathy* and, in return, *Expression of Gratitude, Congratulation*, and *Virtual Affection* remarks such as “hugs” and “kisses”, would normally occur within the last few comments related to the postings.

Messages falling into the *Network* theme were predominantly *Stories* shared among community members and *Access* provided by groups to welcome new members with genuine interests. Group members were welcomed and invited to get together at events or picnics. *Stories* shared are usually about ASD children’s food preferences, how they eat certain food, their dislikes of chocolate, what they adore and dislike, their robot-like or accent-riddled speeches, and, most importantly, success stories in school or at therapy sessions. Parents openly shared their own photos, video recordings, thoughts, and experiences with others.

In addition, messages falling into the *Esteem* theme were coded under the *Validate* sub-theme that mainly concerned confirmations on others’ point-of-view comments, similar to those reported by Coulson, et al. [1]. The *Compliment* sub-theme typically included messages describing success stories shared by parents and other members that uplifted spirits and increased motivation to keep up the good work of raising ASD children. The fewest support messages, on the other hand, were related to the *Tangible Assistance* theme. This is reasonable to expect in an online community where lack of physical proximity between group members imposes limitations and provides challenges to delivering this type of support.

In addressing the second research question on requested and offered information, the findings revealed that the FB communities often requested *Advice* within their ‘postings’ (22.4%). These requests were especially important for parents whose children had just been diagnosed and/or confirmed as having ASD. They were usually in the process of trying to accept the fact that their children could never be the same as other normal children, and this is the time when parents most needed factual information and spiritual support to help them cope. One posting prompted others to reply (via commenting) with some facts, referrals to webpages, links, and advice about how to find autism-related information on the Internet. Subsequently, the data of the sub-theme on *Personal Experiences* indicated that 40.4% of the messages included messages to other members of the FB groups encouraging them to validate, support, and post stories describing similar encounters, once again consistent with the study by Braithwaite, et al. [24]. Other information regularly being offered includes *Advice/Guidance, Referral to Expertise/Experts, Situation Appraisal and Teaching/Factual* sub-themes. A small number of messages also fell under sub-theme of *Announcements*; these were mostly reminders, guidelines, consents, or requests from researchers and regulators advising members of FB pages about procedures and details of upcoming events. With respect to comments, the messages mostly fell into offered *Advice* (25.4%) and requested *Advice* (18.9%) sub-themes, followed by information offered on *Situation Appraisals* (18.2%) and *Teaching/Factual Information* (16.4%) sub-themes. Other comments included information offered on *Personal Experiences* (10.5%), and finally the least on *Referral to Expertise* (9.3%).

Citation Information:
6. Conclusion
The study unveils types of social support messages offered and requested in online communities of FB autism groups. Members of the FB groups value FB as a convenient platform for sharing personal experiences and seeking advice in raising or taking care of children with ASD. This study, however, was limited to only two FB group pages, mainly because these groups were the most active groups that could provide sufficient data for the purpose of the study. This paper reports an exploratory study on FB usage as an online social support tool, particularly for parents and/or caregivers of children with ASD. Further study could be conducted to investigate roles of different types of FB group members and examine the effectiveness of FB as online support community through in-depth interviews and thematic analysis of exchanged messages. The findings described in this paper can provide useful input for program development and intervention services, particularly with regard to social support for parents/caregivers of children with ASDs.

Acknowledgement
This research was partially funded by the University of Malaya High Impact Research Grant (No: UM.C/625/1/HIR/MOHE/FCSIT/16/H-22001-00-B00016).

References


