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Research article

A qualitative study on feeding experiences among caregivers of children with cerebral palsy requiring food texture modification

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ABSTRACT

Background and purpose: Children with cerebral palsy often experience feeding difficulties that require food texture modification and are highly dependent on their caregivers, which commonly leads to malnutrition. This study aimed to explore caregivers' current practices, perceptions, challenges, and ways to overcome the challenges through the provision of food texture modification.

Methods: The inductive qualitative study design was employed. An open-ended semi-structured interview was conducted among ten mothers, and the interviews were recorded. Data were transcribed verbatim and analysed thematically.

Results: Six themes were constructed, namely; current practices (caregivers knowledge level influences readiness to practice food-texture modification which prioritized more on home-cooked food and involving healthcare professionals in the feeding provision); perceptions (child condition and nutritional status influence the practice of food texture modification); challenges (time taken and convenience to prepare food texture modification, access to healthcare services, knowledge and exposure, emotional and child's food preferences); ways to overcome the challenges (caregivers took the initiative in finding information/tools/feeding techniques in practicing food texture modification, tried and trained children with different types of food texture modification as tolerated); personal development (empowered with healthcare professionals and society involvement, resilience and eager to learn more about food texture modification); and

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wishes and expectations (inclusivity from society and healthcare professionals, and improvement of child's nutrition status).
Conclusion: Caregivers of children with cerebral palsy requiring food texture modifications may need assistance from family, healthcare professionals and society as they navigate these difficult situations and deal with a range of emotions when preparing food and feeding their children. Healthcare professionals play an important role to assess the child's risk of swallowing, construct tailored feeding plans, instruct caregivers the way to prepare food textures safely, monitor growth, and ensure the child gets the nutrition they require as well making sure caregivers receive the emotional and social support they need. These findings can help develop beneficial intervention models that incorporate ongoing healthcare professional follow-up, caregiver-led practice, standardized training, and advancements in the field of novel food technologies. In the end, this provides an evidence-based framework that is specifically designed for policymakers to inform social protection programs, subsidized educational settings, inclusive food supply standards, and national guidelines.

1. Introduction

Cerebral Palsy (CP) is defined as a non – progressive disturbance that occurs in the development of the fetal or infant brain. This condition lead to a permanent disorder of the development of movement and posture that affects physical activity [1]. Statistics show the prevalence of CP is estimated to be 1.6 per 1000 live births [2]. Health-related issues were found to occur along with CP such as disturbances of sensation, perception, cognition, communication and behaviour, epilepsy and musculoskeletal problems [3].

Oropharyngeal dysphagia, which is swallowing difficulty, a consequence of issues with the muscles and nerves involved in the swallowing process, is a frequent cause of feeding problems for children with neurological impairments [4]. Safety in the feeding process is crucial and requires management and intervention from healthcare professionals with multidisciplinary teams such as speech therapists, occupational therapists, clinical psychologists, dietitians, medical doctors and others [5]. Management for feeding difficulties among individuals with CP depends on the severity and should be individuals tailored to the issues. Types of management include nutritional management which specifies the food texture and fluid consistency according to an individual's needs and safety [6]. Oral motor therapy, behavioural interventions and medical interventions are among other interventions that might be required for individuals with CP who have feeding difficulties [7].

Food texture modification is one of the interventions to ensure safety during swallowing for individuals with CP who experience feeding difficulties. Benfer et al. (2015) in their study that included a total of 99 young children with CP (65 males, 35 females) aged 18 to 36 months, found oropharyngeal dysphagia and modified diets were more common in children with severe CP than in the general population. Children who typically had oropharyngeal dysphagia took more fluids, which were most frequently deemed dangerous and further suggested for instrumental assessment [8]. This study was supported by another review by Kamal et al. (2022) that suggested texture-modified diets such as pureed or mashed foods, can be advantageous to improve swallowing function in children with CP. The finding also demonstrated that modifying fluid consistency to be thickened such as nectar–thick liquids improved swallowing outcomes [9].

Feeding difficulties can lead to malnutrition and dehydration if not tackled early. The link between dysphagia and the degree of motor impairment highlights the effects of motor control on the complex coordination for an effective and safe swallowing process. According to systematic review by Calderone et al. (2025), swallowing issues can impair general health and quality of life. Chewing issues in particular might result in less food being consumed and resulting nutritional deficiencies. Similarly, the prevalence of choking and aspiration draws attention to the possibility of respiratory issues, which can worsen health and well being [10]. Another study among 100 children and adolescents with CP, aged 3 to 18 years, showed dysphagia associated with poor nutritional status which was more common in patients with more severe motor disability [11]. By modifying the texture of food and consistency of the liquid, children with CP can improve their nutritional status by eating a variety and balanced diet.

Children with CP have special nutritional demands, and caregivers are essential in meeting those needs. In addition to assisting with feeding and monitoring for any possible signs of choking or aspiration, they are often responsible for choosing and preparing appropriate foods, and modifying food textures which pose several challenges for caregivers [12]. The time and effort needed to prepare and feed their children is a significant task, especially if the child struggles to swallow or needs frequent feedings. This can be particularly difficult for caregivers who are also responsible for other duties like work or taking care of other family members. The emotional feeling experienced by caregivers if their child is not eating enough or if they are unable to find appropriate foods that their child can tolerate, might cause the caregivers to feel overwhelmed, anxious, or disappointed. In addition, they could feel guilty or take responsibility if their child has feeding-related problems like aspiration or weight loss [13]. The emotional factors such as concerns about the child's nutritional status and health, as many caregivers believe their child is underweight, the fear of their child choking during feedings due to an impaired or hyperactive gag reflex and uncoordinated swallowing, and the lack of enjoyment in feeding their child are some of the caregivers' worries regarding child feeding [14].

Also, the cost of specialized feeding equipment, such as adapted utensils, modified cups, or feeding equipment, may impose financial pressure on caregivers. If they dwell in a remote area or have limited access to specific foods, they may also have trouble finding the right foods or formula [13]. A systematic review done by Dlamini et al. (2023) demonstrated the daily responsibilities of providing care cause caregivers to experience widespread physical discomfort. Giving care is a devastating, taxing job that is

accompanied by ongoing sadness. Concerning the future of their lives, they are uncertain of their children [15]. Overall, it can be challenging and complex to provide for a child who has CP and feeding issues. To overcome these challenges and ensure optimal performance for their child, caregivers need guidance and resources.

The quality of life of caregivers can be improved by offering proper assessment and intervention to their children with CP that requires food texture modification [16]. By practicing texture modification, the need for medical interventions such as feeding tubes or hospitalizations can be reduced [17]. The ability of caregivers to provide care must be ensured, and knowing their experiences is essential. High levels of stress and burnout among caregivers may put them at risk for diminished capacity for care-giving, which could eventually harm the health and well-being of their children [18]. The stress that caregivers experience can be reduced, their mental health and quality of life can be enhanced, and their ability to care for their children effectively can be increased by giving adequate resources needed such as through education, training, support groups, financial assistance and others [19]. Ultimately, resolving the problems caregivers encounter in managing their children's eating issues and enhancing the well-being of both caregivers and children with CP depends on understanding caregivers' experiences.

There has been some research on the feeding challenges and needs for modifying food texture for children with CP, but there has been much less research on the experiences of the caregivers who are in charge of managing these children's feeding requirements. Previous study has been showed that eating domain using PedsQL questionnaire in determining the quality of life of the caregivers of children with CP were among the lowest score [20]. It is necessary to further explore the caregivers experiences, as quantitative data provided a general understanding whereas qualitative data and its analysis further refined and explained the statistics by exploring the views of the study participants [21]. As caregivers are crucial in ensuring that children with CP receive the proper texture changes according to their level of safety and satisfy their nutritional needs, this is an essential field of research. The absence of continuous advice and assistance from healthcare professionals is one of the biggest problems that caregivers encounter. Often, caregivers need to figure out and experience the difficulties of modifying food texture on their own and may not have access to tools or guidance to aid in making wise choices. Frustration, anxiety, and solitude may result from this, affecting the nutritional status of their children and reduce caregivers' quality of life.

The need for increased training and resources for healthcare professionals in the management of feeding challenges in children with CP is one of the concerns for healthcare settings and policy. This could involve putting more focus on the early detection of feeding difficulties, educating caregivers on how to modify food textures appropriately, and offering caregivers guidance and resources. Healthcare professionals could also work with caregivers to create personalized feeding plans and effectively support supervision and support. Thus, this study aimed to explore current practices, perceptions, challenges and ways to overcome the challenges among caregivers of children with CP that require food texture modification.

2. Materials and methods

2.1. Study design

This study employed an inductive study design with a qualitative approach [22]. This study design was chosen to explore the data without limiting the hypothesis since this topic finding will depend on the environment setting, culture and other factors in a certain location. New themes and patterns emerged based on the data that were coded and categorized.

2.2. Participants

A sample size of minimum 10 is required for a qualitative study [23]. Participants needed were caregivers of children within the age group from 2 to 20 years old with a diagnosis of cerebral palsy that requires food texture modifications (participants were taken from a previous quantitative study) [20]. Interview sessions were conducted until reached saturation and no new information is believed to be found from the participants [24]. At the end of the study, a total of 10 mothers of children with CP participated.

2.3. Inclusion and exclusion criteria

Caregivers were recruited if they had a child diagnosed with cerebral palsy aged 2 to 20 years old who takes food texture modification orally in their daily intake. Caregivers who had children with CP with other chronic illnesses and taking nutrients through tube feeding were excluded.

2.4. Sampling method

Caregivers were purposely selected from earlier quantitative studies which aimed to determine the prevalence of nutritional status among cerebral palsy that requires food texture modification [20]. Children were selected at level IV and level V of the Gross Motor Function Classification System (GMFCS). Previously, their sociodemographic, medical history data and anthropometric data such as body weight, height, mid-upper arm circumferences and skinfold measurement (triceps and subscapular) were obtained. The caregivers were further asked to answer a questionnaire related to the quality of life-based on age group. Upon completion of the session, they were asked if they were interested in further participating in a session of in-depth interviews to explore current practices, perceptions, challenges, and ways to overcome challenges in preparing food texture modifications for their children. From 71 caregivers' data collected in the quantitative study, 20 parents were approached and contacted, and 10 declined due to several reasons – not being

available, not having free time, work constraints and others.

2.5. Instrument

An interview guide was developed and checked by experts in qualitative studies. The interview guide was created using the objectives of the study as well as the findings of literature on caregiver experiences feeding children with CP, specifically with regard to mealtime difficulties and food texture modification [12,25–28]. It consisted of open-ended questions designed to explore caregivers' perceptions, practices, and barriers in depth. In order to overcome any potential language barriers, a bilingual researcher who was proficient in both Malay and English conducted the interviews in the participants' preferred language, which was mostly Malay. Small changes were made to simplify the language and enhance the conversation's flow. This method reduced misunderstandings and made it easier for participants to accurately and comfortably share their experiences. Here was the interview guide that was used in this study based on the three categories (practices and challenges of food preparation, understating and perception of food texture modification, and patient's needs).

2.5.1. Practices and challenges of food preparation

1. What are the current food textures that you give to your children? (The moderator shows pictures of different types of food texture modification)
2. How do you prepare these foods? (Ingredients, cutting, cooking process, serving, duration of eating)
3. How do you feel about the food preparation process? (Easy/difficult) (If having difficulties, what are the aspects - which steps - how, why)
4. How do you give food to your child when eating outside?
5. What are the foods that you currently modify and any other food that you wish to modify according to your child's current food texture modification?
6. How do you feed your child? (Meal time, feeding utensils)
7. Where do you feed your child? (Wheelchair, special chair)
8. How is the feeding process (Coughing, aspiration, swallowing difficulty, choking)
9. Do you think your child is eating enough according to their needs and based on what indication? (If yes/no, why?)

2.5.2. Understanding and perception of food texture modification

1. What do you understand about food texture modification?
2. Who teaches/asks you to do food texture modification, do you think this is necessary for your child? (If yes/no, why?)
3. Do you ever bring your child to healthcare professionals to do any assessment regarding swallowing or raise any concerns about the child's health regarding nutrition or feeding?

2.5.3. Patients' needs

1. Are there any suggestions you think will be helpful to you in preparing food texture modification (Healthcare professionals, food industry, etc.)?
2. Do you ever think of a module/guideline that contains information regarding food texture modification?
3. What other contents will be useful to be added, language, format, and medium to be shared? (Example of the module input – food preparation for food texture modification, testing methods, food recipes, calorie-dense food choice, picture of food portion after being modified)

2.6. Data collection procedure

Data collection was conducted between September to October 2022. Caregivers who agreed to be interviewed were asked to fill in the consent form in a Google form prior interview session. Interview sessions were conducted one to one via online with a stipulated schedule based on mutual agreement between caregivers, moderators and supervisor availability. The interview session was conducted by a moderator who is qualified in the dietetic field and was held online due to pandemic Covid-19, caregivers' preferences and easier to set up time and does not require a venue. All were asked permission to record video with the camera opened to observe body language during the interview session. Conducting online interviews has its drawbacks, for example participant interest and data richness may be affected. On the contrary, participants were able to join from a familiar and comfortable settings due to the flexibility and convenience of virtual platforms, which might have promoted openness while decreasing social anxiety. The establishment of rapport and non-verbal cues, which are frequently crucial in qualitative interviews, may have been hampered by the absence of physical presence. Furthermore, unexpected technical problems such as a bad internet connection or audio interruptions, occasionally broke up the chat and might have prevented in-depth discussion of delicate subjects. Additionally, compared to conventional face-to-face settings, some participants seemed more tired or preoccupied during virtual sessions.

Ice-breaking and an explanation of the objectives of this study were done before the session started. Caregivers were given a choice in answering any questions, especially for questions that they thought might bring a sensitive issue. The session was conducted in both

mixed Malay and English languages depending on the participant's preferences. For any questions that they don't understand, they can ask again, and the moderator rephrased the questions. The questions given did not necessarily follow the order of the interview guide as the moderator checked and went back again to the questions that were not being asked based on the categories before the session ended. Caregivers also were given opportunities to ask any questions related to the nutrition of their child. The moderator clearly stated that there are no right and wrong answers and all data would be kept confidential before the interview session started. Finally, the moderator asked permission to contact the caregivers back if there was a need for clarification and additional information after the transcription process and caregivers were also able to contact back if there was anything that they forgot to add after the interview session ended. Interview sessions were recorded with different sources (screen recorder, voice recorder, and phone video camera). The range time of the interview sessions was 33-80 min.

2.7. Data analysis

The data was analysed inductively to produce themes which open to any new meaning codes by not restricting to the objectives of the study [29]. Based on Braun and Clerk (2006), thematic analysis involves six key steps: familiarizing oneself with the data, generating initial codes, searching for themes, reviewing themes against the data, defining and naming themes, and finally, writing up the analysis [30]. All of the interviews were captured via video with audio and verbatim transcribed by the moderator in Microsoft Word. The transcripts were read for at least two times to become fully immersed and familiarize with the data. To acquire a thorough grasp of the participants' viewpoints, it involved taking initial notes, making observations and recording first impressions.

Two-level coding was performed manually. The use of inductive coding approach allowed codes to be created from the data, free from theoretical frameworks or preexisting concepts. After going over each transcript methodically, the researcher found significant textual passages and gave each one a name (code) that encapsulated its main ideas. Initial codes (1st level coding) were created by the moderator (SK) using the comments function in Microsoft Word. For the second-level coding, 2 additional coders (MSNM and NAAZ) who are in the field were familiarized, briefed and cross-checked the initial codes and performed second-level coding through discussions in Microsoft Word and Microsoft Excel. Iteratively, a coding framework was created and revised as new data was coded. The coders discussed with the moderator (SK) and supervisor (NHH) for any points that were not clear. Finally, all codes were presented and discussed with other team members.

Potential themes were formed by clustering related codes together after first coding. This entailed grouping codes according to similar threads or patterns into more general groups. The connections between codes and emergent ideas were visualized using mind maps and thematic tables. Every theme showed a common meaning among various participants and was backed up by several codes extracts. Discussions were done twice to produce initial sub-themes and further refined themes. At this point, certain ideas were combined, divided, or eliminated in order to maintain internal coherence and uniqueness. Later, it was presented to other team members and participants, in which any disagreements were discussed and finalized based on suitability and capturing meaning from the original transcript.

2.7.1. Trustworthiness

The data achieved saturation after 10 interviews and the decision to stop was based on when there were no new themes emerged on three consecutive interviews [31]. Participants came from various locations and settings as they were from a government hospital, private centers, and community-based rehabilitation (CBR). Participants were also seen to came from various background of education level. To get the participants in this study, the researcher already built rapport with the caregivers during the previous quantitative phase of data collection. Trustworthiness was attained through discussion with other 2 coders in the same field (peer checking) and the supervisor. Other than that, questions in the interview guide were developed and discussed with experts from qualitative to cover research objectives. Participants were ensured confidentiality by making sure to conduct the interview session in a room with no disturbance. During interview sessions, the moderator shared pictures of the food texture modification so that they could see in a visualized form to ensure the information was correct. In addition to interviews, observational field notes were analysed to validate findings. Finally, after the interview sessions ended, the moderator listened to the recording more than 2 times to familiarize with the data and transcribe all the transcripts with referral adequacy (recorder, screen recorder and phone video camera).

2.7.2. Rigor process

Rigor was obtained as after the interview session, the interviewer rephrased the statement shared by the participants, summarized the answers to get the agreement and understood the point given by the participants to avoid assumptions. Field notes to record any face mimic or body language were considered as additional information besides transcripts [32]. To ensure that their experiences were appropriately reflected, a subset of participants was given access to the preliminary findings, and they were offered the opportunity to contact the researcher if they wished to add anything relevant to the scope of the study. Credibility was increased by modifying interpretations and strengthening themes based on participant feedback. This procedure made sure that the results accurately represented the opinions of the participants.

This study achieved triangulation by using multiple sources to increase the validity and reliability of the findings [33]. The qualitative study was done to get a clear picture and comprehensive understanding based on findings from previous data which demonstrated children with cerebral palsy were 40.8% underweight and caregivers had lower scores of quality of life while the eating activities domain was among the lowest scores [20]. The study also involves multiple researchers for data analysis to discuss and interpret the transcript. This can help to identify any potential bias and give different views that might be missed by the single investigator. The process of collecting data, analysing data and documentation was done systematically to make sure the audit trail was

attained [22]. The development of themes, coding procedures, research decisions, and analytical agreement were all clearly and methodically documented. This audit trail helps ensure reliability and enables outside reviewers to follow the study's development.

3. Results

3.1. Participants description

Table 1 shows sociodemographic data of the caregivers and their children who participated in this study. There were a total of 10 mothers, aged between 29 and 49 years old. Their children's age ranged from 2 years 11 months to 15 years 5 months. The majority race of the participants was Malay (n = 6), followed by Chinese (n = 3) and the least was Indian (n = 1). The mothers had various educational backgrounds ranging from secondary school to PhD level. They also sent their children for schooling differently with three of them to private centers and community-based rehabilitation each and four of them not having formal education yet.

3.2. Themes

There were six themes developed in this study which were the current practices, perceptions, challenges, ways to overcome challenges, personal development and wish or expectation. These six themes were further produced by 25 sub-themes and further supported based on the quotes from transcripts. The summary of the findings was stated in Table 2 as follows.

3.2.1. Theme 1: current practice

The moderator started the interview session following research questions by asking about the current practices of what the mothers did for their children in terms of food texture modification. Gaining an understanding of current practices is essential to identifying gaps, needs, and strengths in the way mothers and other caregivers handle food texture modification at home. The everyday life practices, decision-making processes, and coping mechanisms that affect what and how children are fed—particularly those that have specific medical or developmental conditions—are illustrated by this theme. Knowledge was influenced in practising the food texture modification, as mentioned by the following quotes.

> "Interviewer: The soft food, if the carrot is steamed, it has to be mashed, do you upgrade the texture of food for your child?
>
> *P2: We are not brave enough. We try sometimes when we are at home, but when we are busy, we want to prepare the food quickly."* (P2)

Other mothers also added that food modification might affect the nutrition of the food, hence influencing the preparation and acceptance of the food for her child.

> *"I'm very sad when she (child) eats only blended rice (porridge) because she won't get sufficient nutrients from the porridge alone. I have tried adding chicken and fish to the porridge, but she refuses to eat them."* (P7)

All of the mothers mostly prepared home-cooked food for their children according to their children's health status and type of food, as stated below:

> *"He (child) is unable to eat on his own and requires us to feed him nearby, but he can eat like normal. However, when we give him large portions of chicken, he tends to choke and cough, which makes him dislike that. I have noticed that if my son is sick, I give him porridge, but after he eats it for a few days, when I try to give him rice again, he seems to choke. This is what sometimes confuses me as although he is used to eating porridge, if I suddenly switch to normal texture, he seems incapable of eating it even though he doesn't particularly enjoy the texture of the porridge. Before serving him anything with a hard texture, such as French toast, it should be sliced into smaller pieces."* (P4)

The mothers are also involved and seek opinions from health care professionals in the provision of feeding to their children.

Table 1
Sociodemographic data of the mothers and their children.

Code	Mother's age	Children's age	Child gender	Race	Household income	Education level	Occupation	Schooling
P1	34	6 years 11 months	Male	Malay	RM4851 - RM10,970	Master	Private	Private centre
P2	38	9 years 1 month	Male	Chinese	RM4851 - RM10,970	Others	Own business	Not going to school
P3	45	12 years 4 months	Female	Malay	Less than RM2500	Others	Others	Private centre
P4	29	6 years 5 months	Male	Malay	RM2500 - RM4850	Degree	Others	CBR
P5	45	15 years 5 months	Female	Malay	RM2500 - RM4850	SPM	Others	CBR
P6	35	6 years 3 months	Male	Malay	RM2500 - RM4850	SPM	Government	CBR
P7	44	10 years 9 months	Female	India	RM4851 - RM10,970	Degree	Government	Not going to school
P8	49	15 years 2 months	Female	Chinese	RM10, 971 - RM15,050	PhD	Others	Private centre
P9	31	3 years 8 months	Female	Malay	RM2500 - RM4850	SPM	Housewife	Not going to school
P10	42	2 years 11 months	Male	Chinese	RM2500 - RM4850	SPM	Housewife	Not going to school

*1USD = RM4.78.
*SPM = National Secondary School Examination.
*CBR = Community-based Rehabilitation.

Table 2
Themes, Sub-themes, and Quotes of the study.

Subthemes	Quotes	Code
Current Practice		
Parents' knowledge level influences readiness to practice food-texture modification	*We try sometimes when we are at home (*upgrading food texture*), but when we are busy, we want to prepare the food quickly.*	*P2*
Prioritizing home-cooked food over the use of oral nutritional support formula (ONS)	*I have tried adding chicken and fish to the porridge*	*P7*
Involve healthcare professionals in the feeding provision (e.g., advice, troubleshooting etc.)	*The doctor suggested to me, what if we try to improve your son's food texture? Having consumed porridge for a long time, made him unable to tolerate different textures.*	*P4*
Practice preparing your food when traveling or suitable food choices when eating out	*We sometimes choose soft texture of burger such as fish burger at food store or simply chew it before giving it to our child.*	*P1*
Routine practice as in for usual food preparation, meal timing and food choices given to the child	*He may get uninterested with the food prepared, so it depends on his preferences*	*P2*
Perception		
Food-texture modification: Child-centered, food texture modification can help children transition into normal texture	*It's important to make sure your child is ready before making a food texture modification, regardless of whether they accept it or are ready for it.*	*P8*
Food-texture modification: Bloating, blended food is not appetizing, and difficulties in believing and practicing food texture modification	*My son has had a bloated stomach for a while now, so I'm picky about what's in the fridge.*	*P10*
Nutritional Status: child intake is enough, see improvement through eyes	*Her body weight is perfect (which is why the mother only offered chicken once a month).*	*P7*
Challenges		
Technical challenges (e.g., time/convenience)	*It takes her at least 2 h to finish her meal because after one mouthful, she wants to look at something, listen, and then look at it again.*	*P3*
Health services (e.g., speaking in the same language, teaching on feeding and food texture modification)	*The previous dietitian in X hospital also did not force me to feed my son full time. They also have different ways of thinking*	*P10*
Knowledge and exposure: In what should be done (either have no clue) or have less/no knowledge regarding what should be done/practices in dealing with CP children.	*It is quite difficult. Although I have never tried it, we believe that spaghetti blend is not the ideal dish for him to try, therefore we currently only give him porridge.*	*P2*
Child's food preferences and ability to eat certain textures of food	*I make fish around noon, so for dinner at night, switch to soy-sauced chicken. We stir-fry vegetables, but she doesn't like them so I'll prepare her some veggie soup since she dislikes fried foods.*	*P9*
Monitoring the action taken (e.g., could not measure whether it's improving/worsening/no chances for the benefit of the CP child)	*I requested an appointment with a healthcare professional if I wanted to learn how to boost my child protein consumption.*	*P8*
Emotional challenges faced by caregivers of children with CP	*Nobody seems to care that I'm a little stressed about this. I'll set aside time to eat outside since I want to feed my daughter first.*	*P3*
Ways to overcome challenges		
Mother took the initiative in finding information/tools/feeding techniques in practising food texture modification	*It's been more than a year or two since I started practicing, and I learned what foods and amount sizes are best for my child from a dietitian.*	*P3*
The mother took the initiative in giving different types of texture modification according to the child's toleration	*I make an effort to feed anything, sometimes even including ice cream.*	*P6*
Train children in the feeding process (e.g., oral stimulation, feeding setting/ environment etc.)	*I used to perform oral exercise for her when she was a kid, and now we need to clean her teeth at least once a day.*	*P8*
Personal development		
Feeling empowered when healthcare professionals are/are involved in the provisioning process (e.g., decision-making/teaching techniques)	*My child's speech therapist taught us how to steam and mash simple foods so that he (the child) could chew them.*	*P2*
Resilience (e.g., self-learn/high adaptivity/coping level)	*When we meet new people and they see our child, they comment on how skinny he is … let others express themselves*	*P1*
Eager to learn more about food texture modification or CP condition itself	*I find it amusing when she (her friend) says to prepare the fruit (pudding) in this way and store it in the refrigerator to make it easier to eat.*	*P6*
Wish and expectation		
Supportiveness among family members and the community	*Creating a program that we can all participate into encourage parents of children with cerebral palsy to feed their kids gradually*	*P4*
Inclusivity from society and healthcare professionals	*Health care providers should, if at all possible, be involved in community-based rehabilitation, or CBR, and should provide guidance and information regarding appropriate diet for the kids.*	*P5*
Improvement in child's health and nutrition	*I currently only offer her veggies, but I'm doing my best.*	*P7*
Ready-to-eat food availability in the market	*The food company could consider preparing ready-to-eat food as a potential solution.*	*P3*
A standard protocol/module/guideline for a food texture modification practice (e.g., clear instructions, proper utensils/equipment)	*I believe that the most crucial information for the nutrition module should be on the types of food that should be provided and fed to the child.*	*P9*

"*The doctor suggested to me, what if we try to improve your son's food texture? Having consumed porridge for a long time, made him unable to tolerate different textures. It seems as though there is no muscle movement if we don't make him practice or force him to chew. I should adjust the texture to improve his swallowing function.*" (P4)

"*They (referring to a speech therapist) demonstrated to me how to chop food into smaller pieces because my child might not always stick to its current texture. The blended one was what my son used to eat. He can currently chew at the moment. He has acquired this and I'll give him a somewhat chunky texture. We'll gradually upgrade the texture if our child can handle it, so I'll follow him anyhow.*" (P6)

Working mothers sometimes eat or buy food outside. Some of the mothers also shared experiences when eating outside.

> *"We buy outside food and cook occasionally. For instance, if we buy him anything, we typically get items like fried kuetiaw, fried noodles, kuetiaw soup, or kuetiaw ladna (kuetiaw is a type of flat rice noodles). Since the food is already soft when it is served, all we need to do is either mash it slightly or put it in a blender that operates on batteries. We sometimes choose soft texture of burger such as fish burger at food store or simply chew it before giving it to our child."* (P1)

They also had a routine practice for their children in terms of the food preparation and food choices of their children depending on the situations, as mentioned in the quotes followed:

> "We don't follow a fixed menu since occasionally he (the child) gets bored with what he's eating. Sometimes he eat plain porridge with various vegetables and chicken dishes, but for now we just combine everything and make it all at once.
>
> Interviewer: So you're going to chop up the vegetables and chicken food before cooking it?
>
> *P2: You're right, he may get uninterested with the food prepared, so it depends on his preferences."* (P2)

3.2.2. Theme 2: perception

The way that participants perceived changes in food texture became a prominent topic that affected their dietary choices and general actions. Their readiness to accept or maintain food texture modifications for their children was greatly influenced by these perceptions. Effective feeding practices might be implemented with its help or hindered by it. Exploring this theme provides valuable insights into how caregivers interpret advice from healthcare professionals, their confidence in their own judgement, and the degree to which they believe food texture modification is necessary, beneficial, or burdensome. The mothers had a perception that the child's condition influenced the practice of modifying food texture as it was based on the swallowing ability and children's preferences. The child is the priority to decide as demonstrated in the quotes:

> *"It's important to make sure your child is ready before making a food texture modification, regardless of whether they accept it or are ready for it. Given that some children have difficulty swallowing, it may not be possible to force them to take solid food. For example, my daughter, who has reflux based on the results of her barium swallow, she may not be ready yet because solid food eventually makes its way into the lungs, so it's best to start her off with liquids. When we observe that she can protect herself and has gag reflex, the dietitian and doctor suggest that we might try giving her some additional solid food. We don't force her to try, but if she can tolerate solid food, we keep adding a little bit more solid texture, until one day we notice that she can move the food in her mouth. At that point, we might try giving her a little more solid food. Because of this, I believe we need to watch for signs from the kids and support them as well. Some kids at the school seem to tolerate solid food, but their parents just give them milk."* (P8)

The mothers also wanted the best for their children and made sure they received freshly cooked food for their meal time.

> *"We never preserve her food, so I will prepare it fresh for her. I will cook for her in the morning. The ingredients are ready; they were prepped the night before; just add them to the pan accordingly in the morning."* (P9)

One of the parents shared that if the food is not freshly prepared, the child will experience bloating and may further interfere with the time of feeding.

> *"Even though I have to do the same thing every day, I don't mind because I never prepare puree or frozen food when I'm preparing the food. I'm unable to work, and I think that mothers with special needs children are unable to work because they must care for their children around-the-clock. This means that in addition to caring for the son and feeding him, you also have to cook and do housework (washing). I'm not sure why some mothers said, "Don't want to repeat everything," but that's their decision. Perhaps their kids are easy to look after, so they can grab food from the refrigerator. Meanwhile, my son has had a bloated stomach for a while now, so I'm picky about what's in the fridge. Every day, I boil something, like pork bones for soup, to make sure it's nutritious. I used the broth first, steaming the chicken or fish before combining everything together to make the porridge."* (P10)

As the previous study found nearly half (40.8%) of the children that required food texture modification were undernutrition and the mothers noticed these issues.

> "Interviewer: Is the amount of calories he needs each day sufficient for him to grow, in your opinion? How are you feeling?
>
> *P2: Since his weight remains static, I don't think it's sufficient."* (P2)

Alternatively, one of the mothers thought the children were taking enough calories and nutrition even though her child does not frequently take protein sources as she said her child's body weight is ideal.

> " She dislikes the taste and smell of chicken, but I make her drink chicken soup nevertheless, so I don't have to worry about my child's weight; in fact, her body weight is perfect (which is why the mother only offered chicken once a month).
>
> *I don't offer her fish or chicken because I'm scared that since she's only lying down, the cholesterol in those foods won't be able to be processed and could harm her or anything else. If she can walk, it's fine enough."* (P7)

3.2.3. Theme 3: challenges

Mothers discussed a range of challenges they encountered when modifying the texture of food for their children during the interviews. The practical, emotional, and knowledge-related challenges associated with everyday feeding processes were concentrate in this theme. Since these issues have a direct bearing on the sustainability, consistency, and quality of food texture modifications at home, it is critical to comprehend them. By recognizing these hurdles, the study offers vital information for creating more useful, caregiver-friendly interventions, learning resources, and support networks that tackle actual challenges. Some challenges were experienced by the caregivers in preparing food texture modification for their children. Some technical issues such as taking time to make their children finish the meal.

"*Interviewer: Does eating typically take a long time? For instance, we can finish a meal in fifteen minutes. What is the average time it takes your child to consume one portion?*

P1: Between one and one and a half hours." (P1)

"All I know is that it takes 20 minutes to finish a meal, but it really depends on my daughter's health. It takes her at least two hours to finish her meal because after one mouthful, she wants to look at something, listen, and then look at it again." (P3)

"I have to wait for her (the child) to eat or drink anything because I'm afraid that she might choke or become short of breath if she fails to eat it. Sometimes she keeps the food in her mouth, and other times it takes a long time for because I had to wait." (P5)

"He (the child) can withstand eating for a certain amount of time, sometimes up to an hour, as long as he does so. We are now having fun with him. We occasionally allow him to watch TV while we feed him." (P6)

Other mothers added the convenience of preparing food texture modification was one of the issues.

"Interviewer: Do you think that because kids don't eat the same as adults or other kids, it's hard to create food with modified textures? So, what are your thoughts on it? Does it pose a challenge?

P2: It is quite difficult. Although I have never tried it, we believe that spaghetti blend is not the ideal dish for him to try, therefore we currently only give him porridge." (P2)

"My daughter's protein is like this (showing her palm size), so I have trouble finding

vegetables (difficult to get raw ingredients). I also have trouble if my stock (raw ingredients) is not enough and if I'm outside or at someone else's place, I can't get that thing (raw ingredients)." (P3)

Preparing food texture modification needs some equipment and utensils that make the parents feel hustled when going to other places or holidays for more than one day.

"Due to the pandemic, I was only able to take my son back to my mother's house in the Perak region. Visiting my mother's house is like moving into a new home, so I really pack everything—blender, cooker, everything. If you ask me to go to a hotel for a vacation, I will bring everything, but it's difficult because the father has to carry everything." (P10)

Different children had different behaviors that needed to be tackled, as mentioned by one of the mothers, due to her child's tantrum, she needed to rearrange time to do house chores based on her child's needs.

"*She demands attention, therefore I spend my entire day at home devoted to her. I wash clothes at night because I am with her all day in the morning and can spend as much time as I want with her.I have to make dinner at night. When my spouse and my son get home from school in the evening, that's when I do everything. If I don't have time to cook at night, my husband will get me food in the morning."* (P9)

The mothers also faced difficulty when they went to the hospitals for medical care since one of the mothers found it difficult to comprehend the treatment or management that was given by the medical staff. For the intervention to be carried out without confusion, the moms raised concerns about standardizing the medical terminology used among them.

"*The last time the doctor blamed me alone, saying that I didn't want to have the procedure to open the G tube here (pointing to the stomach), which is why my son wasn't getting enough nutrition. However, they just sort of aimed me down. We didn't agree because of the operation—which was related to a prior operation when my son was a baby—my son was weak and his immune system was compromised, which is how he acquired CP. In reality, though, my son was born micro-preemie, everything was fine—no CP condition, lung, heart, or brain issues. He had a brain impairment as a result of two surgeries, so when they offered me a third procedure, the doctor told me you had to accept, but I can't accept it yet. Knowing our children's needs and how they behave is our job as parents. You want to give him an alternative, but he loves to eat. Why? Does this mean that they will become lazy because the option doesn't want him to use up energy when swallowing?*

I've met a few dietitians, but not all of them have been good at advising me; instead, they just like to take notes. Until recently, when I met the dietitians at government hospitals X and Y, I had a clear idea of what I needed to do. We looked at this information (while holding and displaying the ingredients at the back of the milk can), so they could calculate nutrient content accurately because by now, all of the formula milk has already advanced. However, not all dietitians will have access to all of the information. I believe you are not a special mom and you are not taking care of a special need because even if you just read a book, you will never understand. However, we

understand because we have met a lot of good doctors, so we want accurate and good information. I apologize if I was too direct. The previous dietitian in X hospital also did not force me to feed my son full time. They also have different ways of thinking." (P10)

Having special needs children requires caregivers to find more information on expectations in dealing with their children and further improve the quality of life of the caregivers. Some parents seek knowledge on their own and try to schedule their daily time.

"*I've read a lot about the experiences of having children just like this, right? We must learn time management skills. At first, I was incredibly perplexed since I didn't know how to organize things according to priority, but after hearing my husband's advice, I became accustomed to it."* (P9)

The child's food preferences and ability to eat certain textures of food influenced the mother to prepare for the meal as stated by one of the mothers.

"*I make fish around noon, so for dinner at night, switch to soy-sauced chicken. We stir-fry vegetables, but she doesn't like them so I'll prepare her some veggie soup since she dislikes fried foods."* (P9)

Another challenge was making sure that the intake was enough according to the children's requirements and needs. Due to this, some of them will make appointments with healthcare professionals to further discuss their child's nutrition status and monitor the action taken.

"I requested an appointment with a healthcare professional if I wanted to learn how to boost my child protein consumption. During our last conversation, we discussed how to increase protein intake by eating more fish, poultry, pork, eggs, and nuts. The dietitian also suggested protein powder." (P8)

It can be difficult, emotional and stressful for caregivers to provide care for children with cerebral palsy who need their food's texture modified.

"*Nobody seems to care that I'm a little stressed about this. I'll set aside time to eat outside since I want to feed my daughter first. Since I only have my daughter and live alone with her, I might be a little rushed at times. There isn't anyone who could take up my position. My child has a special chair, and when she is full, she sits at the table with me. Since her food's texture is unsuitable for eating outside. I'll give her a taste of the food if she likes it even she is unable to eat it."* (P3)

We occasionally want her to take a large amount of the prepared food, but when she eats little, I become frustrated. When she was younger, I used to mix all the carrots and gave her using the spoon after she was weaned off of the Ryles tube. (P5)

A family with a child like this is unfortunate because I know what happened to me; there is no entertainment, we cannot go out or go on vacation because if I take a girl like this on vacation, it's difficult for her to enter that place, she can't take care of herself. At one point, my family didn't understand that I was looking for one special girl until my mother became ill, which prevented me from seeing my mother. Others frequently assume I'm very selfish because I don't take care of my mother. Of course, I can't take care of my mother as I have to work and look after this girl at times. (P7)

We are Muslims, and it happens that some individuals abuse children, especially if they are children with special needs like this. This may be the reason I quit my job because I'm afraid of leaving my care to others. There are times when I want to use the toilet, but she won't let me. That's the worst. I have to be good at controlling my emotions." (P9)

3.2.4. Theme 4: ways to overcome the challenges

In negotiating the demands of food texture modification, caregivers' creativity, adaptability, and resilience are highlighted in this theme. It exhibits practical solutions that may be shared with other caregivers dealing with similar difficulties. It also gives information about the internal and external resources that caregivers use, like online resources, expert advice, trial-and-error learning, and family support. The mothers tried to seek information by themselves to overcome the challenges as demonstrated in the quotes below:

"It's been more than a year or two since I started practicing, and I learned what foods and amount sizes are best for my child from a dietitian. And I personally read it. She eats three meals a day at the very least; I have been training for him for the past two years." (P3)

In determination to improve their children's nutritional state, the mother also attempted other things.

"Can your kid eat this kind of cuisine, someone could wonder? For instance, when I blended spaghetti because my daughter liked it, many were taken by surprise. In my opinion, everything tastes better when it's cooked, soft, and mixed. However, I do enjoy colors because I believe that all colors have benefits. It could be something nourishing; after all, my daughter always wants to eat, so when I blend it, she goes for it. The fact that the pizza needs to be blended is funny." (P3)

"No one advised me to provide what kind of food to her, because I assume I gave it to her based on her age." (P5)

"I make an effort to feed anything, sometimes even including ice cream, however occasionally certain people choose not to. Although it's chilly, we still want our child to eat healthily. I just fed him; on some days, he accepted, but on other days, he rejected. Spicy food is never a good fit for him. To date, I have only attempted to feed him the meat from the crab; instead of giving him actual fresh seafood, I give him fishcakes or fish balls of some sort. We occasionally feed him nuts, but I always crush and then give them to him. Honestly, I simply want to give him to see if he wants them or not." (P6)

"I want to take care of him at all times, so if he becomes difficult to swallow, I have to add extra water to the bowl to make it smoother like a smoothie texture. I looked around before purchasing this machine to modify food texture for convenience." (P10)

Other than that, caregivers make an effort to train their children who have problems with feeding difficulties that require food texture modification.

"She appears to be able to lick food now. I used to perform oral exercise for her when she was a kid, and now we need to clean her teeth at least once a day. After that, we urge her to perform mouth exercise each time she consumes an ice cream. Previously, she used to be unable to eat cold food; everything had to be hot, including yogurt, which needed to be warmed before she could consume it." (P8)

"At first, I would wait three hours for him to finish a meal. He might need ten feeds before going to sleep, but sometimes he needs a break to go potty or due to other things, which is why it takes three hours. At first, I wanted my baby to finish every dish I prepared; I knew it might take him a long time to finish and not get enough nutrition, nevertheless I also wanted him to practice swallowing more." (P10)

3.2.5. Theme 5: personal development

Many participants considered how the experience aided in their personal development and self-efficacy as they worked through the difficulties of changing food textures for their children. The learning, adaptability, resilience, and self-assurance that mothers acquired over time are all reflected in this theme. It was more than just picking up new cooking skills; it was also about developing a stronger sense of competence, endurance, and self-determination in order to better manage their child's nutritional needs. Examining this issue is crucial because it clarifies the transforming power of caregiving, which is sometimes disregarded in technical or clinical debates. Participants talked about how, in spite of their initial feelings of uncertainty or overwhelm, they became more informed, proactive, and resourceful. Caregivers felt empowered with healthcare professionals' help in managing their children with feeding difficulties as mentioned in the quotes below:

"My child's speech therapist taught us how to steam and mash simple foods so that he (the child) could chew them. However, we have to put food in close for him to eat because his tongue cannot move inside, so we have to hold it and instruct him to bite it." (P2)

Having children with cerebral palsy that have feeding issues, helps caregivers' personalities to develop to become more resilient and well prepared according to their child's needs. They will do anything to make sure that their children get the nutrition by providing a safe environment and safe feeding environment.

"We just take it as it is. When we meet new people and they see our child, they comment on how skinny he is, especially in his legs. It is difficult to explain because the legs do not stand and he is not able to bear weight. Is it that we don't do our hardest? We feed him a lot, but it takes him a while to finish, so we'll wait for him to do so and attempt to give him as much as we can for as long as we can. Let others express themselves." (P1)

He makes a coughing sound as he eats, so we notice that he doesn't always chew. Since his face doesn't get red, it's not like he's choking, so I gave him water after letting him calm down before feeding her child as usual. (P6)

When it comes time for dinner, my child will occasionally act out, but I can always tell when she is hungry. In order to quit giving her food, I first tried to convince her by holding and embracing her and asking what she wanted. Once that worked and she started to feel better, I kept feeding her. (P9)

As husband and wife, we have become used to packing a lot for outdoor activities. When we stay at a hotel, I always prepare the same meal as that is what I do every day. Naturally, there are moments when I don't feel like cooking. In those situations, I prepare the soup in advance, store it in the refrigerator, and when I take it out, I make sure to store it in a high-quality ice pack." (P10)

The mothers were also eager to learn about different types of food that can be given to their children to encourage eating and eventually improve the nutritional status of their children.

"Since my son can eat fruit right away without any problems (though it can be challenging to finish a meal), I find it interesting that she (her friend) is making fruit pudding for her child. Therefore, I find it amusing when she (her friend) says to prepare the fruit in this way and store it in the refrigerator to make it easier to eat." (P6)

Finally, social support from family and community is crucial for caregivers of children with cerebral palsy as it can offer emotional, physical, informational, and practical support, all of which can reduce stress, promote well-being, and improve the quality of care

"Our child is already ten years old, and as parents, we have adapted to his routine. While he was younger, we used to worry a lot, but these days, our family has come to terms with it. It's nothing new to us. We don't need to worry too much because he is already living this kind of lifestyle." (P2)

3.2.6. Theme 6: wish and expectation

In addition to their children's future development, participants shared a variety of expectations and wishes for the assistance they would like to receive from communities, healthcare systems, or educational resources. Mothers' views on the future were reflected in this theme, which includes their wishes for better services, clarity in direction, and more inclusive support networks. Furthermore, reflecting the desire for caregivers to feel valued and supported in their duties, these expectations also represent their goals for the

independence, health, and quality of life of their children. The final part of the interview session was asking about any wishes or expectations that the caregivers need in helping their children with CP. Here were some expectations that they anticipated from healthcare professionals.

> *"Dietitians should offer a program for educating and informing CP parents, as I've seen that these children share similarities with my kid. It's not like my child will choke if we give them rice, but if parents are reassured about it, they might be able to gradually introduce that practice with their kids. Other than that, creating a program that we can all participate into encourage parents of children with cerebral palsy to feed their kids gradually since we can't go straight from porridge, which has a soft texture, to rice, which has a rough texture. As they get bigger, we want to put together everything, including protein sources. Food preparation needs to be taught because it takes time."* (P4)

> *"I believe that in a professional circle around children with special needs, everyone will need to know at least the basics. This way, when healthcare providers attend to the children with special needs, they all need to speak the same language and provide the same education, ensuring that every special needs mother receives the same information."* (P10)

Other than that, one of the mothers wants inclusivity from society to care and be part of them so that if anything happens, they know how to react and respond.

> *"Health care providers should, if at all possible, be involved in community-based rehabilitation, or CBR, and should provide guidance and information regarding appropriate diet for the kids. The society that is closest to CBR is the one that will care if something happens."* (P5)

Besides that, the mothers wished that providing adequate nutrition would help in improving the child's health and nutrition status.

> *"I understand that you are all now urging me to give my daughter more protein by giving her meat, chicken, and fish because I currently only offer her veggies, but I'm doing my best. If God blesses me, I hope to be able to retire earlier because I want to be there for my daughter. After everything is settled, I would like to leave my job as well, but I am passionate about teaching and education, so I'm hoping that God would grant me retirement."* (P7)

One of the mothers gave the opinion to have ready-to-eat food with textures modified out in the market so that they have choices and doesn't burden the parents to prepare food when traveling or eating out.

> *"In my opinion, children with cerebral palsy (CP) can join us for meals if there is someone or anything from anyplace who is aware of the circumstances, as she is not allowed to take a piece of food (food texture modification). Given the variety of foods available for travel these days, all of which are meant for adult consumption, is there one meal that the kids can safely have while traveling? Isn't it true that when you go on vacation, people will pack a slow cooker and a hand blender for their kids? The food company could consider preparing ready-to-eat food as a potential solution."* (P3)

Helping caregivers of children with cerebral palsy by providing knowledge and information in food preparation, texture modification, and other nutrition-related topics is believed to be beneficial as mentioned in the quotes:

> *"How much does the food weigh? It's difficult to calculate how much rice, for example, should be consumed in a day. If it says to take one bowl, what kind, size, and quantity of grams should I use?"* (P1)

> *"… a red flag, or if my child's food needs to be sliced, what tools do I need to make it easier to cut, or even simply providing parents a pamphlet that serves as a guide"* (P4)

> *"If it were possible, it would be like variety of the menu, as occasionally these CP eat nothing but porridge every day. It is necessary to have a diverse menu because my son doesn't always enjoy the same foods as the rest of us, sometimes he gets bored when we eat the same things."* (P6)

> *"I believe that the most crucial information for the nutrition module should be on the types of food that should be provided and fed to the child."* (P9)

4. Discussion

Based on the research questions, the study's findings identified six key themes: current practice, perceptions, challenges, ways to overcome the challenges, personal development, and wishes and expectations of the caregivers of children with CP requiring food texture modification. As children with CP might have trouble when chewing, swallowing or controlling their tongue while eating, thus it's crucial to modify food textures to ensure safety. Depending on the demands of the individual, several texture changes can be utilized, such as pureed or mashed foods, thickened liquids, or chopped or crushed solids. The right texture modification for each individual with CP should be determined in collaboration with a multidisciplinary healthcare professional. This in turn will subsequently improve children's nutritional status and the quality of life of the caregivers. The finding of the results using themes was discussed in the following writing.

4.1. Theme 1: current practice

The Transtheoretical Model (TTM) of behaviour change was proposed by Prochaska and DiClemente (1983), who stated that people go through many phases of preparedness before making a change. Precontemplation, contemplation, planning, action, and maintenance are the steps [34]. When it comes to implementing food texture modification, there is a possibility that caregivers will go through similar phases of readiness. They might not yet be aware of the advantages of modifying food texture. Our study showed the mothers were hesitant to modify food texture mainly due to lack of exposure, in addition to time constraints in managing family matters.

The experiences of mothers when preparing food for their children with CP were examined in a qualitative studies which showed that a variety of aspects such as method of meals preparation, child's specific needs, cultural and religious considerations, and availability of resources and possible assistance either manpower, new cooking utensils or suitable environment. Besides, studies found mothers encounter a variety of difficulties when preparing food, including limited availability of products, time restraints, and the pressure to provide quality food were all taken into consideration [25,35]. Despite all the challenges experienced by the mothers, they still prepared home-cooked food for their children as it is part of the daily routine. In addition, our study also found that some parents are willing to make texture modification when eating outside food or choose from a selection of food that their children can safely tolerate (e.g., pureed, soft texture, easy-to-chew food).

The involvement of healthcare professionals were found to be important as this might influence the practice of food texture modification among families of children with CP. A speech therapist who assesses swallowing function will make suggestions for suitable food textures and liquid consistencies [36]. Dietitians were cited as crucial in creating tailored meal plans that satisfy a child's nutritional needs while also taking into account any texture preferences or requirements. Multidisciplinary rehabilitation was found to improve long-term for individuals with CP [37–39]. Our research revealed that caregivers consult physicians for guidance on safe textures for their children.

Implementing a consistent guideline, such as the International Dysphagia Diet Standardization Initiative (IDDSI) framework, would be beneficial because caregivers continue to prepare meals for their children with CP despite a number of challenges. With the right guidance and support from healthcare professionals, especially dietitians and speech-language therapists, caregivers may provide meals that are safe, acceptable, and catered to their child's swallowing skills. In addition to improving mealtime safety and nutritional sufficiency, this cooperative method lowers caregiver stress by offering specific, research-based instructions. This was supported by the systematic review conducted by Wu et al. (2021) that food texture and liquid consistency modification also can reduce malnutrition occurrence and improve mealtime satisfaction [17].

4.2. Theme 2: perception

Parents generally thought their children with CP experienced feeding issues associated with chewing problems [40]. Weight and mealtime satisfaction improved with nutrition intervention that involved modifying texture and consistency [17]. Additionally, the review among dysphagic individuals concerned with the effect on the taste of the food and enjoyment of the food. Our study found that one of the mothers complained food texture modification caused her child to experience bloating. A possible reason for these health issues might be due to the lower variety of gut bacteria in the food texture-modified diets. This was in agreement with a previous study that discovered a lower gut microbiota among individuals with CP [41]. A review by Trivic and Hojsak (2019) suggested that a full nutritional assessment that takes into account body composition should come before any nutritional intervention. The article suggests that, if safe and appropriate, dietary counseling should be the first step in nutritional support, followed by changes to oral feeding. Nonetheless, enteral nutrition should be quickly started in situations where swallowing is dangerous and oral intake is insufficient, and early gastrostomy installation should be assessed and discussed with parents. The article also emphasizes how common gastrointestinal issues are in children with CP and suggests that they must be promptly identified and effectively managed because it can be more difficult for them to eat and maintain a healthy weight [5]. It's possible that the texture-modified diet increased the prevalence of gastrointestinal symptoms as a result of a mix of factors, such as altered food texture and composition, altered gut flora, and individuals' variations in gastrointestinal function and motility.

When it comes to implementing dietary modifications for children with CP, caregivers' attitudes regarding food texture modification can have a significant impact on their confidence and compliance. To clarify misunderstandings and increase acceptability, health care professionals should emphasize the value of mealtime safety in clear, culturally appropriate instruction. Peer assistance and hands-on training can improve caregivers' abilities and attitudes, and a cooperative, courteous approach guarantees that texture modifications is not seen as a burden but rather as a necessary and feasible aspect of care. Previous studies have shown that social support intervention activities for caregivers with CP children that were carried out practically and directly involving researchers and participants have a significant intervention effect ($p = 0.031$) [42]. This is also supported by a study in Ghana among caregivers of children with CP who struggle with nutritional problems, demonstrating that a training program can help to enhance the quality of nutrition [25].

4.3. Theme 3: challenges

Making sure that the modified foods fulfill each individual's nutritional requirements is one of the primary concerns with food texture modification. Other challenges include texture consistency, time and cost, availability of ingredients and personal preferences. If texture-modified foods are not appropriately balanced with other foods or supplements, their lower levels of calories, protein, and

other nutrients might result in malnutrition. Modifying the texture of food can change its flavour, look, and texture, which can make it less pleasant to eat. Finding a consistent texture that is both appealing for the person and safe for swallowing might be challenging. Foods with modified textures can take longer to prepare and cost more money. Particularly in distant or low-resource locations, some texture modifications may call for specialized products or equipment that may not be easily accessible. It can be challenging to tailor texture-modified foods to individual preferences and tolerance, which can result in decreased consumption and lead to malnutrition [43,44]. Emotional burden needs to be tackled among caregivers of children with CP as shown in our study, caregivers felt overwhelmed in making sure to fulfill their children's needs. This was also demonstrated in a previous study that showed some caregivers felt guilty and worried about failing to provide enough food or water, feared aspiration and choking while eating, having a hard time adjusting to the social isolation that eventually decreased their quality of life. Furthermore, the time and effort needed to prepare and administer texture-modified food causes stress and frustration [27,45,46].

Our study found that some mothers had negative experiences with healthcare professionals when receiving management for their children with CP. Probable cause could be a result of the absence of resources and knowledge from healthcare professionals, feeling disregarded or neglected by healthcare professionals when expressing concerns for their child's needs or feeling overburdened and unsupported while handling the various medical demands of their child [28,47].

This might also be contributed by under sourced healthcare facilities including under staffing which resulted in failure to give adequate attention due to overwhelming workload and lack of competition from the providers [48]. In addition, insufficient assistance by the healthcare sectors could also be contributed by the increase of expenses both directly and indirectly related to the care, especially to families with financial constraints [49]. As an initial step to address this issue can be the development of standardized guidelines for food texture modification such as the International Dysphagia Diet Standardisation Initiative (IDDSI) that provides a globally recognized framework with clear terminology, testing protocols, and classification levels, its uptake varies widely across settings. This highlights the need for formal policies that ensure consistent adoption of such standards to improve patient safety and inter-professional communication [50,51]. Moreover, recent research demonstrates that targeted, IDDSI-based training interventions can significantly improve provider knowledge and compliance with texture-modified diet protocols in care facilities; evidence that underscores the value of systematized education for clinicians [52].

Many caregivers report feeling unsupported after returning home, even though initial nutrition and feeding advice is frequently given during clinic visits or hospital stays. Confusion, incorrect application of food texture, and elevated caregiver stress might result from this disparity. Lack of consistent communication is a significant obstacle, especially when healthcare practitioners employ different terminology, frameworks, or languages. When different professionals give contradictory advice or use new jargon, for instance, caregivers may feel overwhelmed or confused, particularly when food texture levels are not described using a standardized reference such as the IDDSI framework. Healthcare services must develop regular, coordinated, and caregiver-friendly communication that supports the practical use of feeding practices in order to address this issue as one-time consultations are not enough.

4.4. Theme 4: ways to overcome challenges

As discussed, the challenges faced by caregivers earlier in preparing food texture modification for their children that require food texture modification, some mothers tried to find information by themselves before trying to implement and train depending on the child's demands. A qualitative study conducted by Kajsa et al. (2021) explored the feeding experiences among 20 parents of children with feeding problems, they frequently ask healthcare professionals and other sources for information and help. They further strategize their daily life especially when eating out so that the child can get nutrition accordingly [53]. Similarly, another study conducted by Estrem et al. (2017) demonstrated that parents needed a variety of information to manage their children's feeding issues, including understanding the root causes, learning coping mechanisms, gaining access to specialized services and interventions, and being aware of the long-term effects of the feeding issue. Parents also stressed the value of receiving comprehensive and consistent information from medical professionals, participating in the decision-making process, and having access to continuous support [26].

Delivering healthcare services that address patients' and caregivers' needs is crucial for promoting positive care outcomes and perceptions of quality. Effective communication between caregivers, patients and healthcare professionals is essential for care provision and recovery. Patient-centered communication is fundamental for optimal health outcomes, aligning with nursing values of individualized and responsive care. However, achieving patient-centered care and communication in nurse-patient interactions is complex due to various barriers including institutional, communication, environmental, and personal factors. Healthcare professionals must identify these barriers and facilitators to promote patient-centered care and communication in clinical interactions [54]. This study highlighted that some of the caregivers experienced confusion in the management by multidisciplinary team due to the medical terminologies used. Previous study suggested a toolkit which contain daily goals sheet that included structured tools, standardized processes, daily patient-centered rounds, and team huddles. Post-implementation analysis of 495 communication events showed improvements in time to treatment, nurse satisfaction, and resolution of patient issues. The resulting toolkit offers healthcare organizations practical resources for enhancing teamwork and communication [55]. When it comes to preparing texture-modified meals for children with CP, caregivers encounter a number of difficulties, such as limited time, insufficient expertise, emotional exhaustion, and insufficient assistance. To tackle these problems, a multifaceted strategy is needed, including hands-on training, access to pre-made solutions, ongoing professional assistance, and emotional support. Additionally, including food texture adjustment into community-based initiatives and policies can promote safe, sustainable feeding habits at home and lessen the strain on caregivers. By incorporating food texture modification into national policies, providing resources and education for caregivers, subsidizing food items and equipment that are required, and enhancing access to multidisciplinary care, policymakers can significantly improve the lives of those who care for children with cerebral palsy. Policymakers may contribute to ensuring that children with CP eat wholesome,

safe meals at home by addressing these systemic gaps, which will eventually improve health outcomes and lessen the burden on caregivers [6].

4.5. Theme 5: personal development

Kuo and Lach (2012) conducted a qualitative study to investigate siblings' experiences in taking care of individuals with CP. According to the research, taking care of the sibling can be challenging to interpret the needs and wants of their sibling with CP, which can be difficult due to communication barriers. They also need to protect their siblings from being emotionally and physically discriminated against and further sacrifice their own lives [56]. Our study showed that the mothers employed a variety of coping mechanisms to deal with the feeding issues, including asking for advice and assistance, altering their feeding routines, and adopting a positive attitude about the feeding process. The family structure that a child grows up in will actively participate in shaping and promoting behaviors that will stick with him or her throughout life. Early exposure to a variety of tastes and flavors can help to encourage healthy eating in the future. The authors advise parents to set a good example for their children by exposing them to a variety of healthy dietary options [57].

Resilient caregivers are better able to cope with stress, keep a positive attitude, and solve issues. According to several studies, caregivers with higher levels of resilience are better equipped to handle the responsibilities of care-giving, experience better mental health outcomes, and are more likely to benefit positively from their experiences. Social support, taking care of oneself, and having access to resources and information are just a few ways that resilience can be promoted [58,59]. In some instances, caregiver burden was examined alongside various indicators of well-being, including life satisfaction, positive or negative affect, social support, general distress, quality of life, and coping. Among seven studies (14%) in the systematic review conducted by McKenna et al. (2022) investigating the relationship between resilience and burden, resilience was consistently found to be positively associated with several well-being outcomes including quality of life of the caregivers [60].

4.6. Theme 6: wish and expectation

Eloreidi et al. (2021) mentioned in their study that parents wish for their children to have opportunities to participate in community activities, acceptance and understanding from others, and assistance from healthcare and educational systems. The researcher also emphasized the value of social support in assisting parents in overcoming the strain and difficulties that come with raising a child with cerebral palsy which was similar to our finding that caregivers need support from community and healthcare professionals [61]. Additionally, other studies highlighted the complicated interaction of factors, including the child's ability, the physical and social environment, as well as other social views and support, that affect caregivers' experiences [42].

Our study demands knowledge regarding food texture modification such as preparation, position during feeding, food alternative suggestions, food calories and nutrient content and information about the health of individuals with cerebral palsy should be created to support the nutritional status of the children and improve the quality of life of the parents. This was consistent with a study by Shyamani et al. (2018) that understanding nutrition is crucial for creating effective nutrition interventions and enhancing health outcomes for those who struggle with feeding. Individualized nutrition plans can be created by multidisciplinary teams with a variety of knowledge and abilities, and they can also support and direct caregivers in putting them into practice. The researchers highlighted the significance of continuous nutrition education and training for related healthcare professionals in improving and enhancing management of patients with feeding difficulties [62].

The findings of this study have several practical implications for healthcare professionals, policymakers, and caregivers. First, the variability and uncertainty in current practices highlight the need for structured, culturally appropriate training programs for caregivers on food texture modification, particularly aligned with evidence-based frameworks such as the IDDSI. Healthcare professionals — including dietitians, speech-language therapists, and pediatricians should collaborate to develop simple, visual, and locally relevant resources (e.g., videos, booklets, or mobile applications) to guide caregivers in preparing safe and appropriate textures at home.

For policy makers, these findings emphasize the need to integrate caregiver education into routine pediatric or community health services. This could include community-based workshops, caregiver support groups, and interdisciplinary feeding teams in primary care settings. Policies should also ensure equitable access to feeding and swallowing services, especially in under-served or rural areas. For caregivers, the study provides validation of their lived experiences while highlighting the importance of continued learning and collaboration with healthcare providers. Empowering caregivers through ongoing support and feedback, rather than one-off consultations, can improve adherence to recommended feeding strategies and ultimately enhance child health outcomes.

5. Limitations

One notable limitation of this study is the relatively small sample size, which may restrict the generalization of the findings to wider populations. The demographic homogeneity particularly in terms of cultural background, and geographic location may also introduce bias, potentially limiting the applicability of the results to more diverse groups. However, this homogeneity also served as a strength by reducing variability and allowing for a more focused examination of the study outcomes within a specific, well-defined population. This increased internal consistency may enhance the reliability of findings for similar contexts. Studies have indicated that father may have a more active part in making decisions or providing financial support, whereas mother tend to report a greater emotional and physical demand when providing care [63]. Therefore, it's possible that the results primarily represent the opinions of mothers and don't fully represent the experiences of other caregivers, such fathers, grandparents, or paid caregivers. Future studies should aim for

more diverse and larger samples to improve external validity and better reflect the broader population.

6. Conclusion

This study examined caregivers' experiences in managing food texture modification for children with Cerebral Palsy, identifying six main themes: current practices, perceptions, challenges, strategies to overcome challenges, personal development, and wishes and expectations. The findings illustrated how caregivers adapt, acquire skills, and seek support in feeding their children, highlighting the importance of targeted, caregiver-focused training and evidence-based resources. Providing structured, practical, and culturally appropriate interventions by healthcare providers and policymakers can strengthen caregiver confidence, improve children's nutritional outcomes, and enhance the overall well-being of both caregivers and children with CP.

CRediT authorship contribution statement

Sakinah Kamal: Writing – review & editing, Writing – original draft, Resources, Methodology, Investigation, Data curation, Conceptualization. **Nur Hana Hamzaid:** Writing – review & editing, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Sazlina Kamaralzaman:** Writing – review & editing, Resources, Methodology, Investigation, Data curation, Conceptualization. **Shobha Sharma:** Writing – review & editing, Resources, Methodology, Data curation, Conceptualization. **Nurul Hazirah Jaafar:** Writing – review & editing, Resources, Methodology, Investigation, Data curation, Conceptualization. **Phei Ming Chern:** Writing – review & editing, Resources, Methodology, Data curation, Conceptualization. **Nurul Izzaty Hassan:** Writing – review & editing, Resources, Methodology, Data curation, Conceptualization. **Hasnah Toran:** Writing – review & editing, Resources, Methodology, Data curation, Conceptualization. **Noor Akmal Shareela Ismail:** Writing – review & editing, Resources, Methodology, Data curation, Conceptualization. **Ghazali Yusri:** Writing – review & editing, Resources, Methodology, Data curation, Conceptualization. **Muhammad Syahril Mohd Nazley:** Writing – review & editing, Resources, Methodology, Data curation, Conceptualization. **Nur Amira Adila Zaidi:** Writing – review & editing, Resources, Methodology, Data curation, Conceptualization.

Ethics statement

The study obtained ethical approval from UKM Research Ethics Committee, with reference number UKM PPI/111/8/JEP-2022-387, approved on 21 July 2022. Informed consent was obtained from all participants prior to their participation in the study.

Data availability statement

Data will be made available upon request. For request data, please write to the corresponding author.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Dr Nur Hana Hamzaid reports financial support was provided by National University of Malaysia. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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