Article

Disability and physical activity perspectives of hmong mothers who have a child with a disability

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Abstract: Even though Hmong people have a unique history and culture, they are often overlooked and lumped together with other Asian American groups within the United States. Their experiences are rarely examined in depth, particularly when it comes to Hmong families with children who have disabilities. As the number of disabilities among racial and ethnic groups has grown, the services available to and research conducted about a few of those communities, such as the Hmong people, have been insufficient. Traditionally, Hmong people are active with their daily routines such as hunting and farming. Purposeful physical activity like joining a recreational sport team or dedicating a day to go on a walk, is a novel concept for most Hmong individuals. The purpose of this exploratory qualitative study was to understand how Hmong parents perceive their experiences of having a child with a disability and their experiences with physical activity (PA). A total of 10 Hmong mothers were recruited in this study. Semi-structured interviews with open-ended questions were used to explore these experiences and two themes emerged: 1) *Disability: not taboo but…* and 2) *Physical Activity: important but…* Hmong mothers have positive perspectives of their child with disability but it is often overshadowed by cultural views. Hmong parents view physical activity as an important concept but struggle to find ways to engage in it with their child with disability. These themes and future programming strategies for Hmong families are discussed.

Keywords: disability; children; family perspectives; Asian Americans; physical activity

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Introduction

It has been almost 30 years since the last symposium was held for Asian Americans with disabilities by the Council for Exceptional Children in the United States. The purpose of the symposium “Exceptional Asian Children and Youth in Anaheim, California”, was to raise public awareness about the increased number of Asian Americans in school and how Asian Americans with disabilities have been overlooked. Since then, little research has been carried out on this population (Cooc & Yang, 2017). Disabilities have increased among various racial and ethnic groups in the United States (U.S.). However, scant research regarding Asian Americans, especially the Hmong, has been done that could help support these families, and provide better services in both school and community-based settings (Her, 2015). According to the U.S. Census in 2010, 91,224 Hmong reside in California. One fifth of Hmong in California have identified as having or know of someone with a disability (Xiong, 2007). According to Cooc & Yang (2017), Hmong were less likely to report having a disability than other cultures because of accessibility and barriers like knowledge and cultural differences. This can pose as a lack of precise information and challenges in accurately ascertaining the number of individuals within the U.S. who identify as Hmong and have disability. Researchers have shown Asian American students with disabilities are less likely to receive accommodations or interventions than their peers from other racial or ethnic backgrounds (Liu et al., 2018). Asian American students represent 20% of the school-based population (Tucker, 2021), yet only 6% of them receive specialized services such as physical therapy, speech therapy, or occupational therapy (Cooc & Yang, 2017). This low rate of service provision implies that Asian Americans with disabilities are underrepresented, underserved, and have received lower-quality services than other minority groups (Hasnain et al., 2020).

Unlike most other ethnic groups in America, the Hmong at the core is a refugee, tribal, non-literary, animist cultural group almost directly opposite in beliefs and customs from the majority culture of America (Vang, 2021). Historically, Hmong were often classified and mistaken as Miao in southern China and Asia because they were a “non-Chinese” group (Lee & Tap, 2010). Hmong are a minority and ethnic group that does not have their own country but lived in southwestern China and migrated to Laos, Thailand, and other neighboring countries in the mid-1600s. Hmong developed their unique culture over the years of living in different parts of Asia and from having to constantly move from one place to another involuntarily.

During the Vietnam War, the United States (U.S.) recruited Hmong people to be soldiers and fight alongside American soldiers against the Vietnam communists. In return, the U.S. government offered and promised to “take care” of the Hmong people (Vang, 2021). After being defeated in the war, American soldiers returned to the U.S. leaving Hmong people to become a targeted population and were massacred by the Vietnam communists for assisting the U.S. Hmong became refugees in their homelands, had to evacuate Laos, and find their way to escape. Families had to fend for themselves and cross the heavily guarded Mekong River to safety in Thailand. In the late 1970s and early 1980s, the U.S. returned for Hmong families who resided in Thailand’s refugee camps. Hmong families were assigned and relocated to different regions in the U.S. such as Minnesota, North Carolina, and California (Lee & Tap, 2010). Some families were assigned and relocated to different countries like Australia, France, and Canada. Many Hmong families, however, opted to stay in Thailand waiting to return to Laos without fear of retribution from political powers. (Lo & Pha, 2018). Based on the data from the U.S. Census in 2019, the Hmong population in the U.S. was 309, 564.

As described by Nguyen (2016), professionals and service providers require a critical understanding of other cultures and societies' vulnerable and complex experiences to fully understand their perceptions on disability. According to Hwang et al. (2020), Asian American families hesitate to request services for their children with disabilities because of the assumption that they need to be proficient in English. Materials and resources are rarely translated well enough; and the cultural differences felt between the dominant Eurocentric cultures are some of reasons why Asian American families are hesitant to request disability supports and services (Cho & Gannotti, 2005). This lack of access, and perceived lack of understanding of services can decrease the willingness of families to seek help and reduce awareness of the support that is available in the community (Geenen et al., 2001). Rather than reaching out to schools or community providers for these services, Asian American families rely on one another for information (Lo & Bui, 2020). In South Asian cultures, the perception of disability is still evolving away from the “shame of the family” to being a natural and accepted phenomenon (KC, 2016).

There are barriers to understanding physical activity (PA) for South Asian cultures as well. According to Carter et al. (2007), 60% of White individuals meet the Center for Disease

Control and Prevention recommendation that an individual needs to participate in a minimum of 60 minutes per day of physical activity to maintain a healthy lifestyle (Elgaddal, Kramarow, Reuben, 2020) In contrast, only 43% of Asian Americans and 33% of Hmong individuals meet the physical activity guidelines. This means Hmong individuals are half as active as their White counterparts, Hmong individuals are not as physically active after moving to the U.S., in the 1970s (Vang, 2021). Hmong people have historically been agriculturalists and being physically active was a part of their culture (Van duyen et al., 2007). Activities such as growing food, farming, hunting, and housework are considered physical activities and exercising to Hmong (Kim et al., 2007). However, purposeful PA is a novel concept for most Hmong families (Van Duyn et al., 2007). Although their sedentary behavior is more prominent in the U.S., they continue to engage and practice some of their cultural activities such as farming, dance, and a jump-roping game called "dhia yas" (Stang et al., 2007).

The topic of disability is still largely unexplored and often incorrectly identified within the Hmong community. Traditionally, Hmong people are animistic in their spiritual practice and believe that disease, death, and misfortunate are caused by spirits (Her, 2015). The Hmong culture relies on a Shaman who conducts spiritual healing and acts as a psychologist or social worker (Moua & Vang, 2016). A person with disability may be perceived to reflect supernatural, personal, and can be considered as a gift from God or suffering caused by spiritual wrongdoing in the Hmong cultural context (Hatmaker et al., 2010). For disability terms and definitions, the Hmong people have no exact translations for many words. This leads to more misconceptions about the knowledge of disabilities. Hmong often use phrases that convey the intended meaning and use a more extended definition or translation to interpret disabilities. For example, Hmong have historically defined intellectual disabilities as "*ruam*" (retard/dumb), "*vwm*" (crazy), or "*xiam oob qhab*" (mentally unstable). Although it may not be an accurate definition, it has historically made sense to them, which helped them understand disabilities through their own cultural lens (Xiong, 2007). According to Thao (2010), 22% of Hmong individuals define the general concept of disability as people with physical impairment, where 13.79 % view disability as those who use a wheelchair, and 10 % view disability as a mental illness. This means that disability to the Hmong people is often viewed as affecting someone physically.

The Hmong culture is unlike other ethnic groups in America and is almost in direct opposition to the beliefs and customs of the majority culture in America (Thao, 2010). For guidance in this research, Bronfenbrenner's socioecological model was used (Bronfenbrenner, 1974). The socioecological model helps provide insights on the interplay of individuals within their environment and others. It can also be a lens to explore how systems and relationships can affect an individual (Kilanowski, 2017). Barriers and facilitators within this model are interpersonal (families and social networks), intrapersonal (attitudes and behaviors), institutional (school and social organizations), community, public policy, and physical barriers (Gyurcsik et al., 2006). This model helped guide the research and gave a framework for considering the barriers and facilitators for Hmong parents who have a child with a disability. As the Hmong culture is different from American culture, the socioecological model helped guide the researcher to explore, recognize, and understand possible barriers and facilitators that affect how Hmong mothers view their child with a disability.

To date, no studies have explored the experiences of Hmong parents who have a child with a disability. To that end, the purpose of this exploratory qualitative study was to explore the disability and physical activity experiences of Hmong parents who have a child or children with disability/ies. The main research question guiding this study was: How do Hmong parents perceive their experience of having a child with a disability? Additional sub-questions that guided this study were: 1) What is the Hmong family's understanding of their child's disability and 2) How does the Hmong family perceive physical activity as a role in their child's health?

Materials and Methods

This research was ethically reviewed and approved by the Institutional Review Board at California State University, Chico. A broad interpretive approach was utilized in this study. This study aimed to explore and understand how Hmong parents perceive their experience having a child with a disability. The experiences of this population related to disability and physical activity have not been previously explored, and is historically a population that is gatekept, meaning that there are often extra barriers or persons that add an extra layer of access to a population. Specifically, this study used interviews as the primary data collection and purposive sampling to select participants who are Hmong parents of children with a disability and willing to share their experiences. To ensure the research is culturally appropriate and sensitive to the unique experiences of the Hmong community, a Hmong researcher and an additional Hmong parent who had a child with a disability engaged to frame the research questions and generate the research guide. Data were collected over a 3-week time frame using semi-structured interviews with participants, and participants were given the option to have the interview conducted in Hmong language to ensure they can express their experiences and feelings in their native language. Though no participants conducted the whole interview in Hmong, when language pieces were hard for the participants to come up with the English words, Hmong was used. Thematic analysis was used to analyze the data, determine themes, and shared experiences between participants (Braun & Clark, 2006).

Author positionality

It is advantageous in any research endeavor to be aware of the author's perspectives and views of findings. The first author identifies as a Hmong American woman, first-generation scholar, and at the time of the study was completing her graduate coursework in Adapted Physical Activity. The second author identifies as a white, non-Hispanic female, in her 40's who is faculty overseeing the first author. Both authors contributed to interpreting findings and the implications of the study. The findings of this study should be viewed as merely a single interpretation of the experiences of Hmong families with children with disabilities, based on the authors' perspective. In this study, the authors adopted an ontological stance that recognized the existence of cultural and historical influences on the experiences of Hmong families with children with disabilities. The ontological perspective holds that the experiences of the Hmong families are shaped by the cultural, historical, and social content in which they exist. The experiences of families with children with disabilities cannot be fully understood without considering the cultural, historical, and social forces that shapes them (Choi et al., 2008). This statement demonstrates that the perspective is not just an individual opinion but is grounded in existing academic work and acknowledges the importance of considering the broader social and cultural context in which the experiences of Hmong families with children with disabilities occur.

Participants

Participants were purposefully recruited through targeted messages sent to the moderators of support groups on Facebook for Hmong families who have a child with a disability. As a marginalized group, the Hmong community are often "misrepresented, pathologized or problematized" by the research process (McAreavey & Das, 2013, p. 115). The moderator of these groups served as the gatekeeper for this study, and because of the first author's membership in the Hmong community, access was granted to share the study. A snowball sampling recruitment strategy was employed. In this recruitment, natural and organic social networks are utilized and is a "widely utilized" method of sampling in qualitative methods (Noy, 2008, p. 330). Inclusion criteria for this study were participants 1) who identify ethnically or culturally as Hmong, 2) who have a child or children formally diagnosed with disabilities, 3) were at least 18 years old, and 4) were willing to participate in this study over videoconference calls. Ten participants in this study were largely in their 30s and spoke fluently in both Hmong and English. Although participants themselves speak both languages, some preferred to speak one language more than the other within their household. All participants have some level of education, and most were married to an individual that also identify as Hmong. This research did not recruit participants based on a specific disability or set of disabilities, but the majority of the children had a developmental disability. Participant demographics are provided in Table 1.

Table 1. Participant demographics.

Participant	Age	Child/ren Disability/ies	Marital Status	Home Language	Religion
Palia	31-40	Down syndrome	Married	Hmong & English	Shamanism
Chua	31-40	Down syndrome[2] & Hearing loss[3]	Married	English[1]	Christianity
Thoua	31-40	Moderate to severe hearing loss & Speech delay	Married	English	Shamanism
Paj	21-30	Down syndrome	Married	Hmong	Shamanism
Blia	21-30	Agenesis corpus callosum with Colpocephaly	Single	English	Christianity
Kia	41-50	Autism spectrum	Married	English[1]	Shamanism
Peng	21-30	Speech & language delay	Married	Hmong	Christianity
Mee	41-50	Severe hearing loss	Widow	English	Mormonism
Dee	31-40	Autism spectrum	Married	English	Does not identify
Shoua	41-50	Autism spectrum	Single	English	Seventh Day Adventists

[1] Speaks little Hmong; [2] Child 1 of parent; [3] Child 2 of parent

Procedures and Data Collection

Interview Guide

The interview guide was developed through a review of previous studies that have examined Hmong parental experiences or Hmong perspectives on disability (Thao, 2010; Xiong 2007; Vang & Barrera, 2004), and by aligning interview questions within the scope of the research questions. In order to receive feedback, the interview guide was then reviewed by three researchers who have research experience exploring the parental perceptions of disability for feedback. Recommendations from outside reviewers were incorporated by the researchers into the final interview guide. This individual helped review interview questions for clarity and understanding from the Hmong perspective, and alignment of the research questions to further improve content validity. Feedback was discussed and incorporated through an iterative process between the first and second author. (See Appendix A for interview questions).Semi-Structured Interviews

Individual, semi-structured interviews were conducted via videoconference calls (i.e., Zoom or FaceTime). Each participant scheduled a one-on-one interview at a time that best fitted their schedule; and each participant reported (and appeared to be) in their home for the duration of the interview and chose a time that they would have the least self-reported number of distractions. The average length of an interview was 50 minutes.

At the beginning of each interview, participants were given the option of having forms read to them in Hmong for clarification and understanding. However, all participants declined needing forms to be read in Hmong. This accommodation was also applied to the interview process as well, and participants were able to ask for clarification in Hmong, if needed. For example, when participant Palia was asked *"How would you define physical activity?"* Palia replied, *"Can you say that in Hmong?"* After translating the question, Palia responded in Hmong initially and then continued to answer in English. This allowed participants to feel more comfortable during the interview with the intention of capturing a rich data set by allowing more accurate expression of their thoughts and experiences.

Data Analysis

Pseudonyms were used for all participants and names were blinded to the second author to maintain privacy and anonymity of the participants. Interviews were audio-recorded and transcribed verbatim by the first author for analysis. Braun and Clark's (2006) thematic analysis process was followed—(1) familiarization with the data—the first author read through the interviews multiple times while transcribing, revisiting interview notes and any bracketing that took place during the interviews or in debriefing with the second and third authors; (2) coding—data were hand-coded using first cycle coding to look for exploratory themes between participants (Miles et al., 2014).

The first author used inductive coding when looking for exploratory themes. Inductive coding or "literal coding" was used to code in the participants' own words and is "most appropriate when studies prioritize participant voice" (Saldana, 2013). The first and second authors (3) searched for themes; and then (4) reviewed themes together. The first author (5) defined and named themes both individually and then with the help of the second author. Once consensus was reached between authors (6) writing results were used in an iterative process to analyze and interpret potential findings. The thematic process was reviewed by the second author at each stage to examine the dependability of the authors' interpretations (Lincoln & Guba, 1985). The themes and subthemes are shown in Table 2. Though the first author performed most of the analysis, the second author also reviewed the transcriptions to situate the data interpretations, reviewed quotes for themes as well as the breadth of participants who shared the experiences emphasized in the themes and participated in frequent debriefs with the first author after interviews. During each review, any differences in interpretation were discussed until a consensus was found or a new interpretation emerged.

Language differences within the qualitative field have been discussed by researchers. As previously mentioned, the Hmong language does not have an exact translation for certain medical or disability words, so an extended meaning is often used to define the message (Xiong, 2007). Due to the possible non-existing words, the Hmong language may categorize or define English terms into one word or use metaphor phrases to determine the meaning (Moua & Vang, 2016). Often, individuals may speak Hmong and English interchangeably within the responses for better understanding and communication. To keep the authentic content, participants' responses in Hmong are directly transcribed in the results section. Then next to it in parentheses, the first author provided the extended or direct English translation of participants' responses.

For content validity, interview transcripts were sent to participants to confirm the saying or intended meaning. When both the researcher and participants, speak the same language, "there are no language differences present in data gathering, transcription, or the first analysis because first level coding stays closely to the data" (Van Nes et al, 2010, p. 314).

When moving into second-level coding with English language and multinational teams, discussion for the best fit of the English words that closest match participant meaning need to be discussed. Conversely, Temple (2002) argued that it is simplistic to assume that researchers who share the same language community, also share the same meaning. While most of the interviews were conducted in English, the first and second authors had many discussions regarding tone and meaning behind interview phrases, ensuring to the best of their ability, that participant meaning, based on the first authors' understanding and explanation, were maintained.

Trustworthiness

In addition to the traditional threats to the credibility and rigor of qualitative research, it should be acknowledged again that the first author is Hmong and at the time of the study was completing her graduate coursework in Adapted Physical Activity. This insider status allowed the first author a level of "belonging" that was different from the second author. Benefits of this "insider status" include easier establishment of rapport, being sensitive to community needs, and having a relationship with the community thereby gaining faster credibility (Lor & Bowers, 2018). As mentioned above, bilingual researchers have a unique set of challenges that are presented to them when translating their qualitative findings to English. The first author took a positivist approach and treated themselves as a "neural transmitter of messages" (Temple, 2002). The first author (who conducted each interview) bracketed her thoughts prior to the interview and took reflective notes immediately following each interview's end. While it was important for participants to be able to switch between English and Hmong to best capture their experiences, the first author reflectively summarized meaning back to participants at the end of each interview question block to make sure that her interpretation of the experience was what the participant was trying to convey. Interviews were also sent to the participants after they were transcribed to ensure the trustworthiness of the data before analysis. Many participants became emotional during the interviews, and the first author engaged with each individual as best as possible from prior interview experiences and emotional availability. This was achieved by always prioritizing the participant–research relationship over the data generative process. Given the first author's close relationship to the present topic, all data were examined independently by the second author to limit the influence of personal experience or biases.

Results

Two major themes evolved from the data exploration process: 1) *Disability: not taboo but…* and 2) *Physical activity: important, but…*These themes reflect the feeling that came through the participants experiences throughout the interview process. Each interview carried a perceived feeling of "being at odds" with immediate family experiences and the Hmong culture. Participants shared personal experiences with disability and identity that were often overshadowed or rooted deeply in a cultural perspective that they may not share at the same level of previous generations. This unease in understanding where disability and PA culturally fit within the Hmong experience is reflected in the open-endedness and perceived unease portrayed in these themes.

Table 2. Occurrence of identified themes and subthemes.

Theme	Subthemes	Statement of subthemes by participants
Disability: not taboo but...	Positive emotions (proud, loved, happy, amaze, support, advocate)	Shoua, Blia, Kia, Thoua, Dee
	Fate/Beliefs (connection, God given, test, miracle)	Paj, Palia
	Undiscussed/hidden topic in the Hmong community (karma, reject, hidden, not discussed, negative, acceptance)	Mee, Peng, Dee, Shoua, Palia, Thoua
	Cultural views/understanding (language barrier, shamanism, traditional practices, generation, medical, science)	Paj, Kia, Dee, Peng, Chua
Physical Activity: important but…	Definition (movement, exercise, playing, sports)	Mee, Kia, Blia, Shoua
	Positive emotions (excited, proud, impress, great)	Chua, Peng, Shoua, Dee, Blia, Thoua
	Understanding the benefits of doing PA (mental health, physical health, emotional health, development, social skills)	Peng, Chua, Blia, Mee, Shoua
	Participation level in PA (don't have time, schedule, don't exercise, tries to)	Kia, Palia, Thoua, Blia, Chua
	Choice-based opinions (depends on the child)	Palia, Thoua, Shoua, Blia
	Leisure activities (park, walk, bike, fish, hike, dance)	Peng, Mee, Palia

Theme 1: Disability: not taboo but...

This theme was defined as any time participants shared their feelings of disability as positive belonging, but also in the back of their head, overshadowed culturally by peers and older family members who perceive disability as taboo. Parental love was prevalent throughout the interviews. Shoua shared her sentiment thoughts about children with disabilities: "They need to know they are loved..." and praised her child throughout the interview "he is extremely super smart and excels above other kids in his class...I'm very proud of my son..." Echoing Shoua, Blia commented on the love she has for her child and her child's strength "I always encourage her no matter what...they really could, like amaze you...like I've always said, don't let the disability define them...she is very empathetic and could kind of sense my emotion...she is very smart and can be very intuitive". With love and encouragement for their child, there were often religious undertones in the conversations, accompanied by the feeling by participants that there was a "bigger picture" or religious explanation. For Paj, there was a feeling of connecting and belonging with her son, but also cultural overshadowing in her reflection of why she thinks her son is disabled. "I think it's just fate..." she shared:

> God gave them that. Maybe like, I don't know, in the past, somehow we were connected in a way that like I owe him something or he owed me something...so now I have to like make it up to him...so he's paying me through like government payment. (Paj)

As previously stated, Hmong people are animistic in their spiritual and cultural practice (Her, 2015). It is not only God that exists but other spiritual figures of greater powers too. There is the belief that one's life or spirit is connected to the previous and present times. Similar to the concept of karma. The Hmong's cultural perspective of this means that the actions an individual does can carry on to the next life. It can come in any type of form, such as disability. Palia shared a similar viewpoint in her perception of disability and her child:

> I think for me, it is like maybe God wants to test me to see if I can be a better person for myself and for my kids. I don't think of it like it is a sin or it is a taboo…it is more of a pro because they are a miracle. (Palia)

Again, the idea of God repeats itself here, that the individual has done a wrong or admirable action within their previous or current lifetime to create a connection between them and spirits of a higher power.

Not only did participants share their love for their child, but they also voiced how their child motivated them to advocate and share their experiences with others within and outside of their community. For example, Kia used social media to express her experiences, "I post about my daughter on social media and her progress a lot. Just to give awareness to everybody…and to show what we do together or the daily struggle we go through." Thoua emphasized that support and love is being present for the child, "You need to be present, you need to be your child's advocate….you need to understand and tell your child that he or she is doing such a great job and you support them…" Lastly, Dee stated "I want him to do stuff…I don't want to limit him or make him feel like he's different or that he's going to be treated differently… my goal is to help him so that he can live on his own…"

When pulling back to explore the broader implications of disability within the parental experiences and Hmong culture, participants provided insight into how their elders have thought, and the Hmong perceptions/misconceptions regarding disability that currently exist. Disability is a topic that is viewed as taboo, hidden, and undiscussed within the majority of the Hmong communities and families. Mee shared:

> I think overall, surely the Hmong community and families know what disability is. But they don't talk about it because they see it as something negative and so (Hmong: zoo li yog hais cev lawv pheej thuam koj los sis hais ub hais no rau koj) (English: like when you talk about it, they will insult you or say this and that to you) … (Mee)

The idea of hidden is that the community knows it exists but are not talking about it. Also, not only is disability hidden or taboo, participants in this study who have tried to talk about disability are discouraged from bringing up the topic again. Peng shared a similar view that: "In the Hmong community, we don't talk about it because it's more of a shame…" and explains how it is taboo or negative:

> I mean you know, we know it and we see it, but we don't say anything because like, they say, you know, that it is karma. You know like (Hmong: lub ntuj qis qis) (English: [Hmong metaphor] the sky is low), if you make fun of another child then eventually karma gonna come back and hit you… (Peng)

Dee similarly shared their experiences as a parent of a child with a disability within the Hmong community and the cultural barriers those with disabilities face within the community:

> In the Hmong culture, disability is really looked down upon, like (Hmong: oh tus neeg ntawv lau, los nws xiam oov qhab) (English: oh that person is mentally impaired/retarded)…It was not talked about, kind of like a taboo topic…they just kind of brush off the subject and it's kind of like (Hmong: Koj txhob tham txog nws, vim yog koj tham txoj nws ces) (English: You do not talk about him/her, because if you talked about him/her then) you're going to have a child like that… (Dee)

Shoua echoed a similar sentiment, with the same experiences of the Hmong community wanting to separate themselves from someone with a disability and that there is currently not space within the culture to discuss disability or ask questions to better understand or support disability:

> The Hmong community never discussed it. Like, there's no place that we can go to discuss it even with the younger community...it's just a cultural thing...they look down on people with disability or they kind of push or separate themselves from those type of people. (Shoua)

Aside from the broader Hmong community, participants like Palia expressed that her immediate family had trouble accepting her child with disability: "My in-laws, they don't really accept that because they are more old traditional Hmong people...they take it as maybe there's something wrong in the past life...that's why I have this child so it's more like a sin..." Kia too shared how families would keep a low profile about the topic: "I think Hmong parents do not understand it, they're probably embarrassed...it's just not something that they want to bring attention to." Lastly, Thoua shared an insight on how even with the generation gap "I think in my mom's generation, it is taboo, so they don't talk about it...they are more closed-minded...those of us who have already gone to college, they're more accepting...", there are still problems with acceptance "But to be honest with you, it's accepted when it's somebody else's family. It's not accepted when it is in my family."

Those who grew up in a shamanistic household or convert to believing in shamanism shared their experiences of getting tangled in scientific and religious views of understanding like Paj who shared: "In our cultural perspective I overheard my parents saying that he was disabled because like our grandparents were buried in a bad location…I think it is more due to genetic that causes his disability..." Another participant, Kia, shared a similar experience, commenting: "I grew up in a shamanism house religion...," but changed her religious belief after marriage. "My husband is an atheist, and I don't really believe in anything, but I'm not saying that I am an atheist...I don't have a religious preference..." Even though she was taught and continue to have conflicted view with families about disabilities, "Hmong parents don't really know or understand what autism is...they automatically say that the child is retarded...you know that it is because of his spirt or karma from the past..."

Within this largely shamanistic and religious view of disability, parents shared that they did feel perceptions were changing—both personally, and culturally. Some participants in this study shared their journey of that process. Dee shared that "My parents and I initially are shamanistic..." and were told by them that disability is "oh they were born that way because (Hmong: nws tus nstuj plig yeej nyiam li ntawd) (English: his/her spirit likes it like that) ...or their parents were cursed and that's why he or she was born with a disability..." Although Dee grew up being told that disability is somewhat connected with an individual spirit, she now sees it different:

> It's like I know it's impossible to after you (Hmong: ua neeb) (English: do a shaman ritual), his ear to just magically heal overnight...he was born that way so it's impossible for one shaman ritual or ceremony to fix that. (Dee)

Following Dee's experience, Peng's father was a shaman himself "My father was a shaman and so our family believed in Shamanism..." Some Hmong individuals would have expected Peng to follow her father's teaching. However, she commented about her own religious beliefs and how it is not entirely dependent on shamanism practice: "But you know...I am not that religious...it is okay to skip a few shaman New Year rituals for me...I think disability may have been passed down from generation to generation or because of a strand in your DNA..." Even though Peng grew up in a shamanism household, her view and understanding have expanded to a more scientific explanation. This is the same for Chua, "I fall more on the medical side of things when I talk about disability..." She shared that "I grew up in a very traditional shamanism background...they always say it's maybe the spiritual side, that maybe there's something hindering him or her and affecting them..." Yet, her perceptions, like other participants in this study, are shifting and becoming more aware of the scientific reasons some individuals are born with disabilities.

Theme 2: Physical activity: important, but...

This theme was defined as anytime participants shared their PA experiences, both positive and negative, and offered insight to their perception of PA (both personally and culturally). In this study, participants were asked to define physical activity. According to World Health Organization (WHO), physical activity is defined as bodily movement produced by skeletal muscles that requires energy expenditure and is essential for promoting physical and mental health. As a result, participants' definitions were not entirely inaccurate but often added the term exercise to their definition. For example, Mee defined physical activity as "being healthy, having a good positive mindset, and exercise or like being fit...and having movement with our bodies." Kia defined it as "playing sports, just exercising, I don't know moving around I guess..." Paj commented, "Physical activity I guess you can kind of say sports, but then again, more of just outdoor thing, you know like fishing, running, jogging, and exercising..." Again, we see the term exercise is referred to commonly within the definitions given by participants. Blia's definition was "Basically just moving around a lot, exercising at the gym..." and Shoua shared "Physical activity is pretty much getting the body moving. Like exercise or you know, pretty much walking..." Even though participants connect exercise and PA together, they do mention bodily movement and daily activities. Participants commonly viewed physical activity as synonymous with exercise. It appears that physical activity is frequently misunderstood as being limited to intentional activities such as structured exercise or uncertainty. When discussing PA, participants would use the terms PA and exercise interchangeably during the interviews.

Participants viewed PA as an important and positive concept for children with disabilities but did not frequently seek out PA experiences with their child/ren with disability/ies. However, participants shared their positive thoughts of seeing children with disabilities engage in physical activities throughout the interviews. Chua expressed "I think it is a great thing. I feel proud of that individual that they are going outside of their boundaries..." and Peng shared that "I get really excited because you know, in every single child, there is something about them that surprises you..." Likewise, Shoua shared "I think that's really amazing. You know they are able to do or try to achieve something, so it is extremely amazing. I am happy for those who do physical activity." Similar feelings were echoed by Dee who shared that:

> It makes me feel proud that they're doing that, you know, I don't want them to sit at a bench and just be one of the audience, because I'm sure everybody has a passion or love for something, I don't want them to feel like because I have a disability that I can't participate... (Dee)

Overall, participants shared positive feelings towards PA participation by their child. Blia commented that "I'm worried because she might be very clumsy, but I'm also excited at the same time." Thoua shared a similar concern about her children with disabilities participating in physical activity "I am concern about like what they would need to be successful when doing sports or physical activity..." but positive thoughts and expressions followed through her statement "But I love seeing her play and being able to find what tools to give her to be successful..." The participants commonly expressed concern that their child with disability may be at risk of injury. Despite those concerns, Hmong parents believe that observing their child's involvement is a positive experience.

Additional to participants' positive feelings of PA, they provided an understanding of beneficial factors for children with disabilities participating in PA. Peng stated, "I think physical activity is very important…it gives them more social skills…it gives them that extra boost…" and Chua said, "I think physical activity is extremely important because it improves their mental health too…I feel like if I don't at least provide him with the resources, I'm going to fall short as a parent…" Also, Blia shared that "I think physical activity is very important because it is a huge part of development…" Echoing that, Mee commented, "I think it's important for someone with a disability to be active so that their muscles are working… they have at least physical interactions everyday…" The recognition of how PA helps to improve physical, mental, social, and developmental processes of children with disabilities was shared among participants. In addition to those factors, Shoua added that physical activity is important because "It's 100% that they need physical activity or exercise because it helps with your spiritual and mental aspects of your life…that helps your mind and body and everything together…" Participants unanimously agreed that PA is a crucial aspect of the lives of children with disabilities. It was noted that similar to typically developing children, who experience positive outcomes from PA, children with disabilities also benefit from participation in PA.

Knowing the beneficial factors and expressing positive views about PA, participants shared about their own level of participation and what it means to their child/ren with disability/ies. Even though participants shared the importance of PA, most participants themselves expressed not being able to participate in PA as much as they wished to. Again, this goes back to the concept that purposeful PA is a novel concept for most Hmong families. Kia shared "I don't exercise as much as I would like to in the current situation…" and how she has decided not to pursue it "I wish I could take my child out to the park…and so now I've kind of gotten to the point where I'm just like, yeah, we're just gonna stay home because it's too hard." In Kia's experience, she expressed the difficulties in taking her children with disabilities out due to behavioral challenges and demanding care needs when doing something out of the home. Just like Kia, Palia expressed "I will be honest, I don't exercise…" and Thoua who also shared "As a parent… No, I don't exercise or do physical activity…" Other participants continued to share similar experiences like Dee who said, "I try to and if my schedule permits, but I haven't been able to…I would like to though." Or Blia who commented, "As a parent, I don't exercise or do much physical activity because of time and work…" Lastly, Chua expressed, "Unfortunately, I do not. I do not with my schedule right now…" As parents, trying to balance their broader schedules with the care and responsibilities of raising their child, often resulted in extra stress and perceived burden. Corresponding views of participants wanting to but not being able to be active is frequently shared throughout the interview.

When asked about the importance of participation level of children with disabilities, participants viewed it as a choice-based option. Palia shared, "I say it depends on the kids…if she doesn't want to work out then she just does not want to…" Following that Thoua said, "…for someone with a disability, I think that if they want to be active, they should be and should not be stopped because they have a disability…" Despite previous statements on PA being significant and participants not actively engaged in it, there is no indication of negative views or direct enforcement about this topic either. Participants like Shoua goes on to share how "I can't think of any activity that he will not be able to participate in…if he wants or likes to then he can…" Also, Blia shared "I'm really up for anything…I just want her to do something she likes…"

Although participants do not actively encourage or enforce PA for child/ren with disabilities/ies, participants did share some leisure activities that they and their child/ren do outside of the home. Peng commented "He loves the park and goes to the park all the time…", Mee shared "I do like a 15-minute walk or yoga or stretching…he likes soccer so we play soccer sometimes, and Palia said "I like fishing and hiking…she has been into KPOP and dance lately so sometime she just dance around…" Overall, participants perceived physical activity as important and beneficial for a child's health. Although it is viewed as a voluntary task, participants expressed their understanding of how PA helps improve their child's health physically, emotionally, and mentally. Participants recognize the importance of PA and how it can improve the child's overall development and social skills. It made participants feel good when they saw a child with a disability participate in PA, and is something they valued even if they were not actively engaged in purposeful PA.

Discussion

This exploratory qualitative study employed a broad interpretive approach to explore Hmong parents' perspective on their children with disabilities and physical activity. For the participants in this study, their experiences were intertwined in both science and shamanistic or religious understandings. Participants acknowledged the scientific explanation of disability they had received from medical professionals; however, they still carry religious and shamanistic beliefs and explanations from their childhood and culture. As the Hmong culture deeply values their traditional practices and family orientation (Her, 2015), family members and the community are not entirely dedicated to one view or understanding about this topic. Individuals' perceptions and beliefs are often conflicted between the medical or scientific and cultural explanation of this topic.

By framing these experiences within the socioecological model, this study identified perceived barriers and facilitators as to how Hmong parents perceived disability and physical activity. The socioecological model looked at the relationship and affects that the individuals experienced within this topic from their own lens and in more depth (Kilanowski, 2017). Not only did the socioecological model identified the possible barriers and facilitators, but it also unfolded possible changes that can be made to better support Hmong families. Those barriers and facilitators were intrapersonal, interpersonal and community related. Intrapersonal facilitators for participants were identified parental positive views and attitudes about their child or children with disabilities, while barriers were their own conflicting spiritual practices and historical perspectives and pressures. Interpersonal barriers for these participants were a lack of support from both their immediate families and the broader Hmong community. Participants shared the challenges they face because of the taboo nature of disability and how it is not widely discussed or accepted in the culture. Traditionally the Hmong people hold animistic beliefs and consider everything to be connected to spirits (Her, 2015). Their understanding of disability as stated in a study done by Thao (2010), is primarily seen as a physical issue, rather than developmental. Community barriers for these participants were the lack of facilities or specific support groups within the community to discuss and support children with disabilities and promote PA. Participants shared there were rarely support groups or organizations that helped support not only the Hmong family experiencing disability, or other groups to help understand disability better (Vu & Moua, 2020). Most participants expressed the absence of truly having a community or organizations of their own that can discuss this topic and receive targeted resources for their Hmong children. This aligns with the research findings that Hmong families often face barriers in accessing support and services that can help them navigate services for children with disabilities (Baker et al., 2010). As a result, Hmong families tend to rely on one another for support (Lo & Bui, 2020). However, this can be challenging for families who are new to the topic of disabilities or have little understanding. Many questions may arise for those families, such as: where to begin?, how does it look like?, what is it supposed to look like?, etc.

When reflecting on the main research question: "How do Hmong parents perceive their experience of having a child with a disability?', this study identified that Hmong parents perceive their experience of having a child with disability as a positive, but culturally challenging experience. Hmong parents continue to struggle to understand and explain disability from a cultural perspective to their families and community. As for the sub-questions "What is the Hmong family's understanding of their child's disability?", Hmong parents understand the medical explanation of their child's disability, but frequently intertwine meaning to the Hmong cultural aspects of taboo, karma, or spiritual. Lastly, "How does the Hmong family perceive physical activity as a role in their child's health?" Hmong families perceive PA as an important part in their child's health as it can improve their child's mental, physical, social, and developmental health. However, Hmong families in this study did not regularly engage in PA or participate in PA with their children. It is not a priority for the families and their child with disabilities. As previously reported in Vang's (2021) study, Hmong individuals have a lower rate of meeting the recommended PA guidelines and engage in PA at half the rate of their white counterparts. Given that some parents from this study view PA as choice-based or low priority for children with disabilities, it is possible that these children are meeting even lower PA guidelines than what was previously reported (Vang, 2021) . Participants view other life aspects like education and independent living more important or beneficial in the long-term of their child's life (Van Duyen et al., 2007).

By understanding these cultural differences, professionals can use this knowledge to improve services and deliver models for Hmong families who have a child with a disability. Since Hmong communities are multilevel, it is essential to develop and design effective interventions to support and encourage Hmong families to participate in services or activities (Kim et al., 2007). Considering that there are different cultural and religious beliefs, views, and education levels among Hmong individuals and families, it would be beneficial for other professionals to create a targeted but multilevel model that can support parents and children with disabilities (Vu & Moua, 2020). This can be done by presenting culturally relevant activities to increase engagement and encourage Hmong families to participate in available services. Additionally, providing models or services that recognize the cultural viewsand presenting more educational opportunities for families who may want support or resources can provide improved access to the Hmong community. Hmong families prefer health related messages to be delivered by those from the same ethnic group, outreach activities or resources at their local Asian grocery stores and community organizations (Van Duyn et al., 2007). Professionals should consider recruiting another Hmong individual into their team when doing outreach activities and share pamphlets or flyers of resource information in Asian communities in both English and Hmong as it may be the best way to communicate with this population.t

The aim of the study was to explore children across the disability spectrum, the participants' children were by in large those who had developmental disabilities. Although the intention of this study was to recruit Hmong parents, Hmong mothers were the only participants that responded. According to Xiong et al. (2021), Hmong women are more likely to speak up about topics that involve their children compared to men. Hmong men are expected to follow and carry-on traditional practices as the "head of the household". They try to maintain the ideally or "normal" Hmong household family and keep their emotions and thoughts private (Chaxiong, 2022). Topics like disability or medical conditions within Hmong families, are traditionally a topic Hmong mothers would have more awareness of within their family because they are more likely to spend time with their children compared to Hmong fathers (Xiong et al., 2021).

This study used a broad interpretive approach with thematic analysis to gain insider access to a largely understudied culture. By having the first author as a member of the Hmong culture and engaging cultural stakeholders in study methodologies (interview question development and recruitment), the researchers were able to access participants who may have been unwilling (distrust of outsiders) or unable (language barriers) to engage in this research. It is important to consider these factors when engaging marginalized populations and find ways to amplify their voices (Cooc & Yang, 2017). Future studies should aim to consider subgroups, such as Hmong, within the broader Asian population, as their needs and perceptions around disability may vary drastically between cultures. Future studies should also aim to include and support researchers who share the same identity as those who are being studied, particularly those with significant cultural differences, so that educators and other practitioners can gain a more meaningful understanding of minority experiences.

As previously mentioned, the Hmong language does not have certain medical terminology to define the different disabilities. To improve services for those who are Hmong, professional teams should strive to have someone fluent in Hmong available to communicate directly with Hmong families. Although a translated written format can be useful, it is more effective to have someone verbally communicate or interpret information for Hmong families in person (Lee & Tap, 2010). This can help Hmong families to be able to ask questions directly and feel like a relationship is being built between them and professionals. Although some participants in this study were members of various social media parent support groups, some shared their marginalized position in these groups, with few parents identifying as Hmong or being able to relate to their cultural experiences. Connecting parents to other Hmong parents who also have child/ren with disabilities or in a similar situation could help improve the emotional burden placed on these families in a culture still trying to understand the scientific or medical aspects of disability (Lor & Bowers, 2018).

Limitations

There are some limitations to the current study that should be recognized and considered for future studies. Firstly, it should be noted that COVID-19 limited in-person contact with participants for safety purposes. While this did not change the nature of the questions asked, or specific aspects of the interview process, interviews that are conducted over media platforms could have different outcomes than those that are not if parents are nervous around technology. Second, the small participant size may not represent the general population view of Hmong parents and future studies should aim to incorporate large sample sizes to gain a broader understanding of this topic. Additionally, the participants in this study were mostly in their 30's and may share different perspectives than those who are Hmong and are younger or older. Also, the aim of this study was to capture the Hmong experience when parenting a child with a disability. However, participants in this study largely had children who have developmental disabilities. Mothers who have a child with a physical disability may have a much different perspective on parenting. Finally, this study was only able to interview mothers, and the perspectives of fathers or other care providers and family members are not reflected. Future studies should also aim to understand Hmong perceptions from these varied viewpoints.

Perspectives

This study provided insight on Hmong parents shared experiences and perspectives of their children with disability and physical activity—a topic that has yet to be examined. Using a broad interpretive approach, the authors were able to gain an understanding of experience within a group that is largely left out of the research narrative. It is important to identify barriers and facilitators among underserved populations like Hmong families so that service providers can have a broader understanding of how to best serve these individuals in both school and community-based settings. Lastly, to prevent exclusion for Hmong children with disabilities and their families, this research allows professionals and service providers to look at this topic through the lens of Hmong families who have a child or children with disabilities and consider the possible factors that can help build adequate resources and understanding.

Supplementary Materials: Appendix A - Interview Questions

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Appendix A – Interview Questions

Demographic

1. Please tell us your age as well as the age of your child/ren with a disability. If you're comfortable sharing, what is your child's disability?
2. What is your level of education? If any college, are you a first-generation student or graduate?
3. Did you grow up in an urban, suburban, or rural area?
4. Are you single, married, partnered, or widowed? If in a relationship, is your partner also Hmong?
5. What is your current living situation? (With family members, in-laws, parents, siblings, or significant other)
6. What is the primary spoken language at home?
7. Do you have a religion or spiritual practice? If yes, how would you describe it? Was this the same as the experience you grew up with or has it changed over time?

Physical Activity

1. How do you define physical activity?
2. Considering that definition, do you exercise? And if so, how often?
3. Tell me about how important it is to you to be active physically?
4. How important is staying physically active to your family? If important, please share why? If not, please share why?
5. Do you or your family members participate in any physical activity in school or outside of school? If yes, can you please describe/list those activities? If not, can you describe any activities your family participate in outside of the home?

Disability

1. How would you define the word disability?
2. Was disability discussed with you at all when you were growing up/as an adult with your parents, family, or elders? Have you been told by your parents or elders about why a person may have a disability?
3. What do you believe are the reasons why a person may have disabilities?
4. Where do you get your information about disabilities?
5. Do you have or know someone else other than your child, in your family with a disability?
6. How do you feel when you see someone outside/in of your family with a disability?
7. Do you think disabilities are widely discussed in your community? Do you think that disability is accepted or rejected within your community? Can you explain why you feel this?
8. In your opinion, what are important things to consider for someone who has a disability?
9. How supportive is your family and extended family (cousins, friends, neighbor)? How does your extended family interact with your child? How do you feel their understanding of your child's disability? Please explain your answer.

PA & Disability
1. When you see or think about someone with a disability participating in PA, what do you think? Tell me how does it make you feel or think about? 2. Does your child participate in regular physical activity? If yes, can you describe what that/those activities are? If not, can you think of some activities you wish your child participated in or that you plan on participating in the future? 3. How important do you think it is for someone with a disability to be active? Please explain your answer.
Access to community resources
1. Do you take your child to participate in community PA (sport teams, playgrounds, parks)? If yes, how does that make you feel? If not, can you discuss why? 2. Do you feel that community resources are accessible to you? If no, can you think of some reasons why it may be inaccessible? 3. Tell me about some resources you have used? What about resources that you wanted but did not get? What limited you to using those resources? 4. How do you find community resources? (Online, word of mouth, parent groups) 5. What would have been helpful to you when you first learned about your child's disability? 6. Is there anything you would like to share that I have not asked about your experiences or family?

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