



IHEART2U: Empowerment Based Design of Social Support Mobile App Development for Autistic Children Caregivers

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ABSTRACT

Autism spectrum disorder (ASD) is a neural developmental disorder characterized by impaired social interaction, communication difficulties, and restricted behaviours. Understanding the disorder and providing necessary social support for guidance and assistance is vital for caregivers, including educators, parents, and the public. The aim of this research is to design and develop a social support mobile app for autistic children's caregivers named IHEART2U. We design the app by incorporating the empowerment-based design elements to ensure it provides practical assistance but also foster a sense of empowerment and control over their child's development and well-being. Caregivers can feel more confident, informed, and supported in their role. For the design and development, we used the Mobile Development Life Cycle (MADLC) as the methodological approach. During the requirements gathering, we conducted interviews in collaboration with the National Autism Society of Malaysia (NASOM), a private school for children with autism and caretakers. Through thematic analysis, we incorporate four empowerment-based design elements: information support, emotional support, companion, customization, and personalization in the user interface (UI) design of the mobile app. Upon completion of the high-fidelity prototype, we conducted usability testing using the System Usability Scale (SUS) to obtain feedback from the stakeholders. The score was 90.83 above average. The respondents provide constructive feedback on how to improve the app. In conclusion, we believe that by integrating these empowerment design elements, the IHEART2U social support mobile app becomes a source of empowerment, support, and guidance tool for caregivers, helping them navigate the challenges of raising and caring for children with autism. Future work will involve iterative user testing and feedback to further refine and enhance the app's effectiveness.

1. Introduction

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Autism, commonly referred to as autism spectrum disorder (ASD), is a broad term that refers to several problems involving speech delays, repetitive behaviors, developmental difficulties, and social skills. It is a brain developmental condition characterized by hampered social interaction, reduced communication, and constrained behaviors. It is critical for schools, parents, and the public to have a solid grasp of autism as the illness becomes increasingly widely diagnosed [1]. The National Autism Society of Malaysia (NASOM) is a non-profit charitable organization in Malaysia that offers support, care, education, and protection to people with autism and their families. According to the most recent data from the Ministry of Health (MOH), the number of diagnoses for autism spectrum disorder (ASD) in Malaysia has increased significantly over the last ten years. The figure for 2021 showed a total of 589 children aged 18 and below being diagnosed with ASD, up five percent from 562 children in 2020 [2].

Being a spectrum disorder, each person with autism possesses unique strengths and challenges. Some individuals with ASD require significant support from caregivers in their daily lives, while others may need less support and, in some cases, can live independently. A caregiver, whether informal (unpaid) or formal (paid), is someone within a person's social network who assists them with activities of daily living. Caregiving typically addresses impairments related to old age, disability, illness, or mental disorders. Support groups for caregivers of disabled children have been in existence since the early 1980s, providing a platform for gaining information, sharing experiences, and offering emotional support [3-5]. Caregivers of children with autism spectrum disorder (ASD) are believed to experience greater stress compared to parents of children with other disabilities, which significantly affects their financial and overall well-being due to a lack of support and public awareness [6, 7].

Social support has been extensively studied across various disciplines, including psychology, public health, education, rehabilitation, and social work. Support groups allow members with similar challenges to come together, sharing coping strategies, relevant information, and personal experiences, and providing empathetic understanding. In Malaysia, parents of children with special needs have long participated in face-to-face parent support groups or counseling sessions organized by private organizations like NASOM or government agencies such as the Department of Social Welfare (Jabatan Kebajikan Masyarakat). These gatherings offer opportunities to acquire new information, share experiences with other group members, and receive emotional support. This is to align with the National Population and Family Development Board (LPPKN) of Malaysia agenda in ensuring health promotion and well-being stability among the communities [8].

Past research has emphasized the importance of the caregiver community sharing the government's aspirations to ensure the success of policies concerning special-needs education and interventions aimed at empowering individuals with disabilities [9-13]. Hence, the objectives of this paper are twofold: (a) to identify the empowerment-based design requirements and (b) to design and develop the mobile app named IHEART2U aimed at empowering social support for autistic children's caregivers.

To improve their functional abilities, children with autism spectrum disorder (ASD) may need lifetime support and resources, which can be overwhelming for their caretakers, especially parents, and families. To ensure high standards in ASD interventions and to develop into capable carers themselves, parents play a critical role in actively participating in interventions with diverse autistic related experts and practitioners. For children to develop to their full potential, early detection of developmental delays and effective interventions are essential. To facilitate collaboration among family, medical practitioners, educators, and therapists for the early detection and intervention of children with developmental disorders, there is a need to create a network of touchpoints across government agencies, NGOs and communities. Hence, the goal of this study is to design and develop a social support mobile app that can become a one stop platform for caregivers for strengthening

their social support networks of carers. This is because less concentration is dedicated to resolving the problems and difficulties faced by parents and carers, despite the growing emphasis on education and healthcare for kids with autism, notably through early treatments and therapy. It can cause mental instability and emotional stress for these carers to raise and care for autistic people under such intense pressure. They encounter several difficulties, such as increased parental stress, increased mental health worries, marital issues anxiety and depression, feelings of isolation and public dread and others [9-14].

Today, social support groups have evolved significantly to assist individuals facing difficulties and challenges in coping with life situations. Sharing experiences with others who are going through similar situations provides hope, whether through traditional face-to-face meetings or online forums and channels [9]. Technological advancements have also paved the way for leveraging technology to empower individuals, organizations, and communities in supporting caregivers. People are increasingly turning to the internet to seek crisis support, help, or simply to connect with others who share their interests and experiences. In Malaysia, official support group systems are often moderated by government bodies and NGOs. Active agencies such as The National Autism Society of Malaysia (NASOM), Ministry of Women and Family Development (MOWFD), Ministry of Health (MOH) and Ministry of Education (MOE) are responsible for formulating policies related to special needs education and interventions to safeguard the well-being of both autistic children and their caregivers. In addition, online communities such as the Autisme Malaysia Facebook Page (AM), dedicated WhatsApp groups, Instagram, and web portals provide emotional and informational support, offering empathy, encouragement, and expert advice to caregivers alongside traditional methods.

2. Literature Review

2.1 Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a constantly evolving disorder that has been extensively studied in various research papers. It is a neural developmental disorder that disrupts normal brain functioning and has a significant impact on learning, social interaction, speech, and cognitive development, encompassing a person's mental, emotional, and cognitive abilities [15, 16]. According to the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-V) [17], ASD is characterized by limited communication and difficulties in initiating or sustaining conversations, along with restricted, repetitive, and stereotyped patterns of behavior and interests. It can be diagnosed as early as two years old [17]. ASD is considered a spectrum disorder due to its wide range of types and severity, irrespective of ethnic, racial, and social groups. However, early interventions and treatments can improve a person's functioning and symptoms, even though ASD is a lifelong condition [17, 18]. Living with individuals with autism has a profound impact on the well-being of families, as they must cope with unpredictable behavioral issues such as aggression, temper tantrums, self-injury tendencies, as well as sleeping and eating disorders. Therefore, a comprehensive approach to managing children with ASD, especially in providing support to their caregivers, is crucial in effectively handling and caring for them [19, 20].

2.2 The Caregivers

The definition of a caregiver in literature is multi-dimensional in context and often categorized as "formal" or "informal". Generally, a caregiver is someone who meets the needs of children or individuals who are ill or unable to care for themselves [21, 22]. An informal caregiver typically refers

to family members, including parents, partners, friends, or neighbors, who have a significant personal relationship with and provide a wide range of assistance to older adults or individuals with chronic or disabling conditions. These caregivers can be primary or secondary caregivers and may live with or separately from the person receiving care. A primary caregiver is often closely associated with parents, family members, or trained professionals who assume responsibility for individuals with physical or mental disabilities, chronic illnesses, or old age [23, 24]. On the other hand, a formal caregiver is described as a provider associated with a structured service system, whether they are a paid worker or a volunteer. Both paid and unpaid caregivers or carers assist with daily activities.

2.3 Social Support

The term social support based on its theoretical foundation is defined as to understand the impact of social relationships on mental health and well-being. It suggests that individuals with strong social support networks are better able to cope with stress and have better overall health outcomes [25-28]. It explored the connection between social support and its prominent role with caregivers in research related to health, personality, and personal relationships. Social support was classified into perceived support, which is associated with better mental health, and received support, which involves specific supportive actions offered at the most beneficial time. It was also assessed based on structural and functional support. The empowerment of family relationships, friends, and organizational members contributed to structural support, which encompassed emotional, instrumental, informational, and companionship aspects that played a significant role in protecting individuals from the effects of stress. Functional support, on the other hand, pertained to specific functions within the social network [29-31]. The various functions of social support are categorized as follows [25-28]:

- i. Emotional support, also known as esteem support and appraisal support, involves warmth, nurturance, empathy, concern, affection, love, trust, acceptance, intimacy, encouragement, and care for everyone.
- ii. Tangible support, also known as instrumental support, includes financial, material, goods, or service assistance provided through direct means. However, this study did not cover tangible support within its research construct.
- iii. Informational support involves problem-solving through advice, guidance, suggestions, or useful information provided to individuals.
- iv. Companionship support or engaged social support is the support that gives an individual sense of social belonging through shared social activities.

2.4 Empowerment Based Design Principles

Rappaport [32] describes empowerment is an ongoing process in which individuals strive for closer conformity, encompassing mutual respect, critical reflection, and emotional assistance in group participation to achieve their goals through their life efforts and results. Empowerment-oriented roles in the community inadvertently promote interdependence between professionals and clients who require help, fostering collaborative resource utilization. In short, empowerment represents a distinct expression of necessary efforts to cope with stress, adapt to change, and influence community beliefs [33]. Empowerment elements can be broken down into levels. At the individual level, psychological empowerment pertains to the issue of concern and the factors influencing decision-making within organizations and community participation. Various models exist,

including learning from others' experiences, understanding available resources, and developing strategies to cultivate a sense of intrapersonal control, confidence, and improved community engagement [33]. The intrapersonal component of psychological empowerment encompasses self-efficacy, motivating personality traits, and perceived self-control in problem-solving. High self-efficacy can influence motivation to exert effort in completing tasks, persisting longer, and eliciting strong emotional responses to their endeavors. When individuals experience success and possess high motivation, they are more likely to continue learning, making progress, and achieving their goals, thereby contributing to overall self-efficacy [33, 34]. Whereas emotional support, also known as esteem support and appraisal support, relates to the self-regulation of social support, encompassing empathy, concern, affection, love, trust, acceptance, intimacy, encouragement, and caring, valuing everyone.

In addition, companionship support, or engaging social support, provides individuals with a sense of social belonging through shared social activities among specific user groups in specific contexts. It is also contended, perceived self-control or self-determination is achieved through informative caregiver social support constructs, particularly information support in this research. In addition, within the context of information technology, designing for empowerment means creating a system-based solution that promotes self-control. Adequate guidance and informational support, such as advice, guidance, suggestions, or useful information provided to individuals, aid in developing skills for adopting preventive behavior, cognitive decision-making, self-efficacy, and valuing preventive behavior. This approach prioritizes the needs and experiences of users, aiming to create accessible, intuitive, and user-friendly solutions without depending on governing authorities to make decisions about their information needs [35-37].

To summarize, by incorporating the empowerment principles into the design of IHEART2U social support mobile app it is hoped the app will serve as a resourceful tool, offering caregivers access to information, support, and resources to enhance their caregiving experience. The app is dedicated to enhancing caregivers' knowledge, skills, and overall psychological well-being, with the goal of improving the quality of care for autistic children and promoting the growth and development of both caregivers and the children they support.

3. Methodology

This section provides an explanation of the research activities involving the eliciting design requirements through a focus group study up till the design and development of the prototype. For the requirements elicitation, the research adopts a qualitative methodology via a semi-structured interview to explore the perspectives of various stakeholders. In addition, the Mobile Development Life Cycle (MADLC) [38] methodology approach was used for the mobile app design and development. Mobile Application Development Lifecycle Model (MADLC) which has been proposed by Vithani and Kumar [38] is used to develop IHEART2U mobile app, as depicted in Figure 1. MADLC involves seven (7) phases; identification phase, design phase, development phase, prototyping phase, testing phase, deployment phase and maintenance phase. However, for the purpose of this research, we only focus up till the testing phase. MADLC provides a structural approach ensuring all steps are followed in a logical manner, assisting in planning and collaboration with stakeholders. This foster better coordination and communication between the stakeholders, designers, and developers to avoid errors and scope creep during the development process.

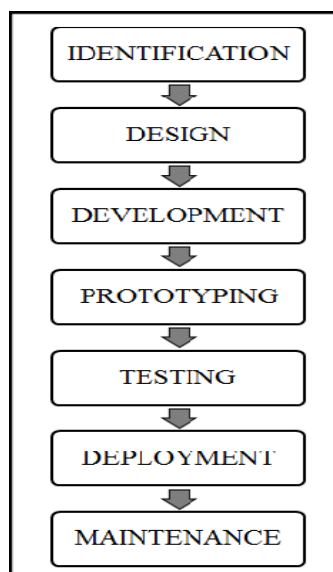


Fig. 1. Mobile development life cycle phases [38]

3.1 Identification or Planning Phase

To gain insight into the research objectives, the initial step involves categorizing the topic area based on a literature review and observation. During the planning phase, the phenomenon addressing the problem is identified through a preliminary study, which supports the research title, problem statement, objectives, research question, scope, significance, and limitations. Preliminary data collection in this phase utilizes published literature sources as a tool to identify, record, understand, and derive meaning. Additionally, observation as a data collection method was employed during the preliminary stage. Observation enables the gathering of knowledge about the researched phenomenon, focusing on human behavior and interactions related to the subject of study [39, 40]. Direct observation is conducted without interaction with the individuals within the social media environment, specifically the Autisme Malaysia Facebook Page (AM), which serves as a support group for ASD caregivers. This prominent unofficial Facebook page for the Autism community in Malaysia has 89,496 members and is supported by 7 admins and moderators since its creation on December 21, 2009. Investigating the effectiveness of Facebook as a communication tool for the support group of parents with ASD children in Malaysia is crucial due to its substantial user base. The objective of this preliminary study is to explore the issues and challenges shared by ASD caregivers within the Facebook group and the types of support exchanged.

To facilitate data analysis and obtain a comprehensive understanding, an AEIOU (actor, environment, interaction, and object) template is utilized as an observation checklist. This template allows for analysis over a specific duration, enabling the examination of individual topics as well as the interrelations among users, objects, and interactions. The findings from the analysis support the research problem statement justification, formulations of the objectives and structuring the research scope. The AEIOU worksheet, presented in Table 1, is employed for data collection starting from March 2023 until June 2023.

Table 1
 Excerpt of observation summary from Autisme Malaysia Facebook Page

Date	Activities (A)	Environment (E)	Interaction (I)	Object (O)	User (U)
March 3	<p>“Down sangat2. 🥹🥹🥹</p> <p>First day at school (PPKI), Yusuf tantrum. He beats & kicks the teachers. Because I am defending the teachers from him, I have been beaten by him too. My tears went down in front of the teachers. I could not make him cool down. I'm failing as a mother. Today he is off school. But he promised me to go back to the school. I wish this time he would control his anger, and the teachers would be alert to what was the trigger.</p> <p>He hates the canteen. Don't let him step on it unless he owns will.</p> <p>I will give him more time. But, if I need to make another decision, I think homeschooling would be the best idea for him.”</p>	<p>Autisme Malaysia FB group.</p> <p>The well-being of the caregivers.</p> <p>Perceived support, coping strategies and quality of life (QoL) of the caregivers.</p>	<p>347 Likes</p> <p>55 Comments</p> <p>4 Shares</p>	<p>Text</p> <p>Picture</p>	Member

3.1.1 Data collection for design requirements

For the data collection, a focus group study was conducted with 5 (five) participants recruited for the interview session [41, 42]. The participants consist of two (2) from the managerial perspectives and three (3) from the caregivers' insights. The first session focused on the managerial perspective and took place at NASOM headquarters at Ara Damansara, Selangor and a private school for autism which is the Olive Tree School. The second session targeted parents with ASD children, serving as informal representatives, and was conducted online via a messenger application due to the interviewees' busy schedules. The interviewees were briefed in advance about the interview objectives and goals to ensure accurate information gathering. The semi-structured interviews with the managerial representative addressed the following topics such as the overall services provided, process, and technology readiness, the details on the organization's definition, population, and experience in supporting the ASD community, the limitations of the existing resources from the organization's perspective, the recommendations and hopes for future benefits for individuals with ASD and the support system.

In addition, the semi-structured interviews for informal and formal ASD children caregiver's group representative to address the following, the overall experience as caregivers to ASD children, the struggles, pain, gain and hope in handling ASD children, the imitations to the existing resources from caregiver's perspective and the recommendations for future benefits to the ASD persons and the support system. The purpose of the semi-structured interview is to gather participants' stories and experiences. This method allowed the selected participants to privately share their viewpoints, guided by adapted questioning techniques that fostered a rapport and encouraged conversation [43-45].

Prior to the data collection commencement, the research has obtained ethical approval from the research ethics board of the university. The participants were given informed consent to participate in the study and explanations were given regarding the purpose and objectives of the study. The

informal and formal participant for P1, P2, P3, P4 and P5 identities were kept hidden due to ethical consideration on privacy of the research participants.

3.1.2 Data analysis for design requirements

The data for this research were collected during the earlier phase through observations of real-life experiences shared by the Autisme Malaysia Facebook community. These shared experiences provided valuable material for constructing stories and identifying themes [40-46]. The Facebook and WhatsApp messaging apps were utilized to facilitate seamless audio-visual interaction between participants and researchers, allowing for the exchange of graphical content and collaborative story creation. This platform enabled participants to express their stories through spoken narratives and incorporate digital and analog elements. The researcher made efforts to support and accommodate participants with lower literacy levels, ensuring that the content was accessible to all. By narrating stories and identifying themes that captured the participants' needs and requirements, the research process became more engaging and dynamic [45]. In addition, for the interviews, a thematic analysis approach was employed to analyze the gathered data. This analysis involved categorizing and examining patterns within the dataset. The thematic analysis approach, adopted from Braun and Clarke [46] in Table 2, was applied in this research to organize data related to the experiences and perceptions of caregivers. The results from this thematic analysis produced the design requirements for the social support mobile app user interface design and functionalities development.

Table 2

Thematic analysis approaches adopted from Braun and Clarke [46]

No.	Phases	Description of analysis process
1	Familiarizing with data	<ul style="list-style-type: none">i. Narrative preparation i.e transcribing data.ii. (Re-)reading the data and noting down initial ideas.
2	Generating initial codes	<ul style="list-style-type: none">i. Coding interesting features of the data in a systematic fashion across the entire data set.ii. Collating data relevant to each code.
3	Searching for themes	<ul style="list-style-type: none">i. Collating codes into potential themes.ii. Gathering all data relevant to each potential theme.
4	Reviewing themes	<ul style="list-style-type: none">i. Checking if themes work in relation to the coded extracts.ii. Checking if themes work in relation to the entire data set.iii. Reviewing data to search for additional themes.iv. Generating a thematic “map” of the analysis.
5	Defining and naming themes	<ul style="list-style-type: none">i. On-going analysis to refine the specifics of each theme and the overall story the analysis tells.ii. Generating clear definitions and names for each theme.
6	Producing the report	<ul style="list-style-type: none">i. Selection of vivid, compelling extract examples.ii. Final analysis of selected extracts.iii. Relating the analysis back to the research question, objectives and previous literature reviewed.

3.2 Design and Development Phase

During the design phase, wireframing and low fidelity prototyping of the mobile app user interface (UI) were created. We use CANVA as the digital tool creating visual presentation of the UI [47]. These visual representations help in defining the layout, navigation, and basic interactions within the app. For this purpose, we use Marvel as the design tool as it offers a wide range of features and functionalities, including wireframe and mockup tools, collaboration and version control

features, and the ability to export designs in various file formats. With Marvel, designers can easily create and share the design, get feedback from stakeholders, and iterate on their designs. Following the design phase, the development phase is carried out to develop the IHEART2U mobile application. High fidelity prototype is built and coded in Android Studio platform and Firebase was used to develop the database to ensure the CRUD (Create, Read, Update and Delete) process in placed.

3.3 Testing Phase

For the testing phase System Usability Scale (SUS) and score by Brooke [48] in Figure 2 were used to evaluate the usability of the app. SUS is a widely used tool for testing usability and user satisfaction in mobile app development. SUS consists of 10 standardized questionnaires using a 5-point Likert scale. SUS is used to help us in evaluating the mobile app's overall usability, its strengths, and weaknesses for better interaction. SUS is administered after the high-fidelity prototype is delivered where the users test and interact with the app while the observer observes and gather feedback. The collected SUS data is then analyzed to calculate a usability score, reflecting the app's effectiveness and ease of use. This score helps identify areas that require improvement and refinement.

	Strongly disagree					Strongly agree
1. I think that I would like to use this system frequently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I found the system unnecessarily complex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I thought the system was easy to use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I think that I would need the support of a technical person to be able to use this system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I found the various functions in this system were well integrated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I thought there was too much inconsistency in this system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I would imagine that most people would learn to use this system very quickly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I found the system very cumbersome to use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I felt very confident using the system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I needed to learn a lot of things before I could get going with this system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Fig. 2. System Usability Scale (SUS) and score rating by Brooke [47]

4. Results

4.1 Literature Review and Observation

To address the first objective of this research which is identifying the requirements for the social support mobile app, we analyzed the collected data retrieved from the literature review, observation, and the interview. Based on the literature review, the researcher categorized the caregivers' issues and challenges into three main areas: (i) the wellbeing of the caregivers or parents, (ii) the perceived support, coping strategies, and Quality of Life (QoL) of the caregivers, and (iii) lack of public awareness. The literature indicated that caregivers, particularly parents of children with ASD, face additional stress, difficulties, and psychological distress. Factors affecting caregivers' health and

wellbeing include concerns about the future success of their autistic children, public perceptions of their parenting style, access to information on symptoms, treatment, and diagnosis, and the availability of government and non-governmental organization.

To verify the findings from the literature review, a preliminary study was conducted using the AEIOU framework to observe online data samples collected from the prominent Autisme Malaysia (AM) Facebook Page during the period from March 2023 to June 2023. Data for analysis were extracted from the AM site, and the findings revealed three major themes (refer to Table 3): (i) the wellbeing of caregivers, (ii) perceived support, coping strategies, and Quality of Life (QoL) of caregivers, and (iii) public awareness. These themes were interconnected with the findings from the literature review and demonstrated how online interactions can serve as an emotional medium for sharing personal stories about the struggles and challenges faced by caregivers. Additionally, it was observed that people tend to share emotional stories less openly, while stories related to the wellbeing of caregivers received the highest number of 'Likes.' Stories about perceived support, coping strategies, and Quality of Life (QoL) of caregivers were most shared on the AM Facebook page, generating the highest number of comments from members and followers. The sharing of information was most prevalent through 'Shares,' confirming that ASD caregivers actively seek information and advice.

Table 3

Support categories summary from Autisme Malaysia Facebook Page

Types of support	Numbers of postings
Emotional support	7
Companion support	22
Information support	10

4.2 Interview – Thematic Analysis

After collecting the data, thematic analysis is employed as a research technique for data analysis. This process aims to propose design requirements for a social support mobile app for autistic children's caregivers. The collected data from the participants is organized into groups and assigned appropriate themes. These themes are guided by the earlier established concepts of empowerment design. By creating themes, the aim is to capture and integrate all coded information into a coherent and comprehensive design requirement.

4.2.1 Data familiarization

The data set obtained from the interviews was presented in a tabular form based on input from five (5) participants which consists of two (2) from the managerial perspectives and three (3) from the caregivers' insights (refer to Table 4). The thematic analysis suggests that, in the next step, the placement of stories is labelled in its initial codes. The stories were familiarized as the entry point for ideas on the potential of design features. The narrative stories were translated into keywords to identify design themes for caregivers' potential communication platform.

Table 4
 Excerpt from the interview raw data of participant 1

No.	Questions	Answers
1	What are the overall services provided by the organization/institution?	NASOM is an NGO that was established in 1987 to provide services and support to ASD persons especially children and their caregivers. We already have more than 1000 registered members and 15 branches at this moment.
2	What is the current digital communication platform used to reach out to the ASD person and their caregivers?	Currently, we have website http://www.nasom.org.my , Instagram and Facebook account as digital platform to communicate with public and ASD communities.
3	What is the limitation to the existing resources from organization's perspective?	With limitations in funds and resources, IT hardware and infrastructure are the biggest barriers for us to migrate from traditional methods to digitization.
4	What is your recommendation for future benefits to the ASD persons and the support system?	In this new era of technology, the advancement of mobile apps would be the new way to get in touch directly to our targeted users in order to personalize their needs accordingly.

4.2.2 Generating initial codes

The coding in this phase is to organize data into meaningful code to represent the issues and challenges of ASD caregivers. It is required to get familiarized with the contents of the transcripts derived from issues and challenges data collected and generate similar codes and match the relationship to generate initial codes in an organized theme. In doing so, the code extract is highlighted in yellow color as in Table 5.

Table 5
 Generating initial codes

Participant	Data extract	Code
P1	i. "When dealing with autistic kids, behavioural correction is crucial. Education will follow easily when behavior issues are settled." ii. "With limitations in funds and resources, IT hardware and infrastructure are the biggest barriers for us to migrate from traditional methods to digital communication."	Behavior correction Behavior issues Communication Platform Resource Barrier
P2	i. "As a small private school, our funds are much dependent on the fees. Besides that, to get a qualified and experienced teachers to work with ASD children is quite a challenge. High expectations and hope to see immediate progress of their child with limited sharing sessions with their caregivers could lead to miscommunication."	Experience Expectation Progress Hope Challenges Dependent Communication
P3	i. "Autism is a wide spectrum and the challenge is different from kids to another. In Uwais case, he also diagnosed as Global Development Delay with aggressive behaviour and speech delay. His reaction is depending on the environment and can swing from calm to extremely happy or sad which I	Aggressive Mood swing Extreme Stressed Dependent

4.2.3 Searching the themes

A thematic map as depicted in Figure 3, illustrates the connections and relationships that contribute to achieving the desired design requirements for the app. In the map, similar colors are used to represent different categories:

- i. The "Theme" (parent node) category consists of 3 data points and is represented by orange.
- ii. The "Subtheme" (child node) category includes 5 data points and is represented by green.
- iii. The "Code" (child node) category encompasses 30 data points and is represented by blue.

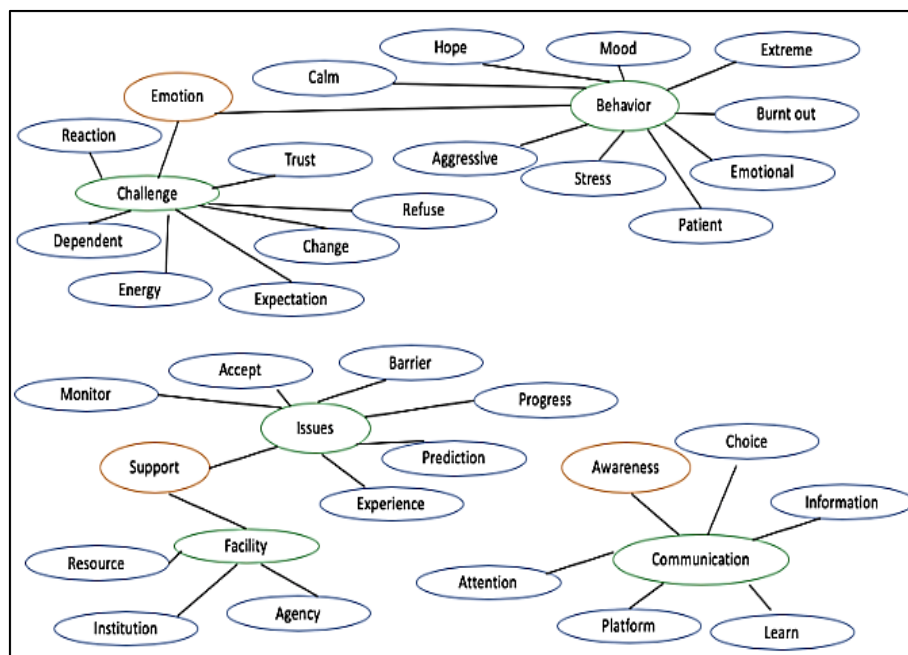


Fig. 3. Generating initial codes

4.2.4 Reviewing the themes

The next step after the themes have been derived from the previous phase is to review and refine the theme to look for inconsistencies or overlay themes (refer to Table 6). This is to identify relevant issues and challenges of the caregivers that have not been included in the previous code, therefore, a new code may be embedded. The overlap code is deleted, and refinement of the new themes is performed to reflect the actual data meaning.

Table 6
 Reviewing themes

Previous theme	New theme
Emotion (self-therapy)	Motivation (self-efficacy)
Support	Self-determination
Communication	Chat
Issues	Query
Mood	Goal

4.2.5 Defining and naming themes

After defining and naming the themes, the final Affinity Diagram is created in Figure 4. The final Affinity Diagram summarize the evaluation of caregiver’s issues and challenges through themes that associated with empowerment design features development that is centered around the elements of motivation, self-determination, awareness, self-efficacy and look and feel. This diagram serves to summarize the analysis of the issues and challenges faced by caregivers, as well as the insights gathered from the interviews.

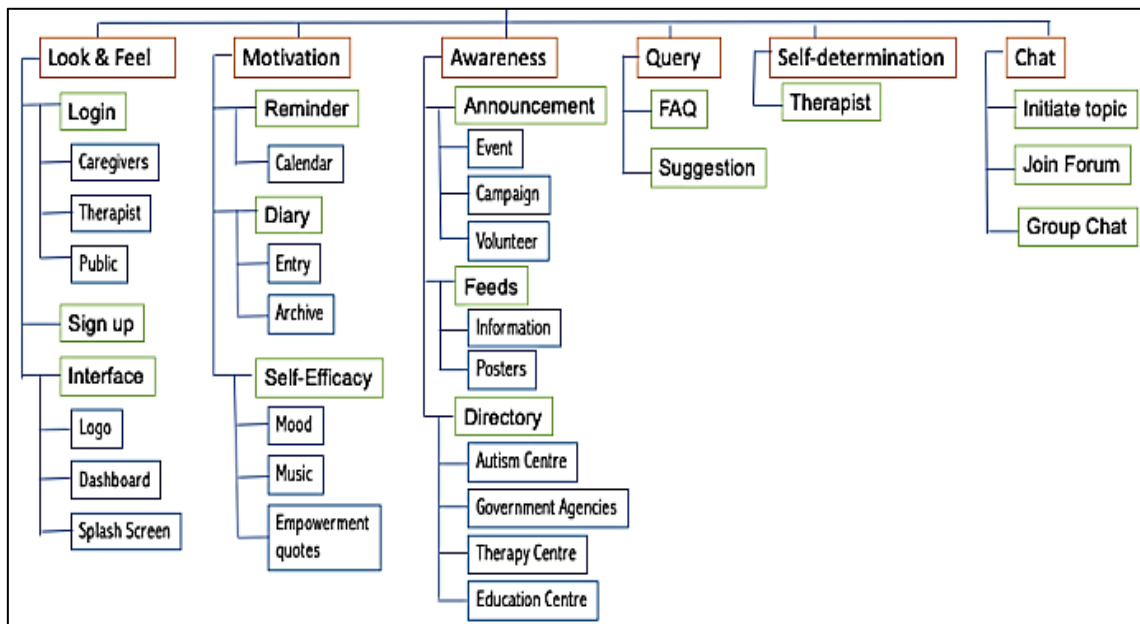


Fig. 4. Final affinity diagram

4.2.6 Producing the report

In this section, we outlined and discussed the proposed empowerment-based design requirements for IHEART2U social support mobile app development (refer to Table 7). Based on our findings, we defined empowerment-based design requirements for social support app in the context of autistic caregivers consists of elements about information and education, accessible resources, emotional support, networking, and skill building. These elements could aid the caregivers in becoming emotionally stable and resilient for them to have the ability to provide optimal care to their autistic children regardless of the situation.

Table 7
 Mapping major themes and sub-themes for the IHEART2U design requirements

Major theme	Sub theme	Empowerment principle	Discussions
Empowerment through motivation	Goal (reminder, diary/journaling) Self-efficacy (self-therapy, motivation quotes)	Design for emotional support	Building upon the concept of goals, users are provided with the option to select a theme that aligns with their desired mood or atmosphere. Element such as the diary/journal feature provide users with a personal space to privately express their emotions, thoughts, and feelings whenever needed. It serves as a place of solace and comfort for users. In addition, the reminder, displaying updates from feeds whereas the

Table 7. Continued

Mapping major themes and sub-themes for the IHEART2U design requirements

Major theme	Sub theme	Empowerment principle	Discussions
Awareness	Informative page (announcement, feeds, directories, Q&A, peer sharing, consultation, feedback, review)	Design for informational support	motivational quotes and providing a boost of encouragement and motivation. The features for this content basically created to raise awareness among caregivers and the public through announcement feature, feeds, updated news, notices, and events related to ASD. In addition, the Q&A platform is provided through chatroom, forum and contacting directly with the therapists/related agencies through the directory listing provided.
Empowerment through self-determination	Chat/ Community (forum, group chat)	Design for companion support	This page provides a direct communication platform through group chat with peers a personal session with therapists virtually, serving as an alternative to face-to-face sessions. In addition, a forum platform is for the users to connect with peers in the ASD community. In addition to responding to existing topics, users are also allowed to create their own discussion topics. Responses to the topics can be made publicly or privately. A real time notification is sent to the individual whenever they received new message.
Look and feel	Login, sign-up, navigation, logo, dashboard, splash screen	Design for customization and personalization	The app's look and feel were created to be inviting, easy to navigate, and aesthetically pleasing, promoting a sense of comfort and familiarity. This is to ensure the learning curve in familiarising with the mobile app usage and navigation is within a short period of time thus making it easier for them to access the support and resources they need.

4.3 Development and Testing

Figure 5 showed the selected screen shots of the IHEART2U social support mobile app user interface that was developed and tested with the users for feedback using the System Usability Scale (SUS). The testing involved five (5) similar users whom we had previously interviewed and gathered the design requirements. This is to ensure the feedback gained is more likely to be relevant to the design requirements gathered during the interviews because they are already aligned with the project's objectives and user needs.

Based on the SUS testing results and the SUS adjective rating [47], IHEART2U mobile app scored 90.83 impressively, placing it on par with the average. Despite the high score, all the respondents have their own respective perceptions and responses towards the functionalities of the user interface (UI). Some valuable feedback was obtained during the testing session. Most agreed that the overall design, navigation, and interaction styles are easy to understand and have minimal learning curve. Nevertheless, few suggested if the app could support media files sharing especially in the forum section to support textual input.

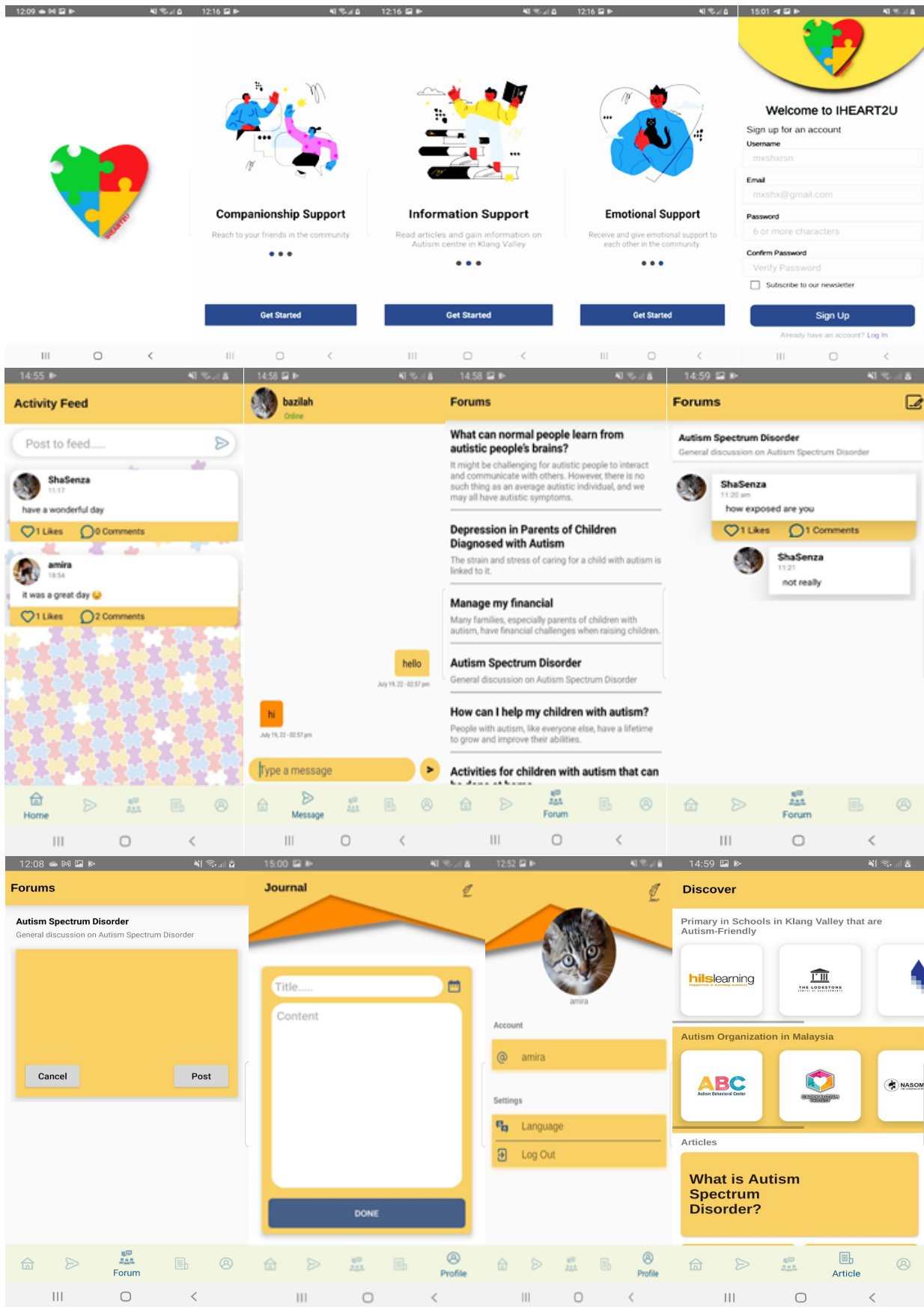


Fig. 5. IHEART2U social support mobile app User Interface (UI)

Additionally, the respondents also requested if this app can be linked to social media accounts for wider sharing of content. Another suggestion was to expand the directory listing to other regions, which are currently limited to information resources within Klang Valley, the capital city. This is to cater for users outside the capital city. Another recommendation was regarding the emotional support feature where users requested a broader selection of private therapists and counsellors' services, in addition to the existing options provided by public governmental agencies. Finally, a representative from National Autistic Society of Malaysia (NASOM) suggested if the mobile app can be integrated with the current NASOM website to ensure the information deliverables are seamless and unified. In summary, while the IHEART2U mobile app demonstrated compelling usability performance in the SUS testing, users' feedback indicates that several enhancements could further improve its functionality and user experience. The suggestions will lead to even greater user engagement and satisfaction in the future.

5. Conclusions

The research's main objective is to design and develop IHEART2U social support mobile app that embed empowerment-based design principles in aiding caregivers with autistic children. Focusing on the local respondent needs, the research employed a qualitative approach for requirements elicitation and Mobile Development Life Cycle (MADLC) methodology for the development. The IHEART2U mobile app user interface (UI) encompasses four (4) main empowerment design features which are information support, companion support, emotional support, and personalization and customization. Despite the high usability score, based on the respondent's feedback, the mobile app user interface (UI) certainly needs further improvements to ensure better user experience (UX). Our future work is to reiterate the design and test with a larger group of respondents by considering different cultural contexts and variations in social support requirements among stakeholders. This research concludes that a support group in a digital platform is crucial for aiding caregivers in managing challenges and emotional wellbeing particularly in an environment where such platforms and services are currently limited in Malaysia context.

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