

**Exploring the lived experiences of hearing
mothers of Deaf children in Lebanon:
A phenomenological study**

Reem El Baba

Doctorate of Counselling Psychology DCPsych - NSPC
Middlesex ID: M00653426

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Table of Content

Chapter 1: Introduction	9
1.1 <i>Purpose of the study and Research question</i>	10
1.2 <i>Exploration of Deafness</i>	11
1.2.1 Parental experiences, responses and coping	13
1.2.2 Statement of the problem	14
1.2.3 Terminology	16
1.2.4 Why mothers of Deaf children in Lebanon?	18
1.3 <i>Significance of the study</i>	20
1.3.1 Knowledge Generation	20
1.3.2 Clinical relevance	21
1.3.3 Social Change	22
1.4 <i>Summary</i>	22
Chapter 2: Literature review	24
2.1 <i>Experiences of mothers: existential paradigm</i>	25
2.3 <i>Conceptualization of Deafness</i>	35
2.3.1 Medical perspectives of deafness	35
2.3.2 Sociocultural perspectives of deafness	40
2.3.3 Communication	49
2.4 <i>Rationale of the study and research aims</i>	57
2.4.1 Value of findings and aims	59
2.5 <i>Summary</i>	61
Chapter 3: Methodology and methods	64
3.1 <i>Qualitative Research</i>	64
3.1.1 Epistemology of the qualitative paradigm: the philosophical underpinning theory of descriptive and interpretive phenomenological research	64
3.1.2 Choice of research approach: Interpretative Phenomenological Analysis (IPA)	67
3.1.3 Recruitment procedure	70
3.1.4 Participants	72
<i>Participants' profile</i>	73
3.1.5 Interview procedure	76
3.2 <i>Interviewer's written observations</i>	78
3.3 <i>Data analysis</i>	79
3.4 <i>Validity and reliability</i>	81
3.4.1 Self-reflection to ensure rigor and validity	81
3.4.2 Triangulation of data sources	82
3.4.3 Existing theory and research	83
3.5 <i>Ethics</i>	83
3.6 <i>Methodological reflexivity</i>	85
3.6.1 Personal reflexivity	85
3.6.2 Reflexivity of the Interview process	86
3.6.3 Reflexivity of the Analysis process	90
3.7 <i>Summary</i>	92
Chapter 4: Findings	94

4.1 Theme 1: Mother's reaction to her child's Deafness: from denial to finding solutions	95
4.2 Theme 2: Mother's meaning-making and acceptance of Deafness	114
4.3 Theme 3: Societal and family reactions to deafness, guilt towards other children and informal support received	133
4.4 Theme 4: Journey and challenges faced with the medical field: from diagnosis to rehabilitation	149
4.5 Theme 5: The choice of education and communication strategies implemented	157
Summary	166
Chapter 5: Discussion	168
5.1 Interpretation of findings	169
1.1.1 The mothers' reactions to their child's deafness: from denial to finding solutions	171
1.1.2 Mothers' meaning-making and acceptance of deafness	182
1.1.3 Societal and the family's reactions to deafness, guilt towards other children and informal support received	192
1.1.4 Challenges faced and journey with the medical field: from diagnosis to rehabilitation	200
1.1.5 The choice of education and communication strategies implemented	205
5.2 Implications	213
5.2.1 Clinical relevance	213
5.2.2 Social Change	215
5.2.3 Knowledge Generation	217
5.2.4 Counseling for mothers of Deaf children	218
5.3 Study limitations	220
5.4 Value of findings and dissemination	221
Chapter 6: Conclusion and recommendations	223
6.1 Existential paradigms	225
6.2 Recommendations for future research	227
6.3 Recommendations for practice	229
References	232
Appendix A	247
Appendix B	250
Appendix C	252
Appendix D	254

Table of Figures

Figure 1. Analysis process done with every interview.	68
Figure 2. Process of integration of the findings from each interview.	69
Table 1. Participants' demographic information and Deaf child's general information	75

Abstract

The conceptualization of deafness is predominantly centered around two perspectives: the medical model which pathologizes hearing loss and congenital deafness as something to fix, and the sociocultural model which views deafness as a cultural identity. Deaf communities have their own distinct culture, values, history, art, language and mode of communication. However, not every deaf person necessarily identifies with these communities. The purpose of this study was to explore hearing mothers' experiences of raising a Deaf child in Lebanon. Five participants were recruited through the Lebanese Center for the Deaf. The mothers had a Deaf child aged 10 to 15 years old at the time of the interview. The study aimed to formulate themes portraying the lived experience of these mothers and examine their meaning-making through an in-depth phenomenological approach. The research method adopted is an interpretative phenomenological analysis.

The superordinate themes are: 'Mother's reaction to her child's deafness: from denial to finding solutions', 'Mother's meaning-making and acceptance of deafness', 'Societal and family reactions to deafness, 'guilt towards other children and informal support received', 'Challenges faced and journey with the medical field: from diagnosis to rehabilitation', and 'The choice of education and communication strategies implemented'.

The findings present the mothers' meaning-making and formulation of motherhood through the grieving process upon hearing the diagnosis. The responsibility and inevitable decisions taken by the mothers created tremendous uneasiness. The choice of hearing devices, schools, and communication strategies affected the child's development and interactions.

Suggestions for practice and future research pertains to the formal and informal support offered to mothers and their families following their needs. Further research is needed to explore the lived experiences of people in the Deaf community in Lebanon and their families to improve services presented by practitioners in contact with this population.

Chapter 1: Introduction

The purpose of this project is to highlight and gain deeper understanding of the lived experiences of mothers who have a child diagnosed with deafness in Lebanon. Although deafness is not a disability, individuals affected are often labeled as disabled (Ebrahimi et al., 2014). The child with a hearing impairment experiences subsequent difficulties and challenges in their way of being, speech and language development which in turn may affect their cognitive and psychological growth. With these information in mind, early hearing detection strategies and interventions, especially in the child's first year are particularly important for their development (Meadow-Orlans, 1994; Rivadeneira, Silvestre & Laborda, 2015). Language stimulation is crucial for the child's linguistic, cognitive and social development (Moeller, 2000). As their child's diagnosis of deafness is conveyed, mothers may go through experiences of grief, a sense loss, and notably denial and anger (Lederberg & Prezbindowski, 2000). Then, mothers are faced with making decisions concerning interventions and treatments that may help with their coping process (Luterman, 1999). Also, stigma perceived by mothers may be due to society's ignorance or the regret of losing a healthy baby (Ebrahimi et al. 2014). Counselling services are developed to guide and support mothers going through the adjustments and acceptance of having a Deaf child (Ingber, Al-Yagon & Dromi, 2010). The involvement of mothers and their children in early intervention (EI) programs and psychosocial support showed a positive outcome in the child's linguistic, cognitive and social development. This also reportedly decreased maternal stress (Opoku et al., 2020; Jamieson, Zaidman-Zait & Poon, 2011).

A fundamental part of the doctoral training is personal development as a process of self-discovery and self-improvement. I spent my formative years between Lebanon and France and I

am still commuting between these two drastically different countries that are populated by individuals that differ further still. Mastering three separate languages, along with the accompanying social etiquettes of when and where they should be applied is challenging, yet rewarding. My upbringing instilled in me a deep interest in languages along with the many factors that contribute to cross-cultural differences. My personal experiences improperly taught me that the acquisition of language depended solely on hearing spoken words. At a very young age, I became intrigued by signing people and learnt that language is not necessarily contingent on sound. I remember, around the age of 8, feeling flabbergasted by a couple of people arguing. I could clearly see the frustration, the anger, yet they weren't uttering any sound. The signing, facial expressions and body language said it all. My mother swiftly asked me not to stare at the Deaf people. I knew I wasn't staring but rather was looking, intrigued and in awe of this powerful language and dynamic. However, I deduced from my mother feelings of pity and shame. She categorized them as '*handicapped*' and I couldn't fathom that. I found myself wondering what challenges this micro-society living amongst the hearing world faced.

1.1 Purpose of the study and Research question

As part of a doctoral project, this research study presents an interpretative phenomenological investigation into the lived experiences of mothers of Deaf children living in Lebanon. The review of the literature provides an informative basis from several fields such as education, medicine, psychology as well as philosophy. A Deaf person may be an active member of the Deaf community and Lebanese Deaf children and adolescents have the choice to identify with the Deaf culture or not. Better understanding of what it is like to be a parent of an older deaf child could help parents of younger deaf children shape care-related decisions (Flaherty, 2015). Additionally, conveying lived experienced would inform professional healthcare practices and help assess

priorities and better inform future research. It was important to define the idea of attending to ‘family’s needs’ which pertains to a family’s expressed desire for services to be obtained or outcome to be achieved (Poon and Zaidman-Zait, 2014).

The main research question that guided the study is: What are the parenting experiences of hearing mothers who have a Deaf child in Lebanon?. In other words: How do hearing mothers experience parenting a Deaf child in Lebanon?.

The following sections present the project’s significance and relevance in the field in addition to the study’s assumptions and limitations. These sections will be discussed in further details and in relation to the study’s findings in the Discussion chapters.

1.2 Exploration of Deafness

The World Health Organization (WHO, 2020) defined disabling hearing loss according to the hearing abilities of the better hearing ear: a loss greater than 40 decibels (dB) in adults and 30 dB in children. Hearing loss can affect one or both ears and may be considered mild, moderate, severe or profound. Congenital deafness is defined as hearing impairment or loss of hearing present at birth or neonatal period, in the womb. If deafness is congenital, then the sensory impairment was not acquired. Congenital deafness drew attention among professionals and practitioners because of its negative consequences on the child’s developmental outcomes (Olusanya et al., 2007). A distinction between the terms ‘hard of hearing’ and ‘deaf’ are highlighted where the former refers to individuals with mild to severe hearing loss and the latter identify individuals with profound hearing loss (Meadow-Orlans, Sass-Lehrer, and Mertens, 2003). For the purpose of this study, deafness refers to the loss of hearing with possible or minimal sound residues.

Out of every 1,000 prelingual infants worldwide, one of them is deaf, 16 have a mild hearing loss and fifty out of the same thousand live with reduced hearing (Meadow-Orlans, Spencer and Koester, 2004). More specifically, one to three newborns out of a thousand are diagnosed with a hearing impairment which makes congenital deafness one of the most prevalent childhood sensory disorders (Ebrahimi et al., 2015; Störbeck, 2012). Though deafness is a universal phenomenon, it would be naïve to presume that deaf people's experiences are homogenous across cultures and groups. Also, Deaf communities have their own linguistic and way of being in every society they pertain to. Thus, the exploration of Deaf worlds in different cultures was deemed important in the literature review.

As I began exploring databases and enquiring about the topic, I noticed the scarcity of publications and empirical studies in the academic literature. Specifically, qualitative data and narratives of this population are almost non-existent, especially in the Middle East. Also, following a systematic exploration, it was clear that a limited number of deaf people in Lebanon have access to basic education (Ministry of Social Affairs, 2012; Bakhos et al., 2022; Broughton, 2018). Since there is little on the subject, further research and investigation into these communities are a starting point.

Even if one is born able-hearing, there is no certainty that this modality will be preserved across the lifespan. Like many Lebanese citizens living in Lebanon, I experienced a war first hand in 2006. I became disturbingly aware that bombs dropping nearby can possibly lead to long-term medical complications, notably hearing problems. On August 4th 2020, I was at home in Beirut when the blast happened in the port. All my senses were alert as I ran towards my family while protecting my ears. I vividly remember the silence I experienced as my mind was trying to process my feelings. This silence lasted few minutes and felt like hours. I then couldn't stop

thinking about Deaf and hard-of-hearing individuals' daily experiences. From an existential point of view, I also pondered about the effects of hearing impairments on individuals' experiences of the world around them and their identities.

1.2.1 Parental experiences, responses and coping

Regarding the parents' experiences, reactions cannot be predicted upon hearing the child's diagnosis and a myriad of emotions may be experienced. A child's disability could trigger responses such as denial, grief, loss, confusion, and anger among many other feelings (Mindel & Vernon, 1971; Steinberg et al., 2019). Parents' reactions depend on different factors including their cultural background, level of education, social norms, religious beliefs, language, values, attitudes towards medicine, beliefs around health, gender roles, acculturative stress and/or parental stress (Whyte & Ingstad, 1995). These factors as well as the access and availability of information and resources may also influence the parents' decision-making concerning rehabilitation and treatment (Steinberg et al., 2019).

Motherhood is defined as the combination of attitudes and behaviors shaped by culture following a pregnancy and the conception of a child (Akujobi, 2011). To avoid a reductionist definition, motherhood also entails taking care of a child and embracing this role (Arnold-Baker, 2020). When bearing a Deaf child, another dimension is added to the mother's identity (Kara & Harvey, 2017). Social constructs and cultural expectations of dominant communities marginalize mothers of Deaf children. In other word, motherhood and disability intersect and cannot be understood in isolation of the values, beliefs and expectations of the hearing world (Landsman, 2008). This leaves hearing mothers feeling alienated and isolated in their dual role of mother and woman (and many other roles in their worlds) as they are associated with the disability. The transition from mother to mother-of-a-deaf-child may be a significantly challenging time (Arnold-

Baker, 2020). Existential crisis may arise when mothers re-evaluate as well as question their lives and conceptualization of personhood. Jacobsen (2006) depicted 'crisis as loss' and 'crisis as an opening of existence' as two of the three dimensions for the phenomenon of life crisis. The sense of loss can involve the person's challenged values, beliefs and sense of self when unexpected events occur. Correspondingly, Arnold-Baker (2020, p. 5) stated: "Motherhood, therefore, is a crisis moment for women; one which can be experienced as either an adversity, a loss or an unfolding of existence". The current study thus aimed to explore mothers' meaning-making of raising a child with a hearing impairment.

Concerning society' stigma and mothers' choices, Alsulaiman and colleagues (2014) investigated Saudi parents' attitudes towards perinatal diagnosis (PND) and termination of pregnancy (TOP) with regards to different physical conditions. This study played a meaningful role in choosing the targeted population. Mothers were significantly affected by society's attitudes and beliefs, notably judgements. Deafness detected in the fetus was highly rated among mothers as a condition for which they would terminate their pregnancy for. A similar study conducted in the United States showed most parents of Deaf children interviewed reported positive attitudes towards PND but none of the parents would opt for terminating the pregnancy (Brunger et al., 2000). These findings suggested that deafness is more stigmatized in Middle Eastern countries than in the West. Thus, cultural norms affect mothers' attitudes and choices in the Middle East (Ayyash-Abdo, 2001; Störbeck, 2012).

1.2.2 Statement of the problem

As mentioned earlier, in addition to the mother's cultural background, the availability and access to information and resources are crucial for the mothers' understanding and acceptance of their child's deafness (Anagnostou, Graham & Crocker, 2007; Meadow-Orlans, 1980). In recent

studies, hearing mothers' levels of stress and their Deaf child's developmental and internalizing problems were found to be interrelated (Rivadeneira, Silvestre, & Laborda, 2015). In other words, the more stressed the mothers reported they were, the more difficulties, mental health problems and delayed language development their Deaf child experienced (Lederberg & Prezbindowski, 2000; Mapp & Hudson, 1997). Rivadeneira, Silvestre, and Laborda (2015) showed that emotional closeness and cohesion among hearing family members decreased the levels of stress experienced by mothers. Also, mothers were more able to cope with the daily challenges of raising a deaf child when support and compassion was offered by family members. Availability and access to EI programs may mitigate parenting stress (Meadow-Orlans, 1995). However, this may not be the case for mothers in Lebanon, as in developed countries, where EIs are not as prominently available.

Screening tests, although widely established in developed countries, are unfortunately not implemented in developing countries (Olusanya et al., 2007). In Lebanon, screening tests are not funded by the Ministry of Public Health (MoPH), thus the tests are not part of the public health sector. Nationwide hospital-based and clinic-based screening programs need to be put in place to implement necessary routine tests. A campaign entitled *Hearing Screening National Awareness* was launched in 2018 for a month and encouraged all hospitals to provide free or low-cost hearing screenings (Ministry of Social Affairs, 2012). The campaign highlighted the importance of early detection for the person's health and welfare as well as the country's economy and productivity (Article 19, Lebanon: Disability and Access to Information, 2015). As the United Nations Children's Fund (UNICEF) representatives in Lebanon reported: 6 in every 1000 children are affected by a hearing loss. The family and child's welfare are of utmost importance but the private-public sectors' cooperation is unfortunately thorny (Republic of Lebanon Ministry of

Public Health (MoPH), 2018). Thus, private funding is needed for the child's health expenditure. The parents' budgets and financial capacities will determine the choice of screening tools that may in turn influence the screening and testing's effectiveness and performance (Olusanya et al., 2007).

In summary of this section, mothers of deaf children's understanding and acceptance of the diagnosis is closely related to the culture they are exposed to and information provided by professionals. Following the footsteps of developing countries such as Nigeria and India, parents' awareness will depend on primary care physicians in referring babies to audiologists or other specialists when hearing problems are suspected (Olusanya et al., 2007). Up-to-date information concerning the disability, the professionals' readiness to support and provide the care and recommendations are needed to make informed decisions (Steinberg et al., 2019). It is important to note that the nature and severity of the child's condition, the parental involvement and effort given to the child are related to the level of parental stress (Patai, 1983; Zahr, Khoury & Saoud, 1994). Thus, exploring the needs and concerns as well as the lived-experiences would better inform practitioners and service providers to attend to the maternal stress experienced.

For the purpose of this study, few terminologies are clarified.

1.2.3 Terminology

The conceptualization of 'disability' is understood in relation with the idea of 'ability' (Kara & Harvey, 2017). Disability is considered outside the notion of normalcy, outed from the usual and viewed as 'abnormal' in society. The understanding of deafness is predominantly centered on two perspectives: the medical model which pathologizes hearing loss and congenital deafness as a condition to fix, and the sociocultural model which views deafness as a cultural identity (Munoz-Baell, and Ruiz, 2000). The medical paradigm of deafness encapsulates

lowercase ‘deaf’ while the uppercase ‘Deaf’ englobes the social model of deafness as cultural and linguistic minorities (Kara & Harvey, 2017). Deaf communities have their own distinct culture, values, history, art, language and mode of communication. However, not every deaf person necessarily identifies with these communities (Meadow-Orlans, Spencer and Koester, 2004). Following Merleau-Ponty’s (2013) idea, the meaning the individual gives to their condition is what matters and is related to the concept of embodiment. Phenomenologically, the person chooses to view themselves as disabled and/or part of a particular community, and these views are congruent with their lived experience and meaning-making (Kara & Harvey, 2017).

The medical view of deafness fixates on speech and lip reading as the only route to optimal cognitive and linguistic development. Deaf individuals constitute a linguistic and cultural minority (Kara & Harvey, 2017). The discrepancies in attitudes and notions of deafness create a breakdown in communication and may have negative social and emotional impact (Mindel and Vernon, 1971; WHO, 2020). Thus, to the hearing world, Deaf people are excluded, isolated and considered handicapped (Munoz-Baell, and Ruiz, 2000). Since the 1970’s, sign language was employed within Deaf communities in developed countries and implemented in specialized and inclusive schools (Roumanos, 1999; 2008). Nonetheless, schooling is rarely available or inclusive for hard-of-hearing or Deaf children in developing countries (Bakhos et al., 2022; WHO, 2020).

Following the sociocultural realm, I personally view the Deaf community as a distinct and well-established cultural group rather than a unit of excluded and ‘disabled’ individuals. Thus, the term Deaf, with uppercase ‘D’, in this study refers to Deaf individuals as a functioning part of society rather than deemed as people with auditory deficiencies (Meadow-Orlans, Sass-Lehrer, and Mertens, 2003). I was in contact with several Deaf individuals, including my sign

language tutor, that did not see their difference as a disability. They all have families of their own, hold decent jobs they either liked or disliked and are part of different social circles. It is clear they are alienated by hearing societies' attitudes and views of their differences.

The following shortcuts are employed to determine relevant dyads: hearing parent of a hearing child H-H, Deaf parent of a Deaf child D-D, hearing parent of a Deaf child H-D and Deaf parent of a hearing child D-H.

1.2.4 Why mothers of Deaf children in Lebanon?

In a Middle Eastern country such as Lebanon, its citizens are accounted for as a collectivistic society where values orientations, morals and social duties, as well as collective interests override personal interests (Ayyash-Abdo, 2001). Thus, extended family members such as aunts, uncles, and cousins may have a role in the nuclear family's dynamics. When I started working with families in the South and the capital of Lebanon, I noticed that mothers tend to take the lead and actively take part in their children's lives. Mothers attend parent-teacher meetings, enquire about their child's school performance, and attend to their medical needs and follow-up with doctors. Also, in my experience as a special educator in a learning center, and as mostly reported in the literature, mothers were noticeably the primary caregivers (Calderon, Bargones & Sidman, 1998; Erbas et al., 2018; Zaidman-Zait et al. 2018). When my colleague and I organized the first Deaf awareness workshops and sessions in Beirut, mothers of Deaf children and adolescents were clearly on the frontline to take as much information from the speakers as they could. Following these observations and findings, it seems important to explore mothers' experiences of raising a Deaf child, and understand their feelings and emotional processes of Deafness. Additionally, pioneering research such as the Infancy Research Group at Gallaudet (Meadow-Orlans, Spencer & Koester, 2004) and the project by Lederberg and Prezbindowski

(2000) around Deaf children and the interaction with parents highlight the role of mothers in the dyad. There is also a cultural awareness and attitude in Lebanon and Middle Eastern family putting mothers on the frontline when it comes to raising children (Ayyash-Abdo, 2001; Erbas et al., 2018; ESCWA/League of Arab States, 2014; Roumanos, 1995; 1998; 2008). Thus, within the nuclear families in Lebanon, mothers are considered the primary caregivers.

Another dimension is added to mothers of Deaf children: motherhood and disability are social constructs (Kara & Harvey, 2017). Mothers may be marginalized for having a Deaf child and viewed as deviant to society's norms. Feelings of shame and isolation may be experienced by the mothers. Examining their perspectives and experiences would convey the different arrays of concerns for professionals working closely with Deaf children and their families. In a study by Ebrahimi and colleagues (2017) with Iranian mothers, concerns about the nature of Deafness was conveyed. For example, concerns about the physical activities, financial burden of rehabilitation, the consequences of the hearing enhancement devices, inappropriate public reactions to their Deaf child, the child's future, institutional support, choosing schools, the possible birth of another Deaf child. Thus, depicting mothers' needs and challenges when raising a Deaf child would provide suitable professionals a clearer picture to offer optimal, individualized interventions and culturally-sensitive support (Lecciso, Petrocchi, and Marchetti, 2012; Meadow-Orlans, 1997; Meadow-Orlans, Sass-Lehrer, and Mertens, 2003; Zaidman-Zait et al., 2018).

The family is considered a fundamental unit of society that has a major role in a child's development. Regarding the family structure, the dynamic between each member, the cohesion, communication, the ease of adaptation and shared values define a family (Seligman, 1991). Additionally, the family of children diagnosed with a chronic condition are negatively impacted (Park & Yoon, 2018). More than 90% of Deaf children are born to hearing parents (Vaccari &

Marschark, 1997) and several researches emphasized the impact of parental attitude towards their children's hearing difficulties (Meadow-Orlans and Steinberg, 1993). Being raised in a hearing family has numerous consequences on the Deaf child and the hearing parents as well. For example, the social and emotional development of Deaf children in hearing families differed from Deaf children who were born to at least one Deaf parent (Kluwin & Gaustad, 1991; Vaccari & Marschark, 1997). The prevalence of depression is reportedly higher in mothers of children with a hearing loss compared to mothers of children with typical hearing (Kobosko & Zalewska, 2011). Also, hearing mothers of Deaf infants are diagnosed with depression at a higher rate than hearing fathers (Meadow-Orlans, 1995). Few findings are gathered from the scarce research in the area of parental coping and differences in relation to how they deal with their Deaf child. Results showed that fathers reported fewer mental health problems and less stress than mothers of Deaf children with cochlear implant (Burger et al., 2005; Spahn et al., 2001; Zaidman-Zait, 2007). Thus, there are gender differences concerning the coping strategies and time needed to deal with their Deaf children; fathers use denial more often than mothers (Anagnostou, Graham and Crocker, 2007). However, a critical view of the results may be held in mind while exploring the differences; is it that fathers are less likely to report problems and concerns? For the purpose of this study, the mothers' wellbeing and experiences are explored and conveyed.

1.3 Significance of the study

1.3.1 Knowledge Generation

Limited research among empirical studies relate to this topic and population specifically. Scientific literature hitherto is mostly focused on countries other than those in the Middle East. Also, while scarce Deaf studies in Lebanon focused primarily on deafness in the medical field

and education systems, no attention is given to parents of Deaf children. This study thus contributes to the literature and professional knowledge by documenting the lived experiences of mothers raising a Deaf child in Lebanon. The aim as mentioned, is to also shed light on mothers' meaning-making of their experiences to better inform practitioners in contact with this population.

1.3.2 Clinical relevance

Before the 1960's, in developed countries, Deaf children of hearing parents were sent to residential boarding schools (Calderon, and Greenberg, 2000). A decade later, Deaf awareness and the importance of including families in their children' educational system emerged (Roumanos, 1998). Since then, the implementation of sign language in school systems in European countries and the United States triggered a shift of attitude from a pathologizing view of deafness to a more inclusive and linguistic view (Mendel and Venon, 1971). However, this approach to deafness is not witnessed in the Middle East and more specifically Lebanon (Bakhos et al., 2022; Broughton, 2018).

The study would help practitioners and clinicians such as audiologists, pediatricians, therapists, speech therapists and mental health professionals shed light on the mothers' challenges and concerns. The aim would be to meet their specific needs and empower their Deaf child by providing suitable psychosocial support (Meadow-Orlans, Sass-Lehrer, and Mertens, 2003). Exploring mothers' lived experiences of raising a Deaf child in Lebanon would also clarify their attitudes and perceptions of the Deaf child and the effect these experiences might have on their wellbeing (Störbeck, 2012). This project also offers clinicians and practitioners deeper insight to offer optimal practices when working with this population. A better understanding of the topic may contribute to the ongoing dialog between practitioners to provide greater services and

interventions when working with mothers and families from a myriad of backgrounds.

Participants in this study are considered co-researchers while the narratives they convey constitute the basis for the interpretation and phenomenological analysis (von Eckartsberg, 1986).

1.3.3 Social Change

In addition to the study's clinical relevance, the current research may also contribute to social change. Deaf individuals may not perceive themselves as disabled but rather shaped by the society and the environment they live in, notably their mothers' conception of deafness. Thus, exploring mothers' experiences in research and literature would shed light on the ways they faced challenges of raising a Deaf child in Lebanon. As mentioned earlier, motherhood and deafness are socially constructed and mothers cannot be taken in isolation from their environment, as part of a web of interwoven everyday interactions (Arnold-Baker, 2020; Kara & Harvey, 2017). Lebanese individuals' personal goals are subordinate to collective goals as influenced by Arab and collectivistic value. In other words, the formation of self-image, self-cognition, private and collective selves are related to the culture (Parkes, Schneider & Bochner, 1999). Thus, information disseminated by the participants' narratives may reduce the stigma surrounding deafness and better inform lay persons in the Lebanese society. Deaf individuals and their hearing mothers would be attended to as unique beings, regardless of their society's inclinations and attitudes (Fjord, 2001).

1.4 Summary

In the literature, congenital deafness and early auditory deficiency are the most examined topics due to the myriad of medical challenges and implications (Munoz-Baell, and Ruiz, 2000). However, Deaf education and Deaf Mental Health were not topics of interest among academics, social scientists, psychologists and policy makers before the 1950's (Roumanos, 1999). By

employing a phenomenological approach, the project enquired about mothers' experiences of a particular phenomenon while reflecting on the meanings given to their experiences. Numerous potential implications exist from the deeper understanding and exploration of the lived experiences of mothers of Deaf children in Lebanon. The investigation of relevant professional literature would offer insight to practitioners in contact with Deaf individuals and their families. This would help formulate best practices, counselling approaches, and framing optimal EI programs while preserving the family's gestalt and needs. Bringing forward mothers' meaning making of their experiences would also shed light on their genuine circumstances. Parents would identify with these experiences and may influence their decision-making that would benefit their children.

The following chapters present a thorough exploration of this topic through empirical studies. Then, the study's design and methodology, the findings and a discussion of the results are presented. Finally, conclusions and suggestions for further research and practices are conveyed.

Chapter 2: Literature review

The literature review provides foundations on existing knowledge and information of the topic of interest. The review of the literature allows the exploration of existing research which gives an insight into what has been done on the topic and what could be the key issues that need to be addressed (Hart, 2018). In other words, it places the research within the context of existing literature, the relationship between the corpus of studies and concepts, helps identify inconsistencies and shed light on what has worked or could be explored further. The literature review was critically appraised and also helped in establishing the gaps in research. Furthermore, the literature review demonstrates my capabilities as a research to appraise, critically evaluate and synthesize existing knowledge relevant to my research topic (Boote & Beile, 2005).

Information acquired for this literature review was collected in February 2020, March 2020, May 2020, June 2020, August 2020, and from October 2020 through February 2021. I utilized databases such as EBSCO academic Search Complete, Taylor & Francis database, SAGE Journals, Google Scholars and accessed peer-reviewed articles from relevant reference lists. The search located around 3700 peer-reviewed papers including book chapters and books. Professor Roumanos at the Saint Joseph University in Beirut was interviewed in April 2019 and conveyed information and academic books regarding the population of interest in Lebanon. The information noted in the interview are relayed in the thesis. He said that ‘handicap, is other people’s stares’ and shared that Deaf persons are most of the time misunderstood. He shared that for the longest time, people thought of Deaf people as paranoid whenever they would think everyone is talking about them. As long as a Deaf person is outed from a conversation, this feeling seemed to overcome them. Another note from the interview pertains to the use of cochlear implant. He witnessed families thinking that a cochlear implant would allow their child

to hear and speak instantly. However, the process is complex. There is a difference between listening and hearing. And from this point Professor Roumanos explained that if the person does not give meaning to the signals received, then the sound is not translated to any word and is definitely left with a blank utterance. Professor Roumanos (1997) shed light on the importance of sign language in education and not only among Deaf persons. He suggests including the whole family of a Deaf child and teaching sign language as part of schools' curriculums.

Search terms and key words were applied to search the databases mentioned and included: *mother, deaf children, deafness, motherhood, mother of a deaf child, lived experiences, experiences, deaf, counseling, coping, parental coping, maternal stress, Lebanese sign language, mother and child communication, phenomenology, interpretative phenomenological analysis, and qualitative research.*

The choice of exploration of mothers' lived experiences are clarified and existential paradigms are explored. Different perspectives of hearing impairments are investigated to better understand the sociocultural and medical perspectives of Deafness. Communication strategies and varied plans of actions identified in the literature concerning the Deaf child's cognitive, linguistic and emotional development are also presented. These factors' effect on the mothers' identity, roles, attitudes and coping are laid down. Finally, the rationale of the study and the aims of the research findings are highlighted.

2.1 Experiences of mothers: existential paradigm

Maternal Identity of hearing mothers of Deaf children

Identity is at the basis of the concept of personhood and the maternal uniqueness of a mother raising a child with a hearing loss may form differently (Kobosko & Zalewska, 2011). According to Bowlby's (1973) *theory of attachment*, infants innately become attached to their

primary caregivers. Whether the child becomes securely or insecurely attached, the quality of the bond and relationship is at the basis of the child's psychosocial development (Bowlby, 2008). Maternal identity is a combination of the mother's representational worlds (Stern, 2020). These mental representations combine the mother's representations of: (a) being-with her child; (b) her relationship with her own mother, (c) her relationship with her child's father; and the dynamic between those representations (Kobosko & Zalewska, 2011; Stern, 2020). The woman's transition into motherhood is shaped through these dynamics: the woman's mental representations, her culture, her temperament, and expectations (Arnold-Baker, 2020).

Since most parents of Deaf children are hearing, the diagnosis and condition seem alien and unknown (Kurtzer-White & Luterman, 2003; Vaccari & Marschark, 1997). As part of the unpredictable nature of birth, the woman is thus *thrown*, as Heidegger (1962) denotes it, into a world that was hitherto unknown to her: motherhood. In other words, mothers are confronted with a new reality that may comprise a different set of expectations, anxieties, ambitions, way of being and behaving. Upon hearing the diagnosis of a child's hearing loss, the mother may experience a number of distressing emotions and reactions close to grief (Bui, 2018; Anagnostou, Graham & Crocker, 2007). The child's condition may reformulate the mother's experience of motherhood (Kobosko & Zalewska, 2011). The mothers' coping is understood and determined according to how well they are able to deal with a myriad of feelings and emotions upon being informed of the diagnosis (Kurtzer-White & Luterman, 2003). How well they are able to cope is not related to the degree of hearing loss (Mapp and Hudson, 1997).

The experience of grief is understood as the death of the baby the mother hoped for and the loss of the future she expected (Kara & Harvey, 2017). Grieving is a subjective and complex matter and may include feelings of denial, anger, bargaining, depression, acceptance and also

growth (Bui, 2018; Kurtzer-White & Luterman, 2003). Thus, mothers may go through a plethora of negative emotions before accepting and acknowledging their child's condition (Anagnostou, Graham & Crocker, 2007; Fadda, 2011).

The so-called grief also pertains to the mother going through an existential crisis (Arnold-Baker, 2020). The crisis of motherhood is considered an existential one as the mother questions and reformulates her life, values, expectations, meanings, purpose and decisions (van Deurzen, 2012). The mother's identity may be lost when communicating with her Deaf child as her personal world may seem destabilized (Kobosko & Zalewska, 2011; van Deurzen, 2012). Theory of Mind (ToM) and maternal insightfulness reflect the mother's capacity to recognize and understand her child's point of view and predict their behavior based on the mental states noticed (the child's motives, desires and complex worldviews) (Lecciso, Petrocchi, & Marchetti, 2012; Oppenheim & Koren-Karie, 2002). This said, hearing mothers had difficulties assessing and understanding their Deaf child's emotional needs. Thus, the mother's perception of herself and her role was negatively impacted. There were recurrent themes reported such as: heightened worrying, anxiety, guilt, sense of loss and grief (Kumar & Rao, 2008; Meadow-Orlans, 1994; Park & Yoon, 2018; Spencer, 2000).

Denial; mothers' first reaction to their child's diagnosis

Mothers may not accept their child's diagnosis at first, numbness may accompany the shock and these feelings may develop into disbelief and avoidance (Kurtzer-White & Luterman, 2003). The mothers may deny the condition and instinctively consult different doctors in the hope of hearing a different opinion (Anagnostou, Graham & Crocker, 2007). The ideal world and child they imagined is too far off from the situation they are in. There is a need to 'fix' or 'cure' the child's hearing.

Another aspect of the mother's life concerns her identity. A psychological transition is needed for the mother to develop her new motherhood identity (Arnold-Baker, 2020). An ontological understanding of their personhood, sense of self and existence is formulated and van Deurzen (2009) explained this as a time of existential re-birth. The transformational period is embodied during pregnancy. The expectation of a child constitutes a transitional time into motherhood that confronts women with the reality of their existence that may not be accepted (Arnold-Baker, 2020). Mothers are faced with challenges affecting their individual experiences as a whole: the physical (Umwelt); the social (Mitwelt); the personal (Eigenwelt) and the spiritual (Uberwelt) (van Deurzen, 2012). The mother has to grapple and make sense of the new responsibilities of raising a child, let alone a child with a disability. A reminder of the mother and the child's mortality is highlighted. The mother is actively changing and adapting to a vulnerable Being which may hold moments of denial of this role, uncertainties and a myriad of responsibilities. Temporality is changing and seems narrow as the mother is confronted with moment-to-moment living at her child's rhythm (Arnold-Baker, 2020). This concept is discussed in further detail in the next subtheme.

Time; mothers of Deaf children's conceptualization of Time

When a baby is born, temporality and mortality are highlighted in the parents' consciousness (de Beauvoir, 2010). The experiential and existential time are defined in relation to the external world (Mueller, 1946). The first year of motherhood highlights the mother's moment-to-moment experiences, in the present (Arnold-Baker, 2020). Time seems flowing yet 'discrete' in many moments such as the child's birth, the time of diagnosis, the time spent commuting to doctors and time spent comparing the child's development and other children (Meadow-Orlans,

Sass-Lehrer, and Mertens, 2003). Arnold-Baker's (2020) findings showed that the mother's sense of time seems to have sped up. This is the experiential and existential time proper to each phenomenon the person experiences and each point in time highlighted (Mueller, 1946). There is a sense of constant change as the baby is developing and there is no structure nor clear routine. Time feels nebulous. The mother's first reaction comes as a shock and numbness, and this is understood as the unfamiliarity and concerns around deafness in the family and society (Fadda, 2011). Also, the diagnosis can be experienced as "an initiation rite of passage", metaphorically moving from one state of personhood to another socially-constructed state (Fjord, 2001, p. 112).

Meaning is given and constructed by mothers, especially as they are encountering deafness for the first time. It is only in hindsight that the person is able to assess the effect their choices had on their lives (Kierkegaard, 1967). The underbelly of our human existence combines freedom, choice, responsibility and temporality as essential tenets of the human condition (Arnold-Baker, 2020; Cooper, 2016). Our freedom of choice and inevitable responsibilities both bring about anxiety. Thus, existential *angst* may be experienced when the mother is aware of the responsibility and freedom of her human condition and the unknown future (Heidegger, 1962; Sartre, 1943). The mother's experience of her child's embodiment after the diagnosis can also give a sense of relief as her concerns and observations were finally recognized medically.

Grief and identity loss

Upon hearing the diagnosis of the child's hearing impairment, the shock and feelings of loss experienced by the mother may be related to the grief of the expected identities and life pictured (Kurtzer-White & Luterman, 2003). The experiences englobe the loss of the mother's identity -being the mother of a 'normal' child- and the loss of the expectations of parenting a 'normal' child. Mothers' grief and identity loss need to be tackled by professionals as part of their

adaptation process (Luterman, 1999). In the study by Anagnostou, Graham and Crocker (2007) on the feelings of parents of cochlear implanted children, grief was reported as the strongest emotion experienced by hearing mothers. Grief is understood in terms of reactions to their child's situation as well as the grief of the mothers' expectations (Kara & Harvey, 2017). The mother thus may not accept the child's deafness and focus on finding solutions so that the child leads a 'normal' life (Zaidman-Zait, 2007). These attitudes seem to hinder the acceptance process because "if they do not learn to accept their child as he or she is, both the child and the parent can never integrate the deafness in their lives in a way that allows them to get beyond it" (Kurtzer-White & Luterman, 2003, p. 235).

As previously mentioned, another aspect of grief refers to the mother's identity formulation. Becoming a mother brings about anxiety and confrontation with the unknown (Arnold-Baker, 2020). For some mothers, the values, meanings, beliefs, and expectations are reformulated and a sense of uneasiness emerges in light of the new experiences (de Beauvoir, 2010). Mother's sensitivity, ToM abilities and the quality of the parent-child communication, determine the cohesiveness of the family and impact their sense of self and identity (Koren-Karie et al., 2002; Lecciso, Petrocchi & Marchetti, 2012; Van Eldik et al., 2004). This also affects mothers' parenting satisfaction (Jean et al., 2018). Chaos and the challenging expectations of facing the unknown reminds the mother of the life she had before. There is a sense of 'letting go' of the urge of controlling what may not be in control anymore (Arnold-Baker, 2020). This shift in attitude brings about 'letting go' of the expectations to reassess and understand what is important in their lives, their Deaf child's needs and formulate a new purpose in life (van Deurzen, 2009; 2012). Thus, the idea of grieving the life prior to the baby's diagnosis.

Anger and Guilt: the adaptation process of mothers of Deaf children

The mother's identity and her sense of her own limitations are reflected in her interaction with her Deaf child. The sense of helplessness is a psychological reaction to the grief experienced and her idea of motherhood seems heavy and like a burden (Kobosko & Zalewska, 2011). The mother's fear of being inadequate and not attending to her Deaf child's needs also trigger feelings of anger (Kurtzer-White & Luterman, 2003). Anger, the survival characteristic that mobilizes our body to fight or flight actual or perceived danger may be overwhelming. A sense of loss of control and disappointment of expectations of 'normalcy' may be overbearing with the mission to make things better. It feels like the response to the diagnosis and the mothers' coping processes are controlling their life (Kurtzer-White & Luterman, 2003). The Deaf child may also change the family dynamic (Burger, 2005). When anger is believed to be turned inwards and towards the Self, depression may be experienced. The mother's role seems too far off from her expectations and her own powerlessness may be highlighted (Arnold-Baker, 2020; Kurtzer-White & Luterman, 2003).

Why would hearing mothers of Deaf children feel guilty? Mothers may blame themselves for their child's deafness, they may feel responsible for not being more careful during their pregnancy for example (Luterman, 1999). Mothers are bombarded with information early on and are expected to make decisions regarding the modality of their child's language and education (Kurtzer-White & Luterman, 2003). They are expected to decide if the child will learn sign language and/or spoken language (oral or visual language), attend mainstream or special schooling system, and choose assistive hearing devices that may be appropriate. The mother's choices and decisions will have tremendous impact on her baby's life, and the consequences cannot be predicted (Arnold-Baker, 2020). The mother's *thrownness* and freedom feel like an impediment to her and her baby's life (Heidegger, 1962). Guilt may also be felt in relation to the

mother's interaction with her other children that may change and need adaptation. Mothers are encouraged to deal with their feelings and cope with the roller-coaster of emotions experienced. Thus, the collaboration of a multidisciplinary team composed of the audiologist, speech and language therapist, psychologist and teachers may be required to work systemically with the family. A holistic approach for the provision of care is thus for the guidance and support for each family member to work towards optimal emotional and social development. In other words, it is about providing support that looks at the person as a whole, not just their physical needs for example.

The Social Dimension (Mitwelt)

As previous sections looked into the mothers' personal experiences of having a Deaf child, this section presents mothers' reactions to social situations and possible changes in their way of *being-with-others* (Heidegger, 1962). As Heidegger conveys it, Being-in-the-world englobes Being-with-others in time and space (Heidegger, Macquarrie, & Robinson, 1962). Mothers of Deaf children are confronted with different experiences, paradoxical feelings and daunting sense of uncertainty (Arnold-Baker, 2020). They are *thrown* in this new role and angst of the lived experiences that defy all expectations (Heidegger, 1962). The mother not only adapts to her new relationship with the baby, but being-with-others is constantly changing as the child grows and her identity is reformulated. In other words, the mother's Social Dimension (Mitwelt) may take different aspects. Developing a relationship with her baby is the first step of the reformulation of the mother's Mitwelt. Non-verbal communication is developed and their interaction is co-created (Arnold-Baker, 2020).

Mothers of Deaf children may worry about their child being seen differently, outed and discriminated against. The probability for their child being bullied for example may engender

fear (Georgiou, 2008). For mothers of children with cochlear implants or hearing aids, another worry reported relates to the appearance of the device on the child's head. Questions such as: Would people notice it?, Would they look at them differently? may come to mind. These ideas may influence the mothers' attitudes and behaviors: they might reject the device which in turn affects the consistency and compliance to rehabilitation. The mother may feel resentment for having a child who behaves differently and may need additional attention, further energy as well as financial support. In Ghana, such as in Lebanon, the lack of financial support creates a burden for parents of Deaf children (Opoku et al., 2020). Also, due to misperceptions and misinformation of technologies available to assist persons with hearing impairments, mothers may believe that cochlear implants are the child's key to their integration within the hearing world (Kurtzer-White & Luterman, 2003). They may in turn accept the implant as the 'cure' and their grief is suspended as a vision for a 'normal' child is finally perceived. In these cases, mothers would only be disappointed and experience reinstated grief when they realize that assistive devices are not cures (Kurtzer-White & Luterman, 2003; Zaidman-Zait, 2007).

For Heidegger (1962), *being-towards* as mode of relating echoes the woman's transition into motherhood. The connection, the love, care and openness highlight the mother's relationship with her baby. In addition, it is about an *I-Thou* mode of relating, an intersubjective space, where the mother attends to the child's needs and tries to understand the child as a whole Being while both parties are mutually recognized (Buber, 2012). The mother moves to a *being-towards* mode of relating to her baby, but also a mode of relating to others in society. In several studies, the mother's worry of social situations was highlighted as the news of the diagnosis was conveyed (Lederberg & Prezbindowski, 2000; Rivadeneira, Silvestre & Laborda, 2015). There is an expansion to how mothers perceive themselves relationally (Arnold-Baker, 2020).

The Physical Dimension (Umwelt) and Embodiment

In previous sections, one aspect of the physical dimension was explored: temporality. This section further investigates the mother's physical worlds and *being-with* her baby and others. Since the 1980's, a range of social sciences and humanities such as feminist studies, sociology, philosophy, anthropology, psychology, and theology increased their interest towards the body (Csordas & Harwood, 1994). In the study by Fjord (2001), embodiment is understood as the combination of the individual's phenomenological experience of their own body, and social constructs attached to their body. The body is a tool the person uses to shape the world they live in, thus the word 'embodiment' (Lévi-Strauss, 1987). The examination of being-in-the-world englobed cultural boundaries and perceptions. For example, the lived experiences of the body as a self would be different for a hearing person compared to a Deaf person. For example, a prelingual Deaf person may experience their body as 'normal' whereas his or her society's representation projects a sense of loss. These views of embodiment include binary oppositions such as the Deaf world versus the hearing world, oral versus sign language, assistive hearing devices versus no hearing devices. The literature put aside the 'bodiliness' of the body and would reduce the body to the self or person (Csordas & Harwood, 1994, p.4). However, *being-in-the-world* is a collection of the body's inter-sensory entities coming together (Heidegger, Macquarrie, & Robinson, 1962; Merleau-Ponty, 2013). For example, 'others' in a hearing world are people who are not able to hear (Landes, 2013). Thus, given society's negative attribution towards people with hearing impairments, the existential concept of freedom is perceptually limited. Nonetheless, the body is not a "bounded entity", but it is limitless (Csordas & Harwood, 1994, p. 2). The body's 'situatedness' extends to the different domains of human existence (van Deurzen, 2012). The body becomes an experiencing agent that the person tries to accommodate to in the world.

In the following sections, the conceptualization of Deafness is presented according to the literature leading to a better understanding of the study's formulation. The medical perspective of Deafness is briefly explored, the sociocultural perspective is then investigated and the communication experiences of mothers of Deaf children are conveyed.

2.3 Conceptualization of Deafness

Exploring the definition of deafness is a crucial step before laying down the research project. On one hand, if deafness is considered a disability to be fixed and treated with assistive enhancing devices, then a medical perspective would be considered. On the other hand, deafness is seen as part of a linguistic minority and a human variable belonging to the Deaf community, thus a social aspect of deafness is embraced (Fadda, 2011; Lane, 1995). The conceptualization of deafness by the mother is not a linear path as the child's milestones are challenged at times and legitimized by social views and by the medical field (Lane, 1995).

2.3.1 Medical perspectives of deafness

Mothers emphasize their child's hearing loss in their daily life (Calderon, Bargones & Sidman, 1998). It is thus important to include information concerning rehabilitation and hearing loss.

Incidence of childhood deafness, prevalence in Lebanon and etiology of deafness

Less than 1% of school-aged children are deaf and despite the small number, a great number of nuances exist among this minority group (Meadow-Orlans, 1980). Hearing assessments and screenings are executed by medical professionals and recorded on audiograms (Meadow-Orlans, 1980). Screenings also help professionals in directing parents towards appropriate treatment

plans, such as hearing devices and interventions, when available. The differences in frequencies of hearing loss would also determine the group the child may belong to: deaf or hard-of-hearing as they do not form homogeneous groups.

A National demographic study for people with disabilities was executed in Lebanon between November 1995 and May 1996 (Roumanos, 2000). Researchers collected data from 63,372 participants in different regions across the country for a total of 3.5 million Lebanese citizens (Roumanos, 1999). However, according to recent data by the Central Administration for Statistic, there are no statistics on Deaf people in Lebanon (Doecke, 2019). Additionally, the World Federation of the Deaf (WFD) reported around 12,000 people living with a congenital hearing impairment in Lebanon in 2008 (Global Survey Report, 2008). Unfortunately, there are no official data and figures portraying the number of deaf and hard-of-hearing people in Lebanon (Article 19, Lebanon: Disability and Access to Information, 2015). An estimated rate of 1 over a 1000 Lebanese child is born deaf or acquire profound sensorineural deafness before the age of two (Tabchi, Rassi, Akl, & Fares, 2000). A more recent survey conducted by the Ministry of Social Affairs (2012) examined the prevalence of individuals with disabilities granted an ‘invalidity card’. They reported around 31,000 in 2001, and ten years later, 77,001 people with disabilities were recounted in Lebanon (ESCWA/League of Arab States, 2014). Thus, the under-representation and under-estimation of people with disabilities in Lebanon is mainly due to the non-declaration of disabilities.

To understand the medical implications of hearing loss, the exploration of possible causes seemed relevant at this stage. A variety of research explored the probable genetic causes, consanguinity also known as ‘blood relation’ - defined as the procreation between partners of the same family line- is prominent in the Middle East, notably Qatar and Lebanon. It is not surprising

that Qatar subsequently reports the highest rate of deafness in children in the world (Störbeck, 2012). Tabchi and colleagues (2000) examined the etiology of 274 Deaf children recruited across Lebanon. More than half (51.82%) related their deafness to genetic causes, with 25.2% due to consanguinity, 15.32% had unknown causes and the rest were caused by childhood conditions such as rubella and perinatal meningitis.

Re-habilitation strategies would be chosen depending on the family's goals and in the child's best interest in achieving social integration (Fadda, 2011). For some professionals, the only way for integration would be the use of auditory-verbal technological devices and for others, learning sign language and focusing on linguistic development would be at the heart of the re-habilitation. In this following section, auditory devices are explored and mothers' psychological aspects of having a child with a hearing device are presented.

Re-habilitation process: Hearing aids and cochlear implants

The World Health Organization (WHO, 2020) clearly states the key elements ensuring optimal outcomes for Deaf children: early identification, appropriate interventions, professional and informal support, and a systemic/family-centered treatment approach. An interdisciplinary approach to these elements would also be appropriate for the best outcomes (Joint Committee on Infant Hearing, 2007). Audiologists, medical physicians, therapists, speech therapists and pedagogical services would decrease the risk of developmental delays and help promote communication and social development.

There are different routes of rehabilitation that Deaf people can benefit from since medical technologies developed rapidly in the last decades. Hearing aids, listening devices, and screening tests are more refined and implemented to identify newborns' hearing capacities. The medical field in developing countries such as Lebanon lack health professionals and have low-quality

resources and technologies for screening and diagnosis (Störbeck, 2012). According to the Convention on the Rights of Persons with Disabilities (CRPD) held by the United Nations (UN, 2006) in New York since 2006, individuals with hearing impairments are entitled to access assistive technologies as a basic right (Borg, Lindström & Larsson, 2009). Lebanon did not ratify with the CRPD but adopted, prior to the convention, the Law 220 on *the Rights of Disabled Persons* referred to as law 220/2000. The law agreed in Lebanon assists people with physical and developmental difficulties and facilitates their admission to medical services and education (Article 19, Lebanon: Disability and Access to Information, 2015). Although the law's implementation is hardly noticeable, the Office for Social Development (OSD) established inclusive classrooms in several schools and improved care for people with disabilities. However, not much changed in terms of individualized plans and stigma around minority groups (Combaz, 2018; Roumanos, 2008).

In general, those who benefit from hearing aids usually have a mild-to-moderate hearing impairment in addition to communication difficulties (Curhan & Curhan, 2016). EIs are crucial for babies and children with hearing loss as well as their families. The referral after the diagnosis helps the child and their family to implement strategies for adaptation. Therapeutic interventions, family-centered interventions and amplifications are examples of EI (Störbeck, 2012).

Counselling for parents, educational interventions for both parents and children, assessments, and support are offered within EI programs (Ahmad & Brown, 2016). For those with profound hearing loss, cochlear implants are better fitted.

For millions of deaf and hard-of-hearing individuals, the stigma, access, cost and perceived overall benefit of hearing enhancement devices affect their readiness for hearing interventions (Curhan & Curhan, 2016). The WHO (2020) reports that among 466 million people worldwide

(5% of the world's population) who have disabling hearing loss and who could benefit from the use of hearing aids, only 17% actually seek help. This suggests that appropriate measures, assistive devices and support services for the optimal development and inclusion of people with hearing impairments are not widely accessible (Article 19, Lebanon: Disability and Access to Information, 2015). Affordable hearing devices and resources are scarce in developing countries (WHO, 2020). Accordingly, "new communication technologies are not a universal fix" and are not available to Lebanese citizens and families of low socio-economic status (Combaz, 2018, p. 18). Comparatively, the Flemish region of Belgium was considered one of the earliest in the world to introduce universal neonatal screening for hearing loss in 1998. The screening became systematic between 4 and 6 weeks of birth (Bosteels, Van Hove & Vandebroek, 2012).

For some, promoting assistive devices and guiding the child to specialized schools would highlight the person's disability (Lane, 1995). The mother's decision of school (mainstream, inclusive or specialized) and mode of communication is fundamentally linked to the decision involving amplification devices (Ingber, Al-Yagon, & Dromi, 2010; Meadow-Orlans, 1995). In terms of cochlear implantation or other devices, three main challenges are reported by parents: (1) the accessibility and availability of devices and services, (2) difficulties managing and sustaining different needs, (3) building collaborative relationships with professionals (Zaidman-Zait et al., 2015; Zaidman-Zait, 2007).

Mothers cope with the permanent condition depending on the meaning attributed to their child's deafness (Fadda, 2011; Spahn, Richter, Zschocke, Löhle & Wirsching, 2001; Zaidman-Zait, 2007). Also, the more the mothers learnt about the nature of deafness and Deaf communities, the more they were able to understand Deaf individuals' capabilities and abilities (Kara & Harvey, 2017). As previously mentioned, without the correct information and if the

mother is in denial, the device may be considered a cure to the hearing impairment and this may in turn cause additional disappointment (Spahn et al., 2001). However, when mothers are able to understand that hearing aids and CI have benefits and limitations, then laying down these materials would encourage “constructive action” (Fadda, 2011, p. 105). Thus, realistic parental expectations would reduce maternal anxiety and accordingly improves mother-child interactions, maternal sensitivity, shared attention, and social functioning (Fadda, 2011; Shelton, 2017). Mothers’ sensitivity to her child’s behavior is referred to as “maternal insightfulness” (Koren-Karie et al., 2002, p. 534; Oppenheim et al., 2009).

As mentioned earlier, the mothers’ attitudes, adaptation to stress, approach to interventions and motivation for communication is linked to social and cultural views (Lane, 1995). The following section investigates and explores the sociocultural perspective of deafness. The parenting attitudes towards deafness and the mothers’ coping strategies are also addressed.

2.3.2 Sociocultural perspectives of deafness

In the literature review, the importance of adopting an intersectional lens when considering the experiences of the participants in this study is highlighted. Several communities in different countries with relevant experiences were explored and presented. Examining connections and discrepancies between social categories and systems sheds light on the plethora of experiences and theoretical explanations of heterogeneous members of groups (Atelwologun, 2018). Such framework in research would thus enhance insight into specific differences and issues that could explain social injustices and inequality.

Such as in the hearing world, Deaf communities established their proper languages, arts, literature, culture, ways of Being and attitudes while taking into consideration individual differences (Böttcher & Dammeyer, 2013). As represented by the intersectionality theory

highlighted, within 90% of families with a Deaf child and hearing parents: identities are shaped and ever-changing as they engage with each other (Kusters, De Meulder & O'Brien, 2017). Deaf studies aim to increase the knowledge around Deaf ontologies and shed light on communities' way of Being (Kusters, De Meulder & O'Brien, 2017). This section explores the sociocultural perspective of deafness and its link to parenting a Deaf child in Lebanon. The choice of communication strategies and mother-child interactions are also presented.

Sociocultural perspectives of deafness and parenting

The identification of deafness affects parents in different ways, and their reactions are influenced by their cultural background which includes, among other factors, their language, religious beliefs, values, gender identities and roles, education level, and geographic location (Steinberg et al., 2019). Mothers of Deaf children's experiences and attitudes cannot be understood in isolation of their cultural and social backgrounds (Kara & Harvey, 2017). There are unique challenges associated with interacting and raising a Deaf child that lead to significant parenting stress (Lederberg & Prezbindowski, 2000). An intersectional approach towards the exploration of hearing mothers raising a Deaf child sheds light on the different layers of commonality and differences within the micro levels (Deaf communities) and macro levels (gender, race, education level, social class). There is an emphasis on the mothers' individual experiences while also describing within-group experiences and differences that arise in each culture explored (Cole, 2009). These challenges include parenting demands, finding adequate interventions, adapting to new communication strategies, consistent exchange with an array of healthcare professionals and dealing with increased expenses linked to the interventions (Zaidman-Zait et al. 2018).

As Professor Roumanos (2000) and Broughton (2018) extensively elaborated on the subject, the academic and school systems are still behind regarding the implementation of Deaf-friendly curriculums and teachings. Although Roumanos' texts and research are out of date, the current system has not changed much (Bakhos et al., 2022; Broughton, 2018). Teachers are not provided with information regarding Deaf culture nor sign language and communication. In the early years of 2000, three schools for children with special needs (such as hearing and visual impairment) were implemented (Combaz, 2018). They worked similarly as public schools and embraced the children's differences. This gave hope to many children and parents regarding their child's future.

According to the lived experiences of 7 Jordanian mothers of Deaf children four major themes were conveyed: increased perceived stigma, fear for the future, increased perceived caregiving burden, and adapting to the disability (Nazzal & Al-Rawajfah, 2018). The study sheds light on the effect and impact of society's attitude towards a person's differences on the mothers' perception of their child's condition.

In Ghana, disability is linked to evil and Deaf people are faced with discrimination and stigma because of these associations (Opoku et al., 2020). To further highlight the stigma, Deaf children's chosen name at birth either disappears or their true name is labelled with the derogatory term *mumu*, which translates to *Deaf* and metaphorically means *stupid*. Society's stigmatizing view of deafness in turn limits the person's chances to show their actual capabilities (Olusanya et al., 2007). The family's attitudes, communication barriers, poor parent-child interactions and the stigma around the disability are all risk factors for mental health problems among Deaf people and their families (Böttcher and Dammeyer, 2013; Meadow-Orlans & Steinberg, 1993; Van Eldik, 2004). According to the study by Kobosko and colleagues (2021) in Poland, parental burnout is an indicator of difficulty in coping with parenting a child with a condition, when the condition is

considered a disability. The mothers' personality trait, more specifically their openness to experience affect parental stress. For example, mothers who are cognitively active, creative, and imaginative are less prone to suffer from parental burnout (Kobosko et al., 2021).

Interestingly, the Deaf child's externalizing problems are not related to the degree of hearing loss but is closely related to the quality of the mother-child communication (Brubaker & Szakowski, 2000). If the child's preferred mode of communication was prioritized, the quality of mother-child communication is significantly improved and this in turn reduces the frustration felt by mothers and their children (Munoz-Baell and Ruiz, 2000; Roumanos, 1998). Parenting styles affected the mother-child dynamic. For example, inconsistent discipline, harsh punishment, and mothers' level of stress are positively correlated with the child's development of behavioral problems (Meadow-Orlans, 1972).

Among Korean mothers of Deaf children, several concerns and difficulties are conveyed (Park and Yoon, 2018). Mothers expressed their frustration with parenting a Deaf child, the struggle in choosing between mainstream and special education, the fear of being alienated from mainstream settings, the potential sacrifices, and the changes in values of life. They also highlighted the importance of services meeting parents' needs rather than having standardized provision of care.

In addition to the alleviation of judgments and stigma, Human Rights include the insurance of employment opportunities that are consistent with the person's competencies. There is an 80% rate of unemployment among people with disabilities in Lebanon (Article 19, Lebanon: Disability and Access to Information, 2015). This rate is due to a missing institutional adaptation, lack of anti-discrimination policies and non-existent social and medical awareness that reinforced negative prejudice (UN Committee on Economic, Social and Cultural Rights

(CESCR), 2016). Furthermore, Lebanese sign language is not a national language (Bakhos et al., 2022). This limits the access to sign language services to a great number of Deaf people. The WHO (2020) recommends the recognition of national sign languages to improve access and the availability of sign language interpreters. Nonetheless, deaf communities in Lebanon brought cohesion through the implementation of Lebanese sign language, with their proper dialects and semantics (Broughton, 2018). The language is recognized in the media, among the few interpreters and in academia in Lebanon (Broughton, 2018). These are stepping stones in the implementation of Human Rights legislation for an inclusive approach of people with hearing loss. This said, hearing mothers' attitudes and perceptions of raising a Deaf child is explored in the literature and conveyed in the following section.

Attitudes of hearing mothers towards deafness

As maternal identity is being formed and the diagnosis established, the representation of deafness as an impairment or pathological condition is influenced by the family's beliefs, the medical professionals' views and culture-bound attitudes (Bosteels, Van Hove & Vandembroeck, 2012; Kara & Harvey, 2017). Hearing parents' feelings, attitudes, and beliefs towards deafness and disability affect their experiences of raising a Deaf child and their decision-making (Fjord, 2001). Mothers were more inclined towards terminating the pregnancy when a genetic defect related to deafness was detected in the fetus (Alsulaiman et al., 2014). The study was done in Saudi Arabia, a Middle Eastern country, which follows, as Lebanon, cultural and social norms. For example, a mother would be highly concerned about having a 'handicapped' child and would worry about their future. There is a cultural belief that individuals with a 'handicap' or certain lifelong conditions could not get married and are not accepted as whole. This shows that mothers are concerned for the child's social acceptance later in time.

The unexpected news and the diagnosis are overwhelming and the child's differences are anxiety-provoking (Mapp and Hudson, 1997). The time upon hearing the diagnosis was reported as the most stressful and affected mothers' quality of life (Burger et al., 2005). As previously mentioned, loss and grief are felt by hearing mothers (Park and Yoon, 2018). The mother may go through an Existential crisis exemplified by the reformulation of her beliefs, values, attitudes and ways of Being before having a child (Arnold-Baker, 2020; Shloim et al., 2020). Also, the stigma endured around deafness negatively affected their wellbeing (Combaz, 2018; Ebrahimi et al., 2015). Negative emotions and maternal stress are reported mostly due to the lack of support from professionals and family members (Park and Yoon, 2018). Mothers' experiences of raising a child with a hearing impairment can lead to positive outcomes if they were provided with significant social support in accordance with their specific needs (Sajjad, Saleem & Aziz, 2016; Vingerhoets et al., 1993). Additionally, the more social support the mothers were offered, the more they were willing to be involved in their child's development and actively searched for interventions (Ingber, Al-Yagon, & Dromi, 2010). Accordingly, family-centered care frameworks seem adapted in offering individualized services to help parents find adequate early-intervention programs, educational, and communication frameworks available and accessible (Poon and Zaidman-Zait, 2014).

Burger and colleagues (2005) examined parental stress of two study groups during the pre-examination time T1 and at a later time T2 when a cochlear implant or hearing aid was placed 7 months after the first test. For parents of children with a cochlear implant, significant impaired quality of life and heightened stress was reported at T1 but no significant difference at T2. This improvement is explained due to the child's adjustment and parents' relief and acceptance of deafness. Parents of children with hearing aids reported significant heightened parental stress and

impaired quality of life at T1 and T2. These findings are explained in few studies exploring the meaning-making of mothers of children with disabilities (Zaidman-Zait, 2007). In the study conducted by Ebrahimi and colleagues (2015) with 90 Iranian mothers, 23% felt ashamed and 42.2% experienced pity towards their own child. Nonetheless, 76% of the sample believed Deaf children can function normally and hold a job. As previously mentioned, the mothers' emotional response to their child's diagnosis may have an impact on their motherhood experiences and sense of self (Arnold-Baker, 2020; Lecciso, Petrocchi, & Marchetti, 2012). Also, the diagnosis can come as a relief when mothers were dismissed by medical doctors or family members when they noticed their child was behaving differently (Fjord, 2001).

Hearing mothers' reports also illustrate the frustration experienced in their interaction with their Deaf child (Hadadian, 1995; Meadow-Orlans, Sass-Lehrer & Mertens, 2003). They noticed the stigma and discrimination against this minority group, despite the execution and implementation of policies and inclusion strategies (Cagulada & Koller, 2019). Brubaker and Szakowski (2000) showed that hearing mothers of Deaf children did not necessarily have harsher punitive attitudes or more dysfunctional parenting behaviors than hearing parents of hearing children. Additionally, as part of their gender role, identity and understanding of their child's deafness, mothers felt responsible to care for and attend to their Deaf child's rehabilitation (Arnold-Baker, 2020; Zaidman-Zait et al., 2018). In other words, and as previously mentioned, mothers are given additional pressure to be involved in their child's overall health, doctors' appointments and developmental activities. Adjustment strategies and coping skills differ according to the family's ethnicity and socio-economic status (Kumar & Rao, 2008; Mapp & Hudson, 1997; Steinberg et al., 2019). These differences are also explained by the discrepancies

of access to social services and other supporting systems and the knowledge around their child's needs (Meadow-Orlans, 1995; Roumanos, 2000).

Mother's coping strategies

Mothers are in need of valid and reliable information, especially when they experience deafness first-hand in the family (Jamieson, Zaidman-Zait & Poon, 2011). Professionals are expected to provide treatments and interventions for the child's optimal development (Munoz-Baell, and Ruiz, 2000). By means of parental networking and strong professional relationships, parents felt more at ease with their child's disability (Vingerhoets et al., 1993; Jamieson, Zaidman-Zait & Poon, 2011). Parental guidance and support, whether formal or informal is also a major concern for parents of Deaf children (Spahn et al., 2001). Mothers may not have optimal support networks to deal with their child's deafness (Calderon & Greenberg, 2000). Within Lebanese communities, mothers significantly lack social and professional support (Roumanos, 1995). These needs can be consistently met through awareness sessions, workshops, lectures and support groups (Meadow-Orlans, 1994;1995). The choice of hearing enhancement devices, the choice of school, communication mode and possible biases professionals may have towards one intervention over the other, all constitute maternal stress (Martin et al., 1987).

Empirical studies did not solely report negative descriptions and experiences: hearing mothers of Deaf children and other disabilities have no differences in reported stress levels and adjustment problems compared to control groups constituted of H-H and D-D dyads (Mapp & Hudson, 1997; Steinberg et al., 2019). This was mainly due to the time taken for mothers to accept their child's diagnosis, the child's developmental age and improved communication skills (Lecciso, Petrocchi & Marchetti, 2012; Meadow-Orlans, 1997). Similarly, 90% of 268 participating mothers in the study by Martin, George, O'Neal and Daly (1987) reported accepting

their child's deafness after 12 months of being informed (Spencer, 2000). Thus, with time and dedication to their child's development, hearing mothers did not view their life and their child's disability as a burden. They saw opportunities for their child and fuel for positive change (Park and Yoon, 2018). Guidance from professionals and social support helped mother in the decision-making regarding their Deaf child, relieved the stress associated with the auditory impairments and positively affected mother-child interactions (Meadow-Orlans & Steinberg, 1993; Roumanos, 2000; Spencer, 2000).

Among Hispanic and Black South African mothers religion and faith were conveyed as coping mechanisms (Steinberg et al., 2019). According to religious beliefs, deafness (and disability) is accepted as a gift of God and empowerment (Kara & Harvey, 2017). Among Hispanic mothers, a minority group in the United States, religious beliefs, prayers, and faith played a role in their decision-making process (Steinberg et al., 2019). For mothers in Ghana, in the study by Opoku and colleagues (2020, p. 9), one mother expressed: "*I have left everything in the hands of Allah; he knows best*". Thus, finding solace from God helped accept their child's condition.

In a Jordanian study by Al-Makharmeh (2016), a balanced view of hearing impairment is conveyed: the social constructivist model. The concept acknowledges the social dimension and argues that disability needs to be seen as a social construction as defined and perceived by society. This includes the social issues and barriers to social inclusion that a Deaf person may experience.

In conclusion of this section, mothers and families affect the Deaf child's development of speech and language which in turn is considered crucial for their cognitive and social-emotional development (Calderon, Bargones & Sidman, 1998). As depicted in the literature, the challenge

for mothers to communicate and understand their Deaf child constituted a major source of maternal stress (Opoku et al., 2020; Jamieson, Zaidman-Zait & Poon, 2011). The mother's social support, maternal stress, choice of language, involvement with their child, mother-child synchrony and reciprocity all affect the child's development as well as the mother's wellbeing (Calderon & Greenberg, 2000).

2.3.3 Communication

Several studies revealed that hearing mothers found difficulties communicating and understanding their Deaf child (Carey-Sargeant & Brown, 2005). These challenges in turn negatively affected the amount and quality of reciprocity (Lederberg & Prezbindowski, 2000). For example, deleterious outcomes occurred when mothers adopted the role of interpreter as an alternative to learning a shared communication system within the family (Kluwin & Gaustad, 1991). Varied factors may explain these differences compared to hearing dyads, exploring these differences seems important in building strategies to overcome those difficulties (Lederberg & Golbach, 2002).

In their research, Meadow-Orlans and Moores (1990) examined typically-hearing parents of Deaf children and noticed that before the diagnosis, mothers were already using visuospatial cues, touch and gestures to attend and engage with their child. Interestingly, the diagnosis affected the mothers' confidence and ability to accept their role as the 'mother of a Deaf child'. This identity and new sense of personhood may come as a shock and the mothers' natural instinct to interact with their child is squelched upon hearing the diagnosis (Arnold-Baker, 2020; Meadow, 1975). The debate concerning the use of sign language versus speech is a cultural one (Humphries et al., 2019). Also, education and knowledge is related in a complex way to family income, resources and leisure time (Kluwin & Gaustad, 1991). For example, the idea that

deafness is directly related to delay in development is a misconception. Linguistic deprivation is the cause of developmental delay rather than hearing impairment (Humphries et al., 2019).

Prior to the interventions and depending on the mother's beliefs and hope for her child's future, a mode of communication is decided. Thus, following the mother's decision, the child's education may include: (a) aural-oral mode, (b) total communication mode that includes spoken language, sign language, lip-reading and visual communication, or (c) sign language solely (Ingber, Al-Yagon, & Dromi, 2010). Upon conveying the diagnosis, doctors expect mothers to make a decision regarding the child's language and education models. They are encouraged to make an immediate choice as there is a short window of opportunity to learn spoken language (Fjord, 2001). However, the critical period for language development is debated in neuroplasticity literature (Flaherty, 2015). Auditory-verbal training is usually suggested to allow better adaptation to assistive hearing devices and improve language acquisition. Thus, the Deaf identity is at times indirectly formed by doctors holding binary views (Roumanos, 2000). The pressure, confusion, sense of loss, and grief are amplified during that period; mothers are expected to digest the diagnosis and make a decision. In Denmark, parents are told that their child does not need to be fixed (Fjord, 2001). This approach makes it easier for mothers to accept the diagnosis. It seems the decision is about having a hearing device or [highlighting *or*] the decision to use sign language which portrays the binary oppositions between the medical perspectives and sociocultural models. Embodiment needs to be valued while Deaf identity and exploration are encouraged. The mother adapts to the image she projects from social constructs (Koren-Karie et al., 2002; Lecciso, Petrocchi & Marchetti, 2012; Van Eldik et al., 2004).

Reciprocity and mother-child's joint communication are positively correlated with positive communication patterns and the child's cognitive and social-emotional development (Calderon,

Bargones & Sidman, 1998). However, the interaction between hearing mothers of Deaf children is reportedly more problematic compared to mothers and children sharing the same hearing status (Ahmad & Brown, 2016). The longitudinal comparative study conducted by Lederberg and Golbach (2002) with mothers of children with hearing loss assessed parental stress when their child was 22 months, 3 years old and 4 years old. The difference in stress levels between hearing mother of Deaf children and hearing mothers of typical-hearing children is significant at 22 months of age. This reveals that around the starting age of language acquisition, the mothers' concerns and challenges in communication emerge.

EI programs, therapy, choice of school, mode of communication, and the choice of rehabilitation may all influence the mothers' and families' attitudes toward their child's deafness (Zaidman-Zait et al. 2018). The Deaf child's linguistic delays, the dyad's discrepancies in their sensory abilities, and the hearing mothers' heightened levels of stress are possible factors affecting the dyads' interaction (Carey-Sargeant & Brown, 2005; Lederberg & Prezbindowski, 2000). The Deaf child's language acquisition, learning and development of secure attachment depend on the quality, intensity, and type of communication established with their mothers (Ahmad & Brown, 2016; Bowlby, 1973). Zaidman-Zait and colleagues (2018) found that Israeli-Arab hearing mothers of Deaf children are encouraged to be involved in their child's interventions. On one hand, when mothers take the lead in their child's rehabilitation, they usually have their child's language development in mind. They also act as 'case managers', have a significant role in advocating for the Deaf community and maintain their role as primary caregivers (Erbasi et al., 2018). On the other hand, some mothers were more passive in their involvement with their child's rehabilitation and were not necessarily actively engaged with professionals in the provision of care (Zaidman-Zait et al. 2018).

Mothers and families of Deaf children find it instinctive to want to integrate them in the hearing world. It is also important to encourage the Deaf child to be exposed to the Deaf world, notably their natural language (Kara & Harvey, 2017). Unfortunately, as most Deaf children are born to hearing parents, they do not naturally acquire sign language at home (Vaccari & Marschark, 1997). The only way for mothers to learn sign language is limited to enrolling their child in a specialized school (Opoku et al., 2020). In several countries, sign languages are accepted and recognized which highlights the importance of exposing children and their parents to sign language for effective development and communication (Napier, Leigh & Nann, 2007). It is necessary to explore the different modes and their effect on mother-child relationships and dynamics as well as the child's development. The exploration of the frequency and nature of utterances, language, touch, gestures and visual attentions employed by hearing mothers and Deaf children (H-D) compared to hearing mothers and hearing children (H-H) is important.

Differences in communication between H-D (hearing mothers of Deaf children) and D-D (Deaf mothers of Deaf children) dyads

This section highlights the possible variations in communication between mothers and their Deaf child. Different dyads of H-D are examined and compared to D-D. A plethora of factors, such as parents' attitudes and beliefs towards their child's deafness, affect the choice of mode of communication in the household whether signed or spoken (Kluwin & Gaustad, 1991; Mindel & Vernon, 1971). Early parent-child interactions and linguistic stimulations mark the stepping stones for healthy attachment patterns, emotional and social development in adulthood as the child grows (Roumanos, 1999; Vaccari & Marschark, 1997; Van Eldik et al., 2004).

Among H-H and D-D dyads, communication strategies are naturally established, either oral mode of communication or visual-spatial mode of communication (Vaccari & Marschark, 1997). Experiences are different when dyads do not have the same hearing capabilities. As

previously mentioned, language development and social interactions become challenging and problematic (Lederberg & Prezbindowski, 2000; Meadow-Orlans, 1997). Many hearing parents have limited or no access to formal and informal support related to their child's optimal learning opportunities such as sign language (Vaccari & Marschark, 1997). Also, the quality of behavior and interaction between H-D and D-H dyads differed negatively compared to H-H and D-D dyads. Thus, the factor that hinders the quality of communication is the mismatch of hearing status rather than deafness or the level of hearing loss (Meadow-Orlans, 1994; 1997).

Researchers highlighted the language delay of Deaf children and found that a 3-year-old Deaf child had the language development of a hearing 22-month-old child. Also, as they grow older, Deaf children seem to compensate for the language delay by using gestures more frequently than hearing children (Lederberg & Everhart, 1998). Consequently, mothers used more gestures with their Deaf child compared to their use of gestures with hearing children. This way, mothers try to model linguistic abilities in the hope of facilitating cognitive development (Lederberg & Everhart, 1998). In the study by Lederberg and Everhart (1998), typical-hearing mothers of Deaf children adapted to their child's communication needs. Specifically, visual communication was highlighted and touch was also used for attention-getting. These are elements significantly used by H-D compared to H-H (Sajjad, Saleem & Aziz, 2016). Interestingly, whether the child was in a total communication program or oral language, hearing mothers predominantly used speech as a means of communication (Lederberg & Everhart, 1998).

Mothers of Deaf children were significantly more protective and controlling of their child compared to hearing mothers of hearing children (Meadow, 1975). Research also showed that Deaf children of hearing parents were more prone to behavior problems compared to hearing children of hearing parents (Schlesinger & Meadow, 1972). This was explained by the negative

attachment patterns developed by the child, poor parental communication, and unrealistic expectations among other factors (Brubaker & Szakowski, 2000). Meadow (1975) also reported that mothers of Deaf children found it hard to establish clear boundaries, had difficulties in being consistent, and felt less confident with their Deaf child compared to mothers of hearing children. Frustration may build-up in mothers who are unable to interact and understand their Deaf children which in turn impacts their perception of adequacy and parental role (Opoku et al., 2020).

The more the family showed cohesiveness and adaptability, the more the Deaf child was at ease with communication which was reflected in the family's dynamic (Rivadeneira, Silvestre & Laborda, 2015). The family structure is thus highlighted. Mothers reported that the family was less frustrated when communication with their Deaf child incorporated sign language (Lederberg & Everhart, 1998). Therefore, mother-child communication is developed naturally depending on the child's needs. EI programs should focus on facilitating the learning environment for successful nonlinguistic communication. Nonetheless, learning sign language is as difficult as learning Japanese or Chinese for an English-speaking person. The study by Napier, Leigh and Nann (2007) found that even mothers with the best intentions to learn sign language, had difficulties communicating with their child because the curriculum is not particularly adapted to the family's context and needs. The mother's and deaf child's worldviews may be different: a hearing person does not necessarily learn or acknowledge what is it like to solely communicate or understand in sign language nor what is it like to live as a Deaf person (Ebrahimi et al., 2015). So, parents are encouraged to be active in the Deaf community and social events, especially in a natural signing environment and where sign language is optimally taught (Napier, Leigh & Nann, 2007; Roumanos, 1998; 2000).

In summary, though the means may be different, the communication strategies of H-D, D-H, H-H and D-D have similar functions: ensuring emotional availability and conveying understandable information (Roumanos, 1995; Spencer, 2000). In other words, parents' readiness to support their children in exploring their environment and conveying their needs improves parental stress and bonding (Jean et al., 2018; Paradis and Koester, 2015). Additionally, the choice of communication depends on the country's openness and access to sign language teachings as well as the parent's willingness to include visual and spatial modes of communication as part of their child's development (Article 19, Lebanon: Disability and Access to Information, 2015; Roumanos, 1995).

Parental Communication strategies

One of the major sources of stress reported by mothers was linked to the worry associated with their child's developmental transitions and their own identity crisis (Arnold-Baker, 2020; Brubaker & Szakowski, 2000). The choice of school, whether specialized or mainstream, affected the child's use of language and integration in the Deaf or hearing world (Roumanos, 2000). Restricting the child's access to their natural language and Deaf world negatively impacts their developmental milestones and their sense of selfhood (Cooper, 2016; Kara & Harvey, 2017). Thus, communication difficulties between parents and their child negatively affected optimal linguistic development and increased parental stress (Mapp & Hudson, 1997; Park & Yoon, 2018). Interestingly, parent-child dyads connect through "synchrony and reciprocity" early on (Vaccari & Marschark, 1997, p. 794). The communication mode (visuospatial and/or oral) is not the key factor that predicts the stepping stones of children's early development but rather the language stimulation and strategies implemented by the parents (Meadow-Orlans, 1996; Meadow-Orlans, Spencer & Koester, 2004). However, mothers and families of Deaf children can better

understand their child's world by using and learning sign language (Napier, Leigh & Nann, 2007). Parental guidance is needed to improve and establish a support system for healthier interactions that would naturally lead to less stress among dyads.

Several studies showed differences in reciprocity between hearing mothers of Deaf children compared to hearing dyads; mothers of deaf children were more likely to be overbearing when conversing (Lederberg & Prezbindowski, 2000). In turn, Deaf children were more passive with their hearing mothers compared to hearing children (Carey-Sargeant & Brown, 2005). Effective communication strategies can be developed through play and story-telling; mothers of Deaf children can build a rapport by incorporating sign language and appropriate strategies (Napier, Leigh & Nann, 2007).

A number of studies highlight the importance of family-centered approach to treatment and effective EI for children with disabilities including hearing loss (Jamieson, Zaidman-Zait, & Poon, 2011; Meadow-Orlans, Sass-Lehrer & Mertens, 2003). Optimal child development and parental wellbeing is promoted through collaborative and supportive partnerships formed between parents and professionals. Positive attitudes in turn positively affect the child's development and adaptation as well as promote the family's wellbeing (Hyassat, 2012). Growing up in a family where hearing parents made efforts to include sign language in their mode of communication resulted in healthy relationships and significant positive overall outcomes in parenting attitudes, stress, and quality of life (Kluwin & Gaustad, 1991; Mapp & Hudson, 1997; Van Eldik et al., 2004). Nonetheless, hearing parents have more difficulties learning sign language which also impedes on their child's learning journey (Roumanos, 1995). Additionally, signing hearing parents often have limited abilities to communicate comfortably and fluently, and they would usually sign exclusively with their Deaf child rather than involving other siblings too (Meadow-

Orlans, Sass-Lehrer & Mertens, 2003). A person can grasp around 30% of verbal speech through lip-reading, which makes it difficult and challenging for Deaf people to fill in the gaps (Ebert & Heckerling, 1995). Thus, connection and communication are restricted. Both parties may not be clearly understood and have difficulties expressing their needs (Meadow-Orlans, 1994; Meadow-Orlans, Spencer & Koester, 2004).

In summary of this section, mothers of Deaf children report higher levels of stress compared to mothers of hearing children (Jean et al., 2018; Mapp & Hudson, 1997; Park & Yoon, 2018). This was in part linked to the stress associated with the diagnosis, the pressure in choosing the mode of communication prospectively employed, the choice of school and other major decisions related to the child's future (Arnold-Baker, 2020; Brubaker & Szakowski, 2000; Opoku et al., 2020; Stern, 2020). Although parental stress was reportedly heightened and decreased the quality of life at the time of diagnosis, cochlear implantation or use of hearing devices improved parental well-being and adaptation (Burger et al. 2005; Zaidman-Zait, 2007). Researchers explained this improvement in terms of time of adaptation, adjustment to the child's hearing impairment, and the use of resources improving the child's disability and the family's quality of life.

2.4 Rationale of the study and research aims

Terms and ideologies emerged such as 'deafhood', to highlight the sociocultural ideology of Deaf communities that have their own values, beliefs and ways of Being (Ladd, 2003). However, do the concepts of acceptance and tolerance apply to Deaf people and families in Lebanon, as minority groups? The determination of the 'critical' age of deafness is now appointed as "prelingual onset" (Meadow-Orlans, 1980, p. 7), meaning before the acquisition of language,

which is recognized at the age of two years old. According to the president of the Lebanese Federation of the Deaf (LFD), parental guidance and support is crucial for the educational and social development of Deaf children in Lebanon. Language acquisition and hearing loss are major factors in human development. Improvements cannot be witnessed if the needs and requirements of parents and their Deaf child are not clearly stated and met (Erbasi et al., 2018; Zaidman-Zait et al., 2018).

No empirical research is found for this particular population in the region except for few medical studies and outdated reports on the educational system for people with various disabilities. The literature on hearing mothers' experiences and perspectives on raising their Deaf children remains scarce.

This study's implication highlight the misconceptions of hearing loss to mothers and professionals in contact with this population. The lived experiences of mothers in Lebanon would shed light on the challenges and misinformation witnessed in the country. Expanding awareness and the normalization of hearing loss would in turn decrease the stigma around deafness.

This research project constitutes the first qualitative study examining the lived experiences of mothers of Deaf children in Lebanon. Information presented in this study would be a starting point in establishing clear-cut guidelines for current and prospective parents trying to adapt and understand their Deaf children's world. The aims of the study are:

- Examine, using a phenomenological approach, the lived experiences of hearing mothers raising a Deaf child in Lebanon between 10 and 15 years of age. More specifically, an Interpretative Phenomenological Analysis (IPA) is employed to investigate the participants' narratives.
- Shed light on hearing mothers' everyday life, examine the challenges and advantages of

parenting a Deaf child while focusing on the concept of motherhood.

- Explore the interactions and communication experiences of hearing mothers and their Deaf child.

The reasoning behind the choice of participants and their child's age will be discussed in details in the next chapter.

2.4.1 Value of findings and aims

This study's findings would add value to the literature of Deaf mental health and motherhood in Lebanon. EI programs are available in Lebanon in private institutions only (Article 19, Lebanon: Disability and Access to Information, 2015). They provide parents with professional support and counselling throughout their child's first years of development (Sajjad, Saleem & Aziz, 2016). EI programs are crucial for hearing mothers of Deaf children as the diagnosis can be overwhelming and they may not have any experience nor knowledge around deafness (Ahmad & Brown, 2016).

The mothers' involvement in intervention programs and rehabilitation reduced the stress experienced and improved the mother-child communication and their understanding of deafness (Zaidman-Zait et al., 2018). In terms of the level of involvement, when mothers felt anger and frustration concerning their child's deafness, they were less likely motivated to be involved in their intervention (Ingber, Al-Yagon & Dromi, 2010). Also, mothers may need information around optimal assistive devices and awareness about interventions necessary for their child's development (Sajjad, Saleem & Aziz, 2016). Adapting to these changes may be crucial. In terms of the choice of assistive devices, in the study done by Ahmad and Brown (2016), all mothers encouraged their Deaf child to wear assistive devices. Time and perseverance are needed to adapt

to the auditory device and the auditory sensations triggered. Mothers and family members may also need to adapt to the device's presence.

The study's findings would also shed light and guide mothers, practitioners and educators for optimal mother-child communication strategies. Swisher (2000) found that Deaf mothers' responsiveness and turn-taking is significantly more notable compared to hearing mothers. The researchers examined the communication and interaction strategies of mother-child dyads during free play. The Deaf child's request is conveyed through eye contact and Deaf mothers are naturally aware of the crucial means of expression and the development of ToM to improve social interaction (Lecciso, Petrocchi & Marchetti, 2012; Swisher, 2000). Consequently, Deaf mothers markedly responded with clear facial expressions or sign language to initiate contact (Spencer, 2000). However, hearing mothers' reports documented more directive and intrusive behaviors with their Deaf child compared to H-H dyads and D-D dyads (Meadow-Orlans, 1996; Vaccari & Marschark, 1997). This consequently negatively affected the child's autonomy and social development and increased maternal stress (Gregory, 1976; Meadow-Orlans, 1994). It is thus important to encourage and guide mothers to improve the use of responsive interaction strategies (Ahmad & Brown, 2016; Swisher, 2000). The reciprocal communications highlight the use of facial expressions, successfully getting the child's attention using visual cues, touching, repetition, and not covering their faces. The degree of responsiveness positively affected the Deaf child's language maturation, play and development of social cues such as joint attention and ToM (Lecciso, Petrocchi & Marchetti, 2012; Lederberg & Prezbindowski, 2000).

As stated earlier, nuanced strategies and nonverbal language such as tactile and visual cues are relayed from the parents to ensure effective communication as well as optimal linguistic and emotional development (Calderon & Greenberg, 2000; Gregory, 1976). Few strategies such as

taking turn, light tapping, signaling and attention-switching are modelled by hearing parents during the Deaf child's first year of development (Mindel & Vernon, 1971). Although these communication breakdowns and strategies differ from those of hearing dyads or deaf dyads, this does not necessarily form negative affect and difficulties in social development among H-D dyads (Lederberg & Prezbindowski, 2000). Interestingly, with time, hearing mothers improved their use of effective communication strategies with their Deaf child (Paradis & Koester, 2015). Thus, mothers gradually adjust their form of communication in the household (Vaccari & Marschark, 1997). Also with time, mothers learnt to employ strategies to gain their child's attention and use facial expressions more clearly (Ahmad & Brown, 2016). Nevertheless, mothers highly preferred their child using their voice rather than intonations while gesturing (Ahmad & Brown, 2016). Mothers' involvement and the improvement in communication skills and learning additional skills concerning deafness is crucial in encouraging and improving the bond with their Deaf child (Carey-Sargeant & Brown, 2005). This in turn reduces the stress related to the communication difficulties and improves the child's psychosocial and language development (Calderon, 2000).

2.5 Summary

The literature mostly focuses on the medical model of deafness by laying down possible assistive options and medical outcomes. There are only a limited number of empirical studies exploring the lived experiences of children diagnosed with deafness and their parents. The lack of studies done in Lebanon around the Deaf community further highlights the need to explore this minority group. In this chapter, the topic of interest was addressed: the choice of the population was clarified, maternal identities and the coping processes of being a mother of a Deaf child, the conceptualization of deafness, the communication differences among mother-child dyads and the communication strategies employed.

The literature conveys the critical window of learning for children's language acquisition. To ensure promising outcomes, Deaf children's communication strategies need to be addressed early on, within the first two years. Interaction and communication patterns play a crucial role in the child's cognitive and psychological development as well as affect parental stress. Deeper understanding of the mothers' lived experiences and meaning given to their experiences of raising a Deaf child allow professionals and practitioners to address specific issues and needs.

The mother's first encounter with the possibility of her child having a hearing impairment engenders a plethora of emotions. Formal and informal support is needed to inform, enlighten and guide mothers in making optimal decisions for their child's future. The mothers' own understanding of deafness, language development, assistive hearing devices and other matters faced in the Deaf world are validated and deepened. The aim would be to explore these meaning-makings and lived experiences to establish strategies and frameworks to help reduce possible maternal stress and guide them through the coping process.

This project is qualitative in nature and a phenomenological research method was chosen as an optimal theoretical framework. Interpretative Phenomenological Analysis (IPA) is defined as a co-constructed depiction of the lived experiences of mothers instead of a structured, rule-bound process (Bosteels, Van Hove & Vandebroek, 2012). A phenomenological exploration and analysis of the meaning-making and lived experiences of mothers of Deaf children is facilitated using this framework.

The study's potential implications for professional practice, pragmatic knowledge about motherhood and raising a child diagnosed with deafness, and the basis for optimal programs trainings and interventions for practitioners are central. Also, the implications for mothers and parents of Deaf children are underlined.

The following chapters include the study's design and methodology, the findings of the interviews done, and a discussion of the results precedes the conclusions and suggestions for further research and practice.

Chapter 3: Methodology and methods

This chapter outlines the epistemological position adopted for this research project. Different qualitative research methods are evaluated and considered for this study. This led to the detailed presentation of the qualitative research framework chosen and conveyance of the systematic approach involved in data collection and analysis.

3.1 Qualitative Research

The conceptual framework was devised along the formulation of the research protocol and an optimal research design was constructively chosen to develop the project. The study aimed to explore the lived experiences of hearing mothers and examine their meaning-making. Thus, a qualitative research was deemed more suitable. According to Husserl (1970), intentionality pertains to the person's perception of their thoughts, memory, imagination, feelings and emotions. I intended to conform to the 'emic' approach (from the subject's perspective) as a basis to this research and as defined in anthropology following the linguist Kenneth Pike's term (Morey and Luthans, 1984). Thus, each participant's depictions, meaning-making and narratives are conveyed rather than following pre-set categories by which the researcher would have tried to transpose. The emic stance gives way to a more etic approach for the analysis. Thus, the insider's viewpoints, depictions and explorations would be translated to a more etic/outsider view (from the observer's perspective) as both approaches complement each other for a well-rounded qualitative research (Morey and Luthans, 1984). This is attained by means of my own reflexivity and bracketing skills of preconceived ideas.

3.1.1 Epistemology of the qualitative paradigm: the philosophical underpinning theory of descriptive and interpretive phenomenological research

The focus of qualitative research is the depiction of human experiences and their meaning-making. Qualitative research englobes a myriad of different theoretical perspectives distinguished for varied types of qualitative inquiries (von Eckartsberg, 1986). For the purpose of this study, the researcher prioritized the “methodological appropriateness as the primary criterion for judging methodological quality” (Patton, 2002, p. 92). As developed by Husserl (1970), the phenomenological descriptive approach represents individuals’ own perceptions and beliefs of a certain phenomenon. A myriad of qualitative research approaches exists such as ethnography, grounded research theory, and phenomenology. Ethnography is mostly used for anthropological, sociological and psychological enquiries to describe cultural depictions (Moustakas, 1994). Ethnographic studies are long-term and researchers take an active role and immerse themselves in the setting of the group studied (Van Maanen, 2011). Thus, with the combination of direct observations and first-hand experiences, the researchers are able to understand, interpret, and deduce coherently the context and dynamics of the culture investigated (Moustakas, 1994). Another qualitative approach examined for this study is grounded research theory. This approach looks at understanding the world from the ‘ground up’. In other words, researchers aim to construct a theory grounded in the data and where the data constitute people’s narratives, thoughts and experiences (Charmaz & Belgrave, 2007). What is considered truth is people’s depictions. Whatever emerges from the persons’ experiences is taken as is and theories are generated according to the meanings given to these experiences (Charmaz, 2006). Regarding interpretative phenomenology, Heidegger’s (1996) ideas shed light on the existential researcher’s role in synthesizing the art of hermeneutics from the participants’ experiences while being loyal to their own narratives and descriptions (Shinebourne, 2011). As mentioned, phenomenology aims to attend to individuals’ unique lived experiences as narrated and

expressed (von Eckartsberg, 1986). This research method constitutes both descriptive and interpretative processes of analysis as it allows the phenomenon to unravel. The researcher then encouraged the persons enquired to actively engage and interpret the phenomenon experienced (Pietkiewicz & Smith, 2014). However, Heidegger's phenomenology moved from a solely descriptive approach of people's experiences to the interpretation of these experiences (Matua & Van Der Wal, 2015). Hermeneutics was broadened, so the concept of Being-in-the-world is highlighted rather than merely knowing and exploring the world (Heidegger, 1996). In other words, the transition to interpretative/hermeneutics approach encourages the researcher to investigate the underlying meanings of experiences rather than taking the narratives at face-value (Reiner, 2012).

To further clarify the terms used, hermeneutic phenomenology is a methodology and an umbrella term englobing the hermeneutic circle of interpretative process and capturing the essence of phenomena – essence-seeking (Dahlberg, 2006). As a method of qualitative analysis underlying philosophical foundations, Interpretative Phenomenological Analysis (IPA) is a much narrower model than hermeneutic phenomenology (Smith and Osborn, 2004). IPA seeks to explore and investigate a particular phenomenon through individuals' narratives and experiences (Larkin, Watts & Clifton, 2006). The study consequently follows an understanding of phenomenology as a philosophical and research approach. Each participant's understanding and own interpretations of their lived experiences are investigated while also implicating my own interpretations. The individual's essence of their experiences is maintained (Husserl, 1970; Moustakas, 1994). In hermeneutics, following Heidegger's (1996) concept, interpreting human experiences summarizes prior understandings and knowledge. Thus, bracketing personal awareness is not necessarily guaranteed (Reiners, 2012).

3.1.2 Choice of research approach: Interpretative Phenomenological Analysis (IPA)

The project pivots around understanding the phenomenon of parenting a child with a hearing impairment in Lebanon thus extracting the thoughts and feelings in the mothers' personal world. The choice of an appropriate phenomenological research method is crucial to the credibility and validity of the proposed research question and phenomenon examined (Reiner, 2012). The research question conceptualized for this project is open-ended and exploratory in nature thus, the research problem guided the choice of research method (Miles & Gilbert, 2005). From a Heideggerian perspective, IPA as an appropriate methodological framework aims to depict and examine the mothers' experiences (Pietkiewicz & Smith, 2014). This design conveys "comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the essences of the experience" (Heidegger, 1996; Moustakas, 1994, p. 11). As part of IPA's idiographic nature, an in-depth analysis of single cases and examination of individual perspective of the study participants in their unique contexts is paramount. Instead of solely focusing on the frequency of themes suggested, the meaning, content of the narratives and participants' depictions are prioritized and are central to the analysis (Smith & Osborn, 2004). IPA can be compared to ethnographic studies where small communities are closely investigated for detailed descriptions about cultures (Pietkiewicz & Smith, 2014).

Interpretation is a subjective matter and the aim is to capture the mothers' interpretation of their own experiences of raising a Deaf child following an etic approach (Morey & Luthans, 1984; Pietkiewicz & Smith, 2014). In other words, empathy and putting oneself in the person's shoes are beneficial when trying to transcribe the participants' intentions and attitudes towards phenomena. The researcher has an active role in the interpretation and is expected to translate the

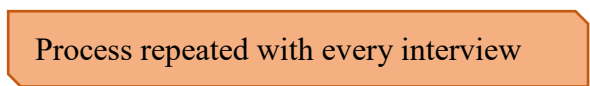
depictions into comprehensible themes while staying faithful to the original meaning-making (Pietkiewicz & Smith, 2014). Thus, a reflective interpretation of transcripts and interviews is needed to understand the experiential gestalt of mothers of Deaf children while taking into account Deaf communities and their respective history and context. According to the dual interpretation or double hermeneutics of the analytical process of IPA, the participants firstly make meaning of their experiences and, secondly, the researcher interprets that meaning to try to make sense of the participants' meaning making (Pietkiewicz & Smith, 2014; Smith & Osborn, 2004). In other words, the researcher tries to explore and decode how individuals make sense of their worlds and tries to understand the participants' perspectives.

Employing IPA brings about several limitations including the sample size, limitations regarding the transferability of findings and researchers' biases and interpretations (Smith & Osborn, 2007). The sample size depends on 1) the researcher's willingness and commitment in providing deep analysis of a single case study, 2) the richness of individual cases, and 3) pragmatic constraints such as time constraints or access to participants (Pietkiewicz & Smith, 2014). As explained by the concept of dual hermeneutics, the findings are viewed as valid accounts of my interpretation of the participant's interpretation of their experiences.

Subsequently, these accounts are considered proper to the sample in this study and would be misleading to generalize to the wider population.

Figures 1 and 2 below depict the analysis process that lead to the integration and synthesis of every interview which in turn formed a final set of themes and subthemes.

Figure 1. Analysis process done with every interview.



Process repeated with every interview

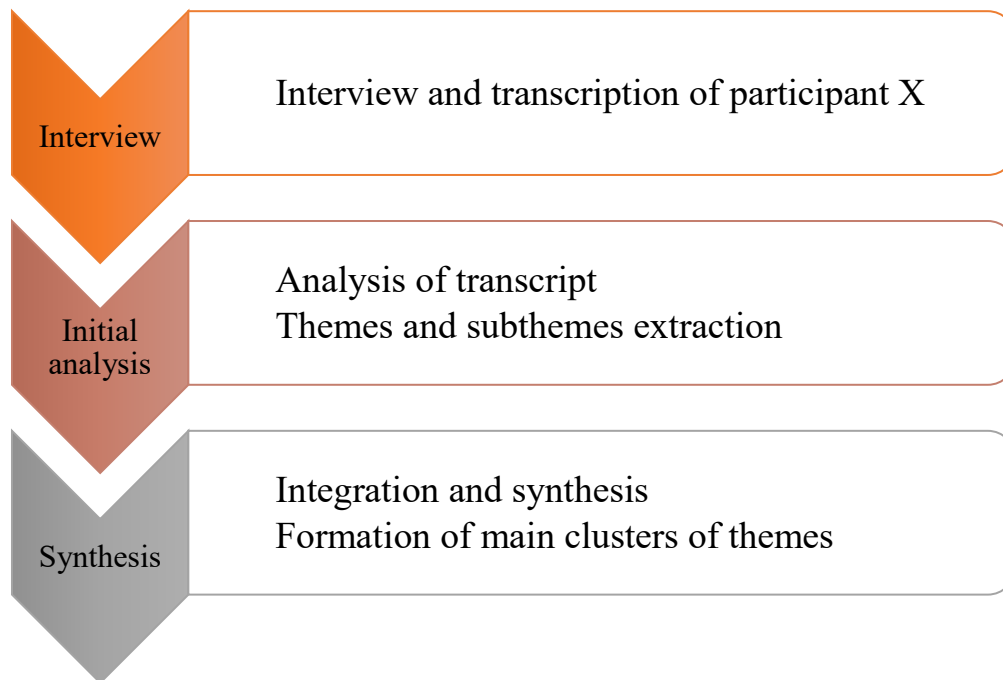
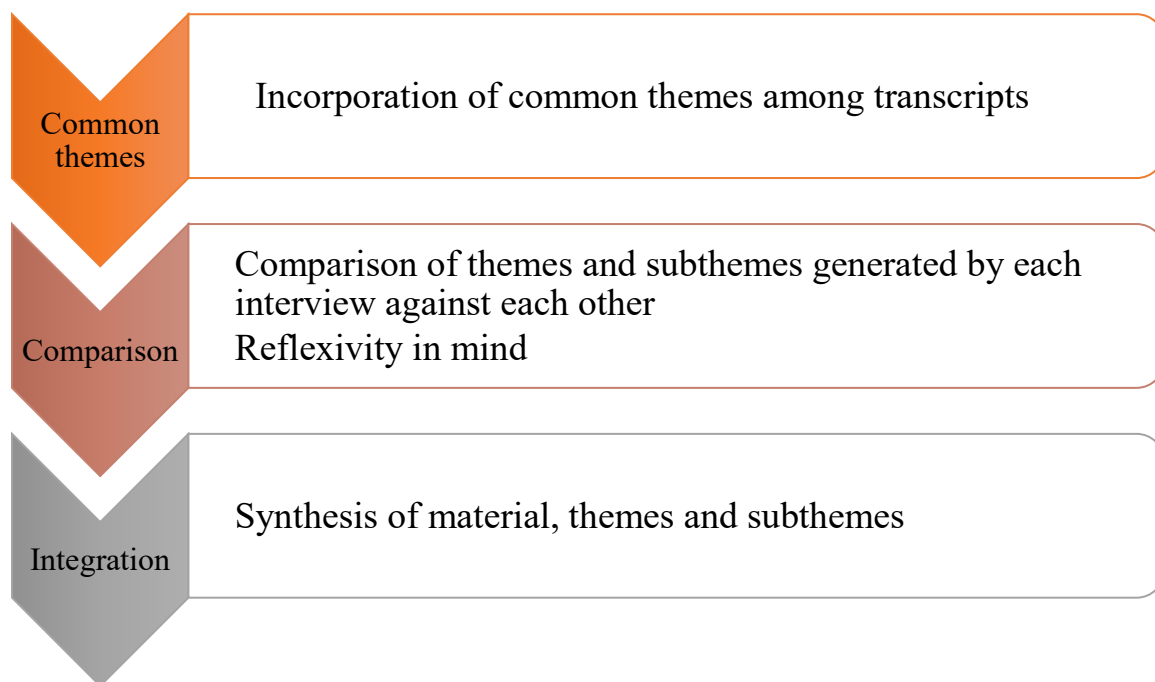


Figure 2. Process of integration of the findings from each interview.



The transcription and analysis of each interview was executed individually. Themes and subthemes are shown with the incorporation of field notes and observations. Also, the researcher's reflexivity during analysis and the whole process ensured transparency and rigor.

This process was repeated with each interview. As depicted in Figure 2, the themes and subthemes were evaluated, compared and synthesized with each other. Furthermore, in the integration part, comparison and refinement of findings of different interviews and transcripts generated a cluster of themes and subthemes representative of the data collected. The aim was to refine the data and findings to better answer the research question and transmit relevant and useful information.

In summary, interpretative phenomenology is used to explore the meaning-making and lived experiences of a certain phenomenon under study, while keeping in mind prior knowledge of the question investigated (Reiners, 2012). Descriptive phenomenology is employed to describe a certain phenomenon while pre-conceived ideas, assumptions and prior knowledge are set aside, bracketed (Husserl, 1970, van Deurzen, 2012). However, bracketing and impartiality are unavoidable since I gained knowledge, have assumptions and became enmeshed with the experiences and area of interest.

3.1.3 Recruitment procedure

Qualitative research studies intend to identify and explore in-depth information and experiences (von Eckartsberg, 1986). Clear inclusion criteria were deliberately stated so as to rigorously contact relevant informants. The sampling strategy is thus labelled as purposeful sampling (Strauss & Corbin, 1990; Suri, 2011; Patton, 2014). The participants' background information was not matched but the aim of the sampling was to increase the credibility of the results following strict characteristics proper to the phenomena studied (Palinkas et al., 2015). Thus, purposeful sampling enables the access to these information through informants in the field to ensure efficiency and validity in the study proposed (Suri, 2011). For this study,

deliberate sampling increases the probability of recruiting participants particularly suitable for the phenomena explored (Park and Yoon, 2018). The participants in this study were recruited through the LFD (2020). The LFD was founded in 2016 and is run by Deaf persons in Lebanon. Their mission is to network and collaborate with Deaf federations in the region and internationally to spread awareness about Deaf cultures in Lebanon. They also aim to attain and implement the rights for the Deaf as declared through the law 220/2000 to empower Deaf people in Lebanon (Article 19, Lebanon: Disability and Access to Information, 2015). The federation presides the Learning Center for the Deaf (LCD), a non-profit organization established in 2001 that provides one of the only available family-based and comprehensive Early Intervention Programs in Lebanon. They also offer services such as sign language courses, professional interpretation services to facilitate communication with the Deaf community as well as improving the social aspect of Deaf people's life by holding seminars, workshops, and trainings.

On May 30th and June 1st 2019, a colleague and I organized the first Deaf Mental Health Awareness Conference for clinicians and the first Deaf Mental Health workshop in Beirut, Lebanon with the support of the LFD and LCD. Thus, I was able to reach out to people in the Deaf community through the LFD and inform them about the prospective research study. More than forty Deaf adolescents and adults were present and I was able to interact and meticulously observe parents of Deaf attendees. I realized that none of the mothers knew Lebanese Sign Language and were consequently left out of the loop concerning their child's means of communication and their role in the community. With time, I cultivated a professional relationship with the LCD director and he was informed of the research project I intended to undertake. Accordingly, I sent the participant information sheet via email (Appendix A) to circulate it to potential participants. My first intend was to follow a convenience sampling

strategy but realized that I would be collecting information from mothers who are easily accessible rather than expanding the breadth of the recruitment to include mothers who did not attend the workshop. The aim is to ensure and optimize the recruitment of participants who are willing to provide in-depth information related to the phenomenon of interest and enable the formulation of comprehensive understandings (Palinkas et al., 2015). Thus, there is an attempt to capture both detailed (in-depth) and wide (breadth) examination of the phenomenon through informants' narratives and interpretation.

3.1.4 Participants

An informed decision was made concerning the dissertation sample number. Data sufficiency and information extraction were kept in mind throughout the interviews. In qualitative research, the sampling procedure aims to recruit informants willing to share enough relevant data to broadly and deeply capture the phenomenon enquired (Elliott & Timulak, 2005; Miles & Gilbert, 2005). Concerning the sample size, instead of determining the needed number by using power analysis, qualitative research commonly rely of the criterion of saturation (Strauss & Corbin, 1990). In IPA, as Pietkiewicz and Smith (2014) clearly point out, random sampling may be counterintuitive when few participants are interviewed. There was a pragmatic consideration during the recruitment process, and I had difficulties contacting potential participants as this is a relatively rare phenomenon in Lebanon. Mothers are skeptical to take part in a study, let alone on video since the pandemic started. Thus, the sample is in part formulated and defined according to the women who were prepared to be included (Smith and Osborn, 2014). For the current dissertation, the sample consisted of 5 mothers of Deaf children. The sample included the participant interviewed for the pilot study. The inclusion criteria are: 1) The mother is hearing and bears one child diagnosed with a hearing impairment; 2) The child is

diagnosed with congenital hearing loss before the age of three (before acquisition of speech and language); 3) The child should be between 10 and 15 years old at the time of the interview; 4) The child may or may not have a cochlear implant or a hearing aid; 5) The mother and her child do not have a diagnosis of any other associated physical impairment.

The reasoning behind the choice of the child's age is as follows: The current study focuses on retrospective depictions of mothers of Deaf children. As their child grows and the critical early years pass, mothers witness different stages of development and reflect on their reactions, attitudes, thoughts and feelings. The research aims to depict these self-reflections that may reveal their coping processes. Since the children are diagnosed with congenital deafness, time would have passed since hearing the diagnosis and the time of the interview. Each participant would reflect on the decisions made concerning the language and choice of school. Also, in hindsight, the mothers may also share their experiences that led them to this point in time with their child. In hindsight, the participants' lived experiences and meaning given to those experiences may have changed and I aimed to depict these changes in the study as well.

Several studies report that the level of education and household income have an impact on the attitude and steps taken towards a child's disability (Hall et al., 2018; Jean et al., 2018; Meadow-Orlans, 1994). Thus, the research aspired to recruit and interview mothers of similar socioeconomic backgrounds and level of education to ensure the sample homogeneity and depict similar background information and experiences. However, due to the sampling strategy, participants recruited did not necessarily have similar backgrounds. This is also representative of mothers of Deaf children in Lebanon as part of the LCD community.

Participants' profile

Names and identifying information were changed and pseudonyms were used to

protect the participants' and their Deaf children's anonymity and confidentiality. Mothers in the study were first informed about the study information over the phone. Research documents were sent via email, and they were given time to think about participating. The participants' demographic information is presented in the table below (Table 1).

All the mothers are married and two participants are in full-time employment while three identify as stay at home mothers/wives. The participants ranged in age from thirty-six years old to fifty-one years old and the mean age of the sample recruited is 40.4 years old. All participants are Lebanese and live with their respective families in the capital, Beirut. Concerning the educational level, one participant completed high school and enrolled in a technical school, three participants completed a bachelor's degree, and one participant earned a Masters' degree.

All participants have a child diagnosed with congenital deafness and all children were reportedly diagnosed with severe to profound hearing loss. Children diagnosed with deafness ranged in age from ten years old to thirteen years old. Three children have hearing aids on both ears and these children are identified as male. The two remaining Deaf children have cochlear implants and are identified as female. One of the participants did not have any other children, two of the participants have 1 other child, one participant has 3 other children and one participant is raising 4 other children. One participant reported seeing a family psychologist three times per year as part of the support program. Concerning communication, all participants reported the employment of spoken language with their children, and four of the five participants indicated that their child learnt sign language.

Table 1. Participants’ demographic information and Deaf child’s general information

	Marital Status	Highest level of education	Employment status	Age of Deaf child (in years)	Sex of Deaf child	Other children	Hearing assistive device
1	Married	Master’s Degree	Full time employment	13	Male	3 older	Hearing Aid
2	Married	Technical School	Stay-at-home mother	12	Male	1 older	Hearing Aid
3	Married	Undergraduate degree	Stay-at-home mother	11	Female	4 older	Cochlear Implant
4	Married	Undergraduate degree	Stay-at-home mother	10	Male	None	Hearing Aid
5	Married	Undergraduate degree	Full time employment (flexible)	11	Female	1 younger	Cochlear Implant

*Participant did not include sign language in their child’s learning. She enrolled her daughter in a mainstream school (not inclusive) with the *United Nations Relief and Works Agency (UNRWA)*.

3.1.5 Interview procedure

Through purposeful sampling, seven mothers contacted the LCD manager by phone and informed her of their wish to participate in the study after reading the participant information sheet. I then contacted the participants by phone to clearly explain the protocol and expectations of the interview while making sure the mothers contacted met the eligibility criteria before proceeding. I also answered any question regarding their participation. The interview was scheduled at a day, time and location convenient for each participant on their own. The participants were given the choice to undertake the interview either in a quiet room at the LCD or in a private room in co-working spaces in Beirut. One potential participant had a Deaf child younger than 10 years old and was not included in the project. Another potential participant retracted her participation as she was not comfortable being on video at home. All other five potential participants followed the inclusion criteria stated for the study. Two participants were interviewed in March 2020 and the first participant was seen in February 2020. As the COVID-19 pandemic breakout reached Lebanon and since the wellbeing and protection of the participants and I are of utmost importance, two participants were interviewed via Zoom in September 2020.

Before the start of each interview, confidentiality procedures were explained in details and participants were given the choice to sign the written consent form (Appendix B) or withdraw their participation after reading the participant information sheet. Once the consent form signed, I administered a short questionnaire to collect demographic information (Appendix C). I took the opportunity to get to know the participants better by asking the demographic questions myself

rather than asking them to fill the form beforehand. The participants were clearly informed that the meeting is audio recorded and the interviews did not last more than ninety minutes in the language they felt comfortable with: Arabic, French and/or English.

Experiential and qualitative data are obtained from retrospective in-depth semi-structured interviews with mothers of children with congenital hearing impairment and no other impairments (von Eckartsberg, 1986; Fitzpatrick, et al., 2008; Mueller, 1946). As a qualitative research pertaining to IPA, an open-ended strategy for gathering data from the participants is established. In other words, the “inquiry is flexible and carefully adapted to the problem at hand and to the individual informant’s particular experiences and abilities to communicate those experiences, making each interview unique” (Elliott & Timulak, 2005, p. 150). Semi-structured interviews are prepared in the attempt to answer specific questions while allowing space for exploration and dialogue (Patton, 2014). A sample of the interview schedule and open-ended questions used for the semi-structured interview is presented in the Appendix D. The sample questions were considered as an interview guide that helped me without imposing a given structure to the open-ended enquiry. The list of questions was sent to all the participants prior to the interview. Although the questions were open-ended and interviews almost free flowing (such as in person-centered therapy), data collection had a clear focus guided by the specific research question (Miles & Gilbert, 2005). Few questions were asked in the closing of the interviews such as: “Would you like to add anything else?” and “Do you have other questions in mind?” following the format presented by Park and Yoon (2018).

A positive rapport is facilitated with the participants and the flexibility of questions allowed “the interview to go into novel areas, and it tends to produce richer data” (Smith and Osborn, 2004, p. 59). As mentioned in previous sections, following Heidegger’s (1960) concept of

hermeneutics and interpretive phenomenology, I gathered information of the topic enquired while keeping in mind preconceived ideas, assumptions and knowledge about the literature (Moustakas, 1994). Prompts were employed to elicit in-depth exploration and narratives relevant to answer the research question. The open-ended questions helped the mothers wander with their thoughts and experiences explored (Maxwell, 2008). Each mother's role in the study is highlighted: they are empowered and considered as co-researchers.

I was in charge of the interviewing and the transcribing. The recordings were transcribed directly after the interview then translated to English. To maintain and conserve original and conceptual meanings behind the narratives, all the transcripts were back-translated. All translations are certified by a sworn translator. The translated and original interview transcriptions were sent to the participants for approval. All the translations were validated by the participants with no amendments.

3.2 Interviewer's written observations

During the interviews, I was encouraged to note observations on a notebook, such as body language, pauses, and the overall feelings and thoughts during and after each encounter. These notes and observations provide additional information regarding incidental experiences and they helped during the interviews to encourage the participants in expanding few ideas shared. The validity and meanings intended by the participants are verified and clarified concurrently. The notes are descriptive and observational while also including my own interpretations and reactions to the context, the topic explored and thoughts shared at specific moments (Elliott & Timulak, 2005). Kvale (2006) explained and highlighted the different factors influencing interview dynamics in qualitative research. I was mindful about the power dynamic that may play a role

throughout the data collection. The aim was to decrease the illusion of mutual interest and bring to awareness the research purpose. In other words, “the research interview is not a dominance-free dialogue between equal partners” (Kvale, 2006, p. 484). Throughout the whole process, intersubjectivity was highlighted: I made sure that my potential interpretations were aligned with the participant’s meaning-making. I kept in mind the power asymmetry and avoided using the term ‘dialogue’ during the interview as it is misleading and manipulative.

The initial interview formed the first foundation and starting point for the prospective data collected. The aim is to obtain relevant and crucial information to better synthesize the current dissertation project. Each interview is unique in the sense that each participant had their specific and individual experiences of raising a Deaf child.

3.3 Data analysis

The depiction of each participant’s rich description of is a crucial part of qualitative research studies. The aim is to offer a clearer in-depth understanding of the data collected by finding meaning through themes used to interpret the phenomenon under examination. The mothers’ complex feelings and thoughts are illustrated and unraveled while referring to the original transcript and direct words associated with their experiences. During the interviews, I directed the questions and flow of information collected so as to get as much relevant data and experiences as the participant was also willing to convey. An emic approach of data collection and analysis recognizes each participant’s role as a co-researcher while integrating an etic approach where the researcher would also be reliable and constitute a suitable judge for adequate analysis (Morey and Luthans, 1984). The latter is successful while staying faithful to each participant’s unique experiences and depictions. The analysis’ objective is to identify relevant themes from the

transcripts and data collected through the interview process (Moustakas, 1994). It is thus a flexible process integrating my input in the form of interpretation, self-reflection and understanding of the emerging findings (Elliott & Timulak, 2005). Systematic and prudent analysis and organization is achieved to make the checking and auditing of the dataset easy to trace and locate. While information and data are captured from different participants, the goal is to integrate the results and reflections to form a coherent piece following the scope of the research study (Strauss & Corbin, 1990).

Although highlighting flexibility, qualitative research has a structure for the analysis. Appropriately following a framework influenced by IPA, the audio recordings' transcriptions were done directly after each interview and the field notes were matched throughout the process. This is part of the primary step for the data analysis: data preparation (Elliott & Timulak, 2005). Thus, the recordings and field notes including observational notes are all under investigation simultaneously for the analysis. As stated by Elliott and Timulak (2005, p. 156), this part is "about the ultimate categorization of the categorization". The same process is replicated with each transcript. Emerging topics were gathered as long as they were significant for the research process and study scope (Smith & Osborn, 2004). Also, emerging themes were grouped and synthesized systematically to keep the authentic representation of each mother's meaning-making and experiences. A synthesis of the phenomenon is thus systematically and conscientiously documented. Each theme, domain, and category depict and communicate the essence of the phenomenon (Miles & Gilbert, 2005).

3.4 Validity and reliability

Validity and reliability of a research study are key factors in the assessment of the credibility and trustworthiness of the findings presented. According to Yardley (2008), four key criteria are presented to demonstrate validity and rigor in qualitative research: the study's sensitivity and acknowledgment of the context, the commitment to the research question and research process, transparency and the study impact and importance. I am able to demonstrate sensitivity to context by being mindful of the participants' socio-cultural context of the research, geographic context, linguistic context, setting and perspectives that could influence what they say and how I, as a researcher, interpret what they say (Whittemore, Chase, & Mandle, 2001). Qualitative studies are thoroughly scrutinized by researchers as bias can be more prevalent compared to quantitative studies (Brink, 1993). In quantitative studies, the research validity refers to "the precision in which the finding accurately reflects the data" and reliability is defined by the coherent and systematic application of the analytical procedures (Noble and Smith, 2015, p. 2). Additionally, rigor and trustworthiness are examined (Long and Johnson, 2000). The following strategies are employed to ensure rigor and validity.

3.4.1 Self-reflection to ensure rigor and validity

Self-reflection and bracketing accounted for biases and subjective interpretations that may influence the findings (Moustakas, 1994). It is now clear that bracketing of preconceived ideas and knowledge on behalf of the researcher go against the understanding of interpretative phenomenology. Also, obtaining 'objective' knowledge is a quasi-impossible and a flawed understanding in qualitative research (Yardley, 2008). The incorporation of the participants' and researcher's interpretation bring about the rich investigation of the phenomenon (Miles & Gilbert, 2005). To reduce any bias or preconceived ideas about a certain part of information, I made sure to

note throughout the analysis, all reasoning and standpoints about the mothers' narratives. Additionally, in the field notebook, I ensured the demonstration of my thought processes during interpretations and transcript analysis (Noble and Smith, 2015). This way, the discrepancy between the transcripts' interpretation and the investigator's own input are cleared. The aim is not to eradicate personal experiences and assumptions but rather bring to consciousness these insights, possibly use them in the inquiry process while not actively influencing the research findings (Maxwell, 2008). As the first criteria to improve rigor, I was aware of the participants' contexts and way of Being. I was curious about their description of the environment they live in and interact with. I was also mindful of the research context as the start of the pandemic may have affected the mothers' wellbeing, location and access to services (schools, hospitals and clinics) as well as their readiness to share as they were at home.

3.4.2 Triangulation of data sources

The triangulation of data sources enabled the accurate synthesis of information provided from the interviews, observations, field notes and feedback from other professionals. In other words, in order to capture accurate reactions, meanings and interpretations of the text, different sources of information were incorporated. The field notes and memos noted depict the participants' body language, the different aspects of my experiences throughout the interviews and data analysis that are mostly in accordance with the study aims. I also consulted a colleague, a sign language interpreter working in Mental Health in London, to offer feedback that added richness to the interpretation while also noting possible biases. The professional's feedback is not necessarily more valid than the investigator's interpretations, but they encouraged looking at the data with a different angle for some of the themes presented. The combination of these data

sources enabled the generation of insights and reflections that helped form thorough and robust findings.

3.4.3 Existing theory and research

Another validity testing strategy employed for this project is about extensively looking and comparing existing literature. Peer-reviewed articles, dissertations, and organizations' reports were scrutinized. By using the literature, information relevant and connected to the aims of the research study established a framework and expectations of the phenomenon explored. The research process as well as the study's impact and aims were kept in mind (Yardley, 2008). Existing literature's rigorous process of analysis and existing categorization were useful in the formulation of this thesis (Elliott & Timulak, 2005). In other words, these pieces of information were not the focus or basis of the project but rather starting points in the development of the research inquiry and the study conceptualization (Maxwell, 2008).

3.5 Ethics

The research process applied the ethical code of the *United Kingdom Council for Psychotherapy (UKCP, 2019)* and the *British Psychological Society (2014)* as well as the UKCP (2018) safeguarding guidelines. The purpose of ethics in qualitative research is to guide the study in tackling any initial and ongoing challenges to meet the objectives of the research while maintaining the right of the research participants. The primary consideration is to preserve the participants' autonomy, dignity, respect for their privacy and confidentiality. Highlighting ethics in qualitative research sheds light on the importance of power relationships throughout the whole research execution. After explaining the purpose of the study thoroughly and before the start of the interview. All participants were given the choice to sign a written consent form for their participation and were informed of the interview's recording. Also, the mothers were informed of

their right to withdraw their participation at any point in time during the project without any consequences until data is anonymized. The study aims, duration expected for participation, and confidentiality strategies are included in the written consent form.

Due to the sensitive nature of the research topic, painful memories and emotions may arise during the interview. Participants were nonetheless able to discuss their experiences and share their thoughts and feelings in a confidential and respectful setting. I invited the participants to openly notify me if they felt any discomfort or distress at any time. In the Lebanese culture, topics around Mental Health and disability are considered taboo, and they often bring feelings of uneasiness. Furthermore, existential issues may arise and I was therefore sensitive and mindful of how the questions were affecting the mothers. For example, the participants' body language and tone of voice was attended to, even during the interviews on Zoom; the way they held themselves while they were reflecting. I am aware that my role in this project was purely for the research and not as a therapist. Nonetheless, an empathetic stature and counselling skills were employed at times to help participants feel contained and safe (Pietkiewicz & Smith, 2014; van Deurzen, 2012). A debriefing form was handed out to all the participants and were also sent via email with my details and the supervisor's. The debriefing form included a list of recommended Mental Health centers and organizations if they wished further psychological support.

I followed the Data Protection Act 2018 (UK Legislation, 2018) to handle all information and personal data conveyed by the participants. A project code was assigned for each participating mother and I was in charge of the data transcription. Identifying information were changed to protect anonymity. The mother's name, her child's information, other names mentioned, and any identifying information were changed to ensure privacy and confidentiality. All data provided were transferred to an encrypted USB stick and the original recording was deleted upon

transcription. All personal information presented by the mothers, including the signed consent forms, are stored in a locked drawer separately from the other files, such as the field notes, and will be destroyed after 10 years upon the study submission.

3.6 Methodological reflexivity

The following subsections present my self-reflections during the interview and analysis process. The aim was to highlight my thoughts, feelings and assumptions about the mothers' narratives, the experience of interviewing them and analyzing transcripts.

3.6.1 Personal reflexivity

Reflexivity as part of qualitative formulations is useful to reduce biases and possible personal insinuations articulated by the researcher. Also, reflexivity is crucial to explore how my role as a researcher may have impacted the interaction with the participants during the interview and reflect on the data analysis process (Shinebourne, 2011). This research is the continuation of my learning journey about Deaf culture and motherhood. I have multiple interests in this research topic as a psychotherapist in-training living in Lebanon, a person who learnt sign language by choice and curiosity. I am using this knowledge to raise awareness and allow Deaf Lebanese people to access psychological therapies and health services. My concern around having a Deaf child grew with time given that 90% of children with a hearing impairment are born to hearing parents (Vaccari & Marschark, 1997). Experiencing a war first-hand in 2006 and an explosion in 2020 also highlighted the different senses we take for granted. Many people in Lebanon unfortunately lost their sight, hearing or limbs during this war and recent blast. I never gave meaning or importance to my senses as they were simply there and they were relatively perfectly functioning. I was considered a 'normal-looking' child. I see the world and experience

my surrounding differently now. The connection I have with my body and senses is heightened and I am appreciating them.

Ever since I can remember, I was always mindful and empathetic towards people who were excluded for their differences. Those differences would range from weight, hair color, physical disability, socio-economic status and intellectual abilities. I was in a school that included children and families from different backgrounds. I remember how scary and worrying it was to be possibly left out and *othered*; without any friend. Reflecting back on my school years, I remember wanting to belong to a group, acting and looking like the majority of the girls in my class. I witnessed the repressed emotions and isolation ensued with some classmates and I always wondered what their parents thought about this. I am sure none of the parents send their kids to school hoping they would be bullied or rejected. I projected this idea onto my younger brother as I would worry about him being the target of bullies. This definitely meant that I held a position as a researcher that assumed that being different engendered hardships in our society.

3.6.2 Reflexivity of the Interview process

Before the first interview, I practiced the questions I prepared with a fellow classmate to get an idea of how I will handle the note-taking, my concentration and focus, and the technical problems that may arise during the interviews. These questions can be found in the Appendix D. I gained more in confidence and awareness after this mock interview. The actual interview process required full attention as I was attending to the participant's narratives, body language and energies in the room. As mentioned, due to the lockdown and the COVID-19 restrictions, I was forced to schedule and hold two interviews through video. Observing and interpreting their body language and non-verbal communication was harder. One of the mothers was holding the phone up to her face and the other one placed it in front of her. I could not see much of their

body. I nonetheless noticed when they were fidgety and attended more to their facial expressions. I was also conscientious of their tone of voice and their voice fluctuations.

The interview and questions progressed naturally as the mothers were readily open to share their experiences and did not need much prompting. Compared to the clinical setting I am used to, I found my role as an interviewer interesting. I was attending and focusing on the person's narratives as I would usually do in the therapy room but I did not look to have any clinical input. The interviews were not about their mental health but about their lived experiences, their dynamics with their Deaf child and their family, their motherhood experiences, and notably the challenges of living in Lebanon while raising a Deaf child. I felt I had an active stance during the process as the interactions were moving effortlessly. I had the interview schedule in front of me all along yet allowing the mothers to open up freely. I did not feel the need to redirect the conversation as their narratives were relevant. I was mindful of keeping a neutral position to avoid suggesting any standpoint and not lead the conversation in a specific direction.

I was keen in providing each mother with a safe and contained space. The setting helped in maintaining the interaction private and confidential as no echo or anyone could interrupt us. The room where the three face-to-face interviews took place was at a co-working space in the capital, Beirut. The area was privatized for the interviews. The setting includes a café where anyone in the premises can order and take it to their reserved areas. The space is especially friendly, well-lit and inviting. The three participants directly made a comment about the *nice vibes* the place had. I was also very pleased of the room: it was as well-lit, large, with pastel-colored walls and furniture and had comfortable chairs. It portrayed the space I was trying to

create and it was definitely an optimal setting. The neutrality, privacy and warmth of the space were useful for conducting the interviews.

Concerning the two interviews held on video, I felt I was not in control of the space nor the environment. I was also worried about the internet connection and was aware that this would probably be an obstacle. I asked the participants to choose a suitable space and time where they would feel comfortable expressing themselves freely without being interrupted nor worrying about someone eavesdropping. The mothers confirmed their connection at home was stable and did not find any trouble finding a quiet and private space. During both interviews, I did not feel any differences compared to the face-to-face format except for the body language considerations mentioned earlier. It seemed that I was in their intimate space and I made sure to conduct the interviews at the office to maintain professional boundaries. One of the mothers sat in her balcony by the garden and the other participant felt comfortable in her living room. I managed both interviews as I did with the previous ones to preserve a systematic and controlled process to some extent. Information-presentation and the debriefing process were uniform at all times to give all participants equal chances of receiving similar information.

I made tremendous efforts not to have any input by keeping my words and expressions neutral but in few instances, I wanted to enquire more about certain anecdotes but realized it would be off the scope of the study, thus refraining from going deeper into the experiences. I also did not want to look like a robot and kept my reactions true to myself. I comforted the mothers when they needed support and reassurance. I made sure to keep the researcher's hat on and proceeded without any therapeutic interventions. Even through video, I allowed silences when the mothers needed to stay with their feelings and provided a safe space to cry.

At the beginning of the first interview, I noticed myself mimicking or mirroring what the participant was portraying. For example, if she was talking in an upbeat manner, I found myself enquiring in a higher pitched and enthusiastic voice. This observation allowed me to re-calibrate my behavior and keep a professional and neutral stance all along. A lot of what the mother was portraying resonated in me and I empathized with what she experienced such as people's looks and curiosity and her reaction to her child's deafness. On other occasions during other interviews, I attended to thoughts such as 'that is a Lebanese trait' and 'this is a culture-bound behavior' during the narration. For example, several mothers described the doctors' behaviors and motives when the diagnosis was made. The mothers felt the doctors were business-oriented and did not care much about the human part of the process. They noticed the doctors and practitioners were highlighting the costs rather than guiding them to optimal rehabilitation routes. I understood the mistrust felt towards medical professionals and I thought about my worries if I ever have a child with a certain condition. One of the mothers considered herself lucky for being in contact with an audiologist and surgeon who were humane. This information instinctively reminded me that a lot of practitioners in the field genuinely dedicate their expertise, time and support to their patients. The Hippocratic Oath was maintained which also brought faith back to the medical world when it comes to Deaf health in Lebanon. I wondered if there was a baseline for the improvement of these services and if I could get ahold of the doctors committed to their patients' best interest and wellbeing. During the interviews, I was reminded about the death of a child they longed for, the child they waited for. I was reminded of the mothers who described the pain of losing a child. The indescribable and inevitable pain was translated into tears for all of them.

Another topic to consider and given the method of analysis relying on the researcher's understanding of the individual's experiences: clarifications during the interviews were earnestly enquired. I would not take any of their statements and experiences at face value. The aim was not to assume I understood what the mothers were explaining. This in turn helped in remaining faithful to the participants' lived experiences. I did not presume that when the mothers talked about the lack of support from the family, they intended to talk about their husbands for example. For most of them, their own mother's lack of encouragements and reassurance affected their way of Being around their child and coping process. In summary, horizontalization and giving the participants' statements equal value helped in staying with the mothers' narratives rather than assume what seems to be important to them.

At the end of the interview, one participant expressed her wish to follow up with me in a therapeutic setting and I had the surge of anxiety concerning boundaries. I reminded myself that my role in this setting is purely for research purposes. Additionally, at the beginning and at the end of the interviews, I clearly informed the participants of available psychological services if they felt the need for further support. I handed each one of them and sent by email, a list of centers and hospitals across Lebanon that offered free or low-cost psychotherapy sessions and other mental health services. Making this statement and clarification decreased the stress I felt around the possible dual role that participants might perceive.

3.6.3 Reflexivity of the Analysis process

As a childless woman and a person who has not been exposed to Deaf or hard-of-hearing relatives, I was mindful of this during and after the interviews. The narratives were intriguing to me and I was keen in looking into them further as the mothers unraveled their own experiences.

Consequently, during the analysis I had this feeling where I almost had a 'blank slate' to start from with no personal and lived experiences. Nevertheless, I could not bracket the knowledge and information I gathered through the different articles and studies I read to formulate the study and literature review. However, since no previous research was published on the lived experiences of mothers of Deaf children or any of this sort in Lebanon, I found it challenging to highlight relevant themes that may be important to underscore.

The process of IPA as a method of analysis seemed systematic at first. The qualitative nature of the study is stimulating and demands interpretation without being too subjective. It seems at times that I wanted to find 'unique' units or themes so as to pinpoint possible culture-bound behaviors, beliefs and attitudes. I thus made sure to closely follow the analysis process by reading and re-reading the narratives to truly grasp each participant's lived experiences and meaning-making of their journey. I documented my thoughts and feelings during the interviews in a notebook and distinctly wrote my reflections during the analysis. I approached the data in a horizontalization approach to phenomenology and kept the focus on this particular set of information while bracketing preconceived and/or possible judgements. This helped highlight assumptions made during the interviews while keeping in mind, and in-text, my interpretive analysis.

I am particularly intrigued by most of the mothers' positivity and enthusiasm in their narratives and wondered if their words were calculated so as to show a 'positive' image of Deafness and parenting a Deaf child. This is apparent with the first participant I encountered. I kept in mind that this particular mentality may be Middle Eastern, where mothers are expected to present their best assets and would go as far as exaggerating the positive aspects of their children's life and achievements. I wondered if the mothers were compensating for their child's

condition by showing this positive image. Were they maybe compensating for the guilt they felt? Did they feel responsible for their child's Deafness and needed to convey deafness in a positive light? I also wondered if the participants were amplifying and elaborating on their child's strengths so as to compensate for the impairment. I bracketed these preconceptions too during the analysis so as to not bias the interpretation and relied on the mothers' narratives and meaning-making. Due to my background as a psychologist in-training, I wanted to put these interpretations and space for interventions on the side so as not to delve too deep in the clinical aspects of the transcripts' content and participants' behaviors.

During the analysis process and given the nature of the research, I was particularly attuned to the mothers' reactions to their child's deafness. I made sure to also attend to other fundamental worlds. For example, for four participants, the family and society's reaction to their child's deafness generated a plethora of feelings and thoughts. They were keen on being advocates for the Deaf community in Lebanon. Thus, in existential understanding and following Emmy van Deurzen's (2012) description of the four basic dimensions of human existence, the themes regard the mothers' interactions with their social world and were influenced by their personal world. The mothers' reactions to their family's worries and concerns of their child's future did not form an obstacle and allowed them to project progress and success.

3.7 Summary

A deeper understanding of the lived experiences of mothers of Deaf children in Lebanon is presented in this study. IPA is identified as the optimal and relevant research method for the study's objectives. I englobed the role of the interviewer and transcriber and it is well-defined along the research progress and interviews. The research process and data collection as well as participants' recruitment were clearly stated in this chapter. Each participant received, via email,

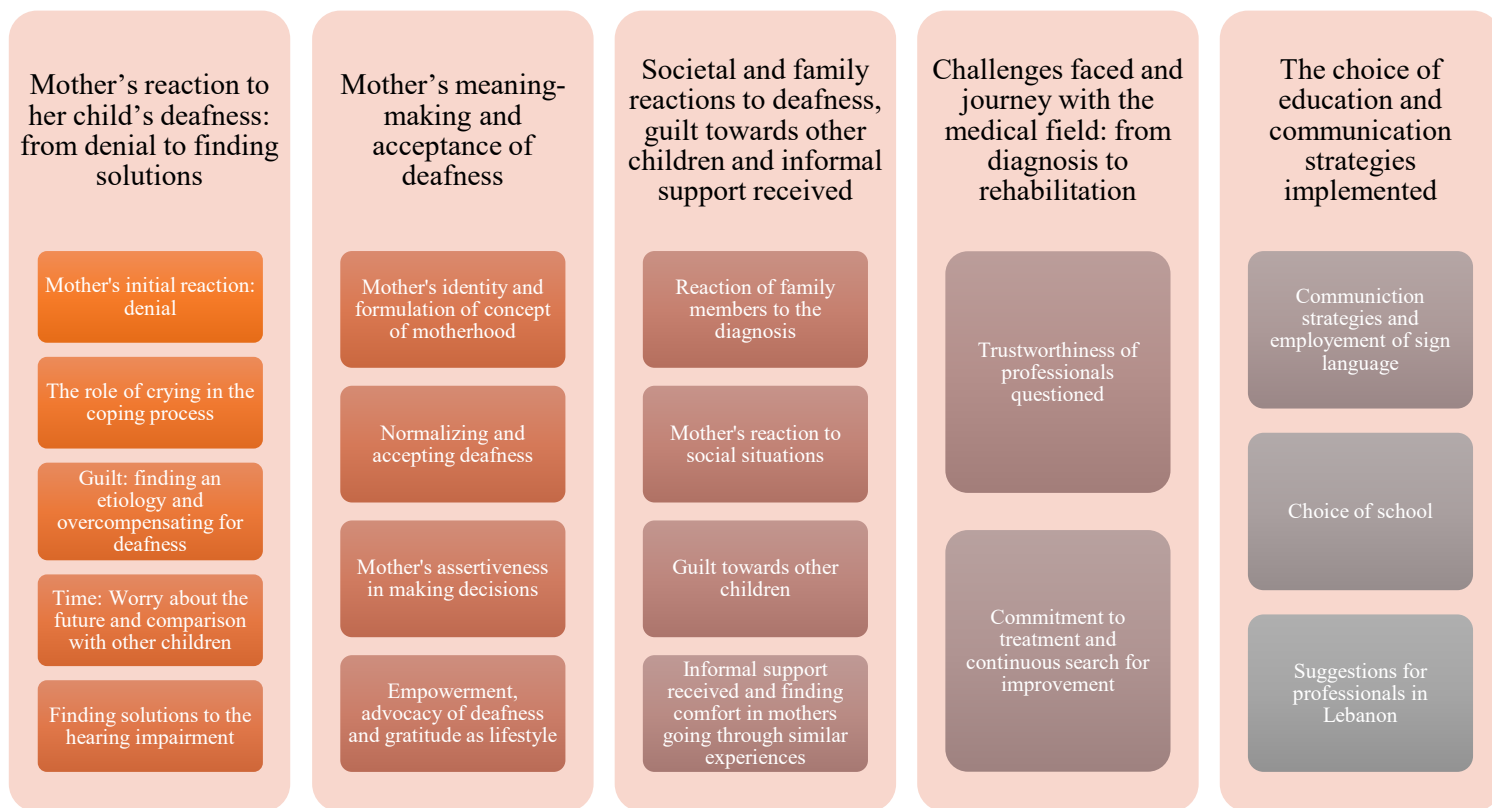
all the necessary documents related to their participation in the research, including the interview schedule. I ensured the protection of each mother's identity and information conveyed by separating and anonymizing all identifying information from the transcripts and forms. Subjective experiences and participants' rich descriptions were depicted using open-ended enquiries. As the interviews were completed and transcriptions obtained, the data analysis was accomplished and reported. The following chapters present the detailed results and findings that lead to the exploration of the research question and study objectives. A discussion of the results and conclusion including suggestions for further research and future practice are then presented.

Chapter 4: Findings

The interviews' analysis enables the identification and exploration of five superordinate themes: 'Mother's reactions to her child's deafness: from denial to finding solutions', 'Mother's meaning-making and acceptance of deafness', 'Societal and family reactions to deafness, support in rehabilitation and mother's social impact', 'Journey and challenges faced with the medical field: from diagnosis to rehabilitation', and 'The choice of education and communication strategies implemented'.

From the narratives within the five superordinate themes and after meticulously categorizing the topics and themes throughout the interviews, eighteen subthemes showed to reflect the mothers' discussions of superordinate phenomenon (see Figure 3 below). Verbatim are included in the findings' section in support of the themes to illustrate the phenomenon explored. For the purpose of reporting the findings, mothers with corresponding numbers are presented according to the code given before the interviews. The first mother interviewed is referred to as mother #1 and the participant interviewed chronologically after is noted as mother #2 following through until the last participant interviewed, presented here as mother #5.

Figure 3. Superordinate themes and subthemes shown from the interviews



4.1 Theme 1: Mother's reaction to her child's Deafness: from denial to finding solutions

The first superordinate theme relates to the mothers' reaction to their child's diagnosis of the hearing impairment. All the mothers' reactions highlighted the experience of grief. The notion of denial, the role of crying, guilt towards their Deaf child, worry about their child's future and finding solutions were underlined throughout their journey. Each of these subthemes is explored in more detail in the coming sections, leading up to formulating a clearer understanding of the mothers' reaction to their child's deafness.

The mother's initial reaction: denial

This category captures the mothers' ways of dealing with their child's diagnosis.

Throughout the interviews, there are recurrent reflections to the feeling of being in denial as one

of the core feelings and first emotions experienced upon hearing the diagnosis. They are trying to make sense of the processes as they are digesting the results.

Mother #1 rejected the idea of her son having something ‘wrong’:

“I mean I was wishing I wouldn’t hear this news but I knew there was something, I had doubts. I don’t know, maybe there was no reaction. I had no reaction at all.” - #1

Mothers #3, #4, and #5 did not accept the diagnosis at the first encounter and either asked to redo the test or saw another doctor. It seems they rejected the doctor as well as the diagnosis.

“First of all, my family doctor referred us to this doctor. That doctor asked for hearing tests, I didn’t like it so I went to another doctor. And I also went to another doctor and they also asked for the same tests and I finally was convinced. I needed to check with several ones to make sure. I needed to trust them.” - #4

Another illustration of the concept of denial is conveyed by mother #3. Similar to mother #4’s experience, the diagnosis ascribed by professionals in Lebanon did not persuade her at first:

“I was in denial for a while and re-did the screening test another time. No one surrenders after the first time. It was hard. (...) I was in denial and in a state of unconsciousness that didn’t last long, like 10 days and realized that I can’t sit like that without accepting reality, I have to confront this.” - #3

As shown in the statements by mothers #3 and #4 above, there is a need to check and recheck the tests before accepting the diagnosis conveyed. Mother #2 rejected the diagnosis. In hindsight, she described her reaction and concluded that the denial is turned into acceptance when she realized that solutions could be found and applied:

“I was saying to myself: No, of course not, it’s not true, no, of course not. Until I finally saw the hearing tests’ results and I heard it. I then believed it. I was literally lying to myself by saying it wasn’t true. I mean why would this child be like that? But there is a problem and we can solve it.” - #2

The fluctuation between denial and hope is echoed by mothers #3 and #4. They oscillated between the hope of finding out that the hearing impairment is not permanent and the ‘gut feeling’ highlighting that their child may have a hearing problem:

“But when I took her to the doctor’s, I was 99% sure she couldn’t hear and had a 1% hope. And I was holding on to this 1% and forgot about the rest. So, when the doctor told me that she couldn’t hear in both ears, I felt the world falling apart. It was a huge shock to me. Although I was sure that she couldn’t hear. I would think to myself: “maybe she had fluids in her ears” and would create excuses, just to say that she wasn’t Deaf.” - #3

Besides the reaction and rejection of the diagnosis, all the mothers were then faced with the hard truth that hearing enhancement devices were needed. For example, mother #5 meticulously described her experience at the doctor’s clinic. As with mother #3 and #4, she could not believe it and rejected both the diagnosis and the doctor instantly. She could not

picture her child with a device all her life. It was clear that the person related with the diagnosis was rejected as well:

“When he told me about hearing aids forever, I couldn't take it. I couldn't listen and I rushed out of the room and went home (...) It was hard for me, it wasn't his [doctor's] fault at all but I just did not want to believe him. I did not want to believe it. - #5

The rejection and denial are palpable when mother #3's daughter started wearing the hearing aids. It sounds like mother #3 wanted to condition herself 'not to see' the hearing aids in order to perceive her daughter as a 'normal' child:

“Her hair was short but I trained myself not to notice them. This way I perceived her as a normal child. I have to persuade myself that she is a normal child. If she is a normal child then I can't see the hearing aids. I would place them without giving much attention and I was very harsh with myself.” - #3

Mother #3 was in Bad Faith (Sartre, 2001) during that period. Few months after placing the hearing aids, mother #3's daughter had the cochlear surgery on one of her ears. After a complication with the cochlear implant, the doctor consulted the mother about the procedure. Mother #3 was adamant about her daughter not going back to being 'Deaf' as she would be without the enhancing device. She could not fathom the idea of having a Deaf child and it seemed like mother #3 considered the cochlear implant as a cure rather than a tool that enhanced her daughter's hearing. The way she describes this experience is paralleled with the first experience with the doctors:

“I mean I couldn’t accept my daughter going back to being Deaf. Impossible. He said: “there is no choice, we can see her brain! Her life or her hearing?” I said: “No no, she dies, but don’t leave her Deaf” - #3

Bargain was part of mothers #2 and #3’s grief. They wondered why this happened to them and their child. The question *why* accentuated the notion of bargain:

“I mean why? Why me? What did I do so that my son turned out like that? That’s the first wondering. Then, I started thinking about him. Why him? Why can’t he hear?” - #2.

“At the beginning, I was in denial, and every time I looked at the mainstream hearing aids like that, I would cry. I mean why? (...) Why will my daughter turn out like this?”. The wonders of God. I couldn’t accept this from the bottom of my heart. - #3.

Similarly, as the fluctuation expressed by mothers #3 and #4, mother #5 reflected on the process she went through:

“I would give myself hope and then change my mind about that, and then go through the same cycle over and over again.” - #5

I wonder whether #5 was trying to convince herself rather than being authentic with the process of acceptance and taking her time to digest her child’s condition. Mother #2 first projected the denial onto her son by saying ‘*he has nothing*’ and by rejecting the word ‘handicap’. She was then aware that the word ‘handicap’ did not necessarily have a negative connotation and she decided to employ it with her son as a way to empower him:

“I mean at first, I would advocate to my son that he has nothing. I would tell him: “so what you have a hearing impairment, you will overcome it”. I wouldn’t accept. I wouldn’t tolerate even to this day if my children said “no we can’t”. Yes, you can. You always can.” - #2

In summary of this subtheme, each mother expressed their reactions to the diagnosis differently but they all inherently expressed denial at first as they did not want to believe the diagnosis. Three of them went to several doctors before accepting the test results. Another part of the journey was also rejected by all: the hearing devices. The enhancement device made the condition concrete, visible and it is a daily reminder too.

The role of crying in the coping process

Crying is an overarching theme among all the mothers interviewed. It is part of the process, the grief. Crying is a powerful and much needed coping strategy developmentally for children and adults as well (Sharman, Dingle & Vanman, 2019). Crying has positive values when psychologically induced by the person to release tension and negative emotions (Efran & Spangler, 1979). For babies and infants, it is a useful tool and signal to the caregiver, but for adults, crying is used for cathartic release of emotional pain or joy.

Mother #1 was resisting her tears during the interview as she wanted to maintain the image of a ‘*strong mother*’. She felt that crying is a form of weakness. She nonetheless felt contained and released the tension she experienced during our encounter.

“This is maybe the second time I shed a tear. I had a close friend, she was my boss and the school coordinator, we were talking one day and I cried for the first time in front of her (...) You know, I

didn't cry because he was like that, I cried for them [her children]. I was so sorry for them. This was my reaction.” - #1

Mother #1 expresses the hurt and guilt she felt towards her children and believed that crying is her way of exteriorizing that feeling into an emotion. Mother #1 holds a certain image of herself that seems rigid. With time and as her child grew older, she was finally able to release all her repressed emotions and feelings. It's possible that this made her feel more vulnerable. It was also easier for mother #4 to repress her feelings and not talk about her son's deafness as it would make her cry.

“I really can't, because I start crying. I use it as a protection. I don't open up.” - #4

For mother #5, the consultation day was still vivid and she remembered crying for hours. Her mind and her idea of motherhood processed the diagnosis as a death of a baby she longed for:

“I was crying a lot. I went back home after this long day and I realized that she really can't hear. I spent 3-4 hours crying on the phone with my husband and not knowing what to do or what to feel. It was a very very hard day.” - #5

She highlighted the act of crying in her journey when she underscored words such as 'very' to describe the tremendous sadness expressed through crying:

“I was going from crying, to crying and more crying and then thinking that I shouldn't judge the situation too quickly”. - #5

Mother #5 practices self-compassion and allows herself to cry. All the mothers have one thing in common related to the image they try to project and the image they hold of a 'good mother'. Societal expectations put tremendous pressure on who they 'should' be and act as mothers. This shapes an inauthentic persona that they still try to let go:

"That's how I expressed myself. I sometimes tell myself to stop crying because it isn't the time to breakdown and cry, I need to think about solutions and so on" - #5

As previously depicted by mother #3, the sight of the hearing aids is a constant reminder of her child's impairment. Her whole being is exacerbated by her daughter's deafness and the hurt was clear:

"I was a person completely demolished. I would cry every time I would put the hearing aid. (...) My heart would cry for her." - #3

Reflecting back on her experiences, mother #2 is aware that the meaning given to crying differed compared to her previous experiences. For example, she felt pity towards her son and compared him to other children, which in turn made her feel sad. The idea of a *perfect* child is mostly on her mind:

"I used to cry because I would think: poor him. Why is he like that? Why are others' children okay and my child is like this? If he would play with other kids I would cry. It's as if he was a sick child and I would cry all the time. And I would be sad. It's like all children shouldn't have any problem whatsoever." - #2

The role of crying in mother #2's journey is ever-changing and appraised differently. She shares that she does not feel pity towards her son but feels heavy and sad when she thought about his hearing loss:

"Now, I cry but I feel that I'm not crying for this, because I overcame it." - #2

Comparably, mother #4 comments that the diagnosis shook her to her core for the first few months. Vocalizing: *I really wanted him to hear. I really did want him to hear* while also highlighting the loss of the child she hoped for. She reflects on the meaning she gave to her son's existence now. It seems that for mother #4 and #2, time helped a lot in challenging their thoughts and picturing their child differently:

"It was at first something very hard for me, I would spend my days and nights crying. It was a shock in my life. But I realize now that he is the best thing that happened to me in my life." - #4

Crying, as mother #2 expresses it, is an existent/present component in the dynamic regarding her son's diagnosis. She would be tearful when someone asks her about her son which shows the grief and loss she feels towards the child she imagined:

"I used to cry a lot. I still cry a lot until this day, a lot a lot. The only thing that... I mean I would cry all the time. If a person asked me how is your son, I would cry." #2

Similarly, presently, mother #5 articulates the effect of her child's diagnosis on her own way of being, she is more sensitive to people's sufferings and cried more easily and this is comparable to mother #1's narrative earlier in this section. It sounds like time and the fact that their child overcomes a lot of challenges helps the mother to let go of the sadness they force themselves to hide for so long:

"I am much stronger and assertive BUT I cry very easily and I am much more sensitive. Anything makes me cry. Seeing a child suffering makes me cry. These things remind me of the pain I went through. This how it affected me." #5

In summary of this subtheme, crying, according to all the mothers interviewed, is a major release of emotions. They judge themselves for crying but soon realize that they were going through grief. And this grief represents the child they expected, the mother they were hoping to be for that child and they were also anticipating the life they may have or not have.

Guilt: finding an etiology and overcompensating for deafness

The concept of guilt highlights a complex process. There is a particular dynamic between feeling guilty for the Deaf child and guilty for other children when the mothers raised more than one child. All the mothers feel guilty for raising a child that had an impairment. Three of them questioned their pregnancy and wondered if they may have impacted the child's neurological systems and auditory systems. Finding a cause to the deafness is needed to also alleviate the guilt and understand the etiology. Guilt towards their Deaf child is transformed into actions to overcompensate the lack of hearing.

Mother #1 wanted to know the causes of her son's hearing impairment and did not get answers from health professionals. She felt guilty her pregnancy might be the cause:

"I wanted to know the exact reason. I was in excellent health and I am very cautious during every pregnancy, with my diet and mental health for example because I know it is very important. But I don't know what happened." #1

Mother #1 persistently communicates the guilt experienced in the first few years of her son's life. Despite knowing she is not the cause of her son's condition, this guilt feeling fueled her to find solutions and improve their quality of life:

"Yes yes yes, I felt guilty. I did all of this and I felt guilty. That's why I had this motive to heal him and was eager to find solutions, and to guide him." - #1

Guilt is also expressed by mother #3, which lead to wonderings and unanswered questions regarding the cause of the hearing impairment:

"I would blame myself: "could this be some kind of neglect from my part?" I mean why? What did I miss and is there anything I didn't do?" - #3

Overprotecting and devoting the time to their Deaf child came from the place of guilt for the impairment and worry of not doing enough. Both mothers #1 and #2 share their experiences of treating their child as a baby:

“My relationship is a lot like he’s a child, a baby. I treat him like a baby. For example, if he wants to go to the toilet, I have to be present, of course not inside but I have to be present. He can’t take a shower by himself if I wasn’t there. If he wants to get his clothes, I get it for him, I sometimes help him too. If he wants to go to the kitchen to eat, I have to prepare the food and feed him. The relationship is a lot, I mean he has grown and he can do stuff, that’s what I say to myself. But no, he can’t do stuff. I have to always help him. And that’s wrong I know.” - #2

I understand from the mothers’ narratives that the word *guilt* also leaves residues of the feeling of pity. The idea of feeling guilty is different from feeling pity, because feeling guilty comes from a sense of responsibility directed towards oneself while feeling pity concerns the other person. The mothers are oscillating between those two notions and feelings.

There is a strict and almost punishing tone to mother #2’s perception of herself. She does not feel ‘good enough’ and accounted for her son’s deafness and any negative experiences he may have that might not be related to being Deaf:

“I feel pity sometimes. I feel pity towards him a lot. I feel guilty, but what did I do? But that’s it, there is guilt and pity towards him I feel that it’s my fault. Everything is my fault. Even if my son gets a bad grade in school sometimes, I feel I wasn’t good enough and didn’t do enough.” #2

In summary, all the mothers compensate for their Deaf child by being, as it seems, ‘*over-present*’ as one of them expresses. The mothers are at first determined to know the causes of the condition and turned their energy to overcompensating for their child. Their behaviors also come from an underlying feeling: pity. They felt bad and pity towards their Deaf child and are hands-on to make their life easier. This is discussed at length in the coming sections.

Time: Worry about the future and comparison with other children

The narratives within this theme describe the mothers' experience of the time taken for the diagnosis to come out, the time 'wasted' for the child to get the intervention needed and the time spent commuting to doctors and practitioners. The comparison made between their child and other children also highlighted the time 'wasted' without the optimal interventions and the lag in learning. The developmental window of language acquisition is substantial.

Mother #4 reflects on the idea of time and the time of diagnosis. She shares:

"If they caught it earlier, and I knew at 6 months, I would have accepted the idea earlier and had time to digest and won't feel like the child lost time in his development. He wouldn't have struggled to be on the same level as children his age. His speech would have been better but that's it." - #4

Examples of participants bringing the concept of time includes mother #5's account and the sense of wishful thinking in her narrative. It is clear that she was repeating 'what if' sentences to reduce the uneasiness of the journey she went through and could go through as her child passes through another milestone:

"I feel that we were late. I always say I wish we were able to diagnose her earlier, I wish she didn't put the hearing aids first. I wish she was able to hear a day earlier and so on." - #5

Mother #1 believes her son has a 'bright' future ahead of him and does not see his deafness as an impediment:

“I really see his future being very bright. Very (...) He can be anything he wants. Just like his siblings. He will even be better than his brothers and sisters. I am not being too optimistic but that’s how I see it”. - #1

While she is emotional and upset, mother #3 also shares the picture she has of her daughter’s future accomplishments. This picture gives the impression that harsh expectations are already given for her child:

“I would tell her: “I really see you as a bright person in the future” and I truly believe she will be something big (...) I feel that I will be with [daughter’s name], hand in hand, until she becomes somebody. My daughter has to excel, my daughter has to become someone special.” - #3

Mother #3 also takes the responsibility of helping and supporting her daughter. Her daughter’s deafness contributes greatly to the anxiety feels around the image she has of her, her accomplishment, and being keen on never needing anyone for anything:

“What actually worried me about her future is to die before she is able to depend on herself; before seeing her relying on herself and never needing a brother, an uncle... This is what always worries me and makes me anxious” - #3

The notion of the future englobes the child’s development and society’s acceptance or rejection. The social world is highlighted here. Despite expressing their optimism, mothers #1 and #4 reflect and convey their worries regarding their child’s future and people’s interaction with them.

“I accepted him as he is. I love him as he is. But all my worries concern the future. I wonder what he will be when he grows up, his friends, if he notices any differences, will it be hard for him? All of those thoughts (...) Will he be able to adapt? Will they accept him? (she cries)” - #4

*“But how would this kid live, find a job, be in school? What would the reactions be?
(...) No, I am scared because he is very nice and very naïve, maybe because he is a teenager. He is a person that maybe could be easily made fun of or taken advantage of ... Well yes and I guess in my unconscious I worry because he is Deaf” - #1*

The worry of being manipulated by people and seen as a ‘handicapped’ by society is also expressed by mother #2. She repeatedly uses the word *everything* and it seems like a form of exaggeration. A multitude of questions comes to her mind:

“I mean, there was something, everything, everything will be hard on him; in education, communication with people, in society, there is a handicap. (...) Would my son face difficulties in the future? Will he be able to continue his studies? Will he be able to find a job? Will they take advantage of him at work because of his deafness? I would always think about the future.” - #2

Mother #2 elaborates on the worries about her child’s safety. It looks like all the mothers are afraid and worried about their child being rejected, deceived and judged by others. They have faith in their child but are particularly worried about other people’s attitudes:

“I would mostly be worried about this constantly, like a real obsession, it was molestation or rape [silence] I looked it up, and Deaf children are more at risk and the percentages are higher.”

- #2

In addition to manipulation and being taken advantage of, bullying is expressed as a major concern in their child’s future and interaction with people.

“Like every parent, I really worry about her future. That’s not what I feel with her sister. I really worry about bullying and so on. She is very shy and weak. She does not defend herself.” - #5

“I worry about bullying but I am sure he would face it” - #4

Being ascribed with deafness worried all the mothers of their child’s development and possible learning difficulties they may experience. The mothers would observe other children and compare their capabilities, level of understanding, and language acquisition. Mother #4 has an image of her child, and she assesses this image compared to what seems like others children’s reality:

“The whole heartache was about getting him where I always longed for him to get. (...) This was a huge problem for me. I would always check and compare [son’s name] with other children and from the books I read. (...) My sister has two daughters; I had them as reference to every milestone and that’s when I noticed that my son had some delays.” - #4

Additionally, I noticed that the pressure mother #4 puts on herself when she compared her son to others somehow made her fail to notice the actual changes he made.

“I wanted him to be on the same level as his peers his age, he lost time. You see? (...) But what also breaks my heart is the time wasted. The period we lived with him was very stressful, we were waiting for him to speak, to walk and function normally.” - #4

By comparing her son to other Deaf individuals, such as the school director at the LCD who earned a doctorate in education, slightly eases the stress about the future for mother #2:

“Dr. H was a role model for me, I mean he has a hearing problem and look what he got and what he achieved. I always see this clearly. And I know that in the moment, a lot of children graduated from Dr. H’ school and got decent jobs, teachers, and that’s a plus. That’s why I am bit relaxed, a bit, not a lot”- #2

Mother #5 understands her daughter’s difference but does not find it as an obstacle for being in a healthy and loving relationship:

“I know that she will be educated and there's a high chance that she will find work, maybe in things related to Deaf individuals, or maybe not related at all. So, when it comes to relationships, she will have to be with someone who understands her, who will accept her condition as it is.” - #5

Mother #5 has a mission to equip and expose her child to all the tools needed for optimal growth and development and I wonder if this has to do with overcompensating too, as mentioned in a previous subtheme. Her main concerns are conveyed:

“The whole house system changed, we were looking for speech therapists, inclusive schools and so on. I became obsessed with the future (laughs nervously) (...) I was scared that she had neurons that were pruning too fast and that would affect all her senses. I was scared that she would lose her eyesight for example.”- #5

To summarize this subtheme, concerning the child’s development, all the mothers share the same eagerness to help and support their child in their development. The aim is to optimize their chances of having a prosperous future and be at the same level as any other person their age. It also seems that all the mothers are keen on turning their child ‘*into someone successful*’ because they feel responsible for their failures and successes. Another reason relates to overcompensating for their condition. All participants compare their child to other children their age and express their worry concerning society’s view of their deafness. Time, as an experiential and existential concept is discussed in details in the next chapter.

Finding solutions to the hearing impairment

All mothers, without exception, thought about solutions when the diagnosis was digested. They echo the need to find optimal interventions, devices and guidance to help their child. It is some sort of action-focused strategy needed to reduce the worry and stop focusing on the negative and the disability.

Mother #1 realizes she was not in touch with her own feelings regarding the deafness and directly thought about solutions to her son’s hearing impairment. She took the full responsibility to ‘heal him’ and found a motive:

“After the meeting with the doctor, while driving, I was thinking “How will I help him?” The minute I got in the car. You might think it’s very cheesy but this is really what I was thinking

about (...) Maybe I was in denial. I think it was denial. But then it turned into: "What to do?" in a realistic way! Since we got the news, I directly thought about practical stuff." - #1

Mother #4 made it a mission to find solutions and echoed what mother #1 expressed. It sounds like they realized their child's development depended on how well they coped:

"I was first shocked and then I had to adapt and think about the solutions. I had to find solutions. Our lives changed upside down." - #4

In a matter-of-fact-manner, mothers #2 and #3 listed the steps they decided to follow as an optimal strategy to improve their child's wellbeing. This reduced much of the anxiety related to the diagnosis. They intellectualized their feelings and thought about practical solutions:

"Well okay my child doesn't hear and they have a hearing impairment and I put the hearing aids. And with the hearing aid he can hear, even if it wasn't clear. At least he can hear. There's a problem and we can solve it."- #2

"I started researching about possible solutions. I swiftly enrolled her in the EI program, even before the implant. We first put the hearing aids and then I asked them what would the next step be. They informed me about the EI program." - #3

There is some sort of urgency in the mothers' narratives in finding solutions, enrolling their child in suitable interventions programs or choosing the right tools for their children. Mother #1's main goal is solution-focused: looking for elucidations and ways of '*making his life better*'. When asked if she would prefer using cochlear implants instead of hearing aids, mother

#1 explains she does not regret any decision made regarding her son's condition and removes the blame for any complication. On the same line of thought, mother #5 describes her experiences of both devices:

“For the hearing aids, I didn't accept them at all so I really wasn't prepared to explain to her anything. With the cochlear implant, it was much easier for me. We had plenty of time to adapt and I needed this too. We started working with the speech therapist and fine-tuning the implant. We really wanted her to hear, she was excluded and isolated from everything.” - #5

As part of the solutions to their child's condition, the mothers embraced the role of deciding on the hearing enhancement devices. Finding solutions is a way of coping with the diagnosis while realizing that time was 'wasted' before the diagnosis was posed. Thinking about the practicality and interventions as the diagnosis was confirmed was a major part in the acceptance process. However, they were pressured by health professionals to make a quick decision. They were not supported emotionally and were not given much information regarding optimal interventions. This is discussed in further details in the sections under: *Mother's assertiveness in making decisions* (section 4.2), *Informal support received and finding comfort in mothers going through similar experiences* (section 4.3) and *Trustworthiness of professionals questioned* (section 4.4).

4.2 Theme 2: Mother's meaning-making and acceptance of Deafness

The participants' meaning-making of their child's deafness and their conceptualization of motherhood is emphasized. Formulating a meaning to their experiences motivated them to see their child as a whole Being rather than a person with a disability. This led to their acceptance.

Each mother's tumultuous journey is described in their own way which lead up to forming an in-depth understanding of how the mothers manifested their concept of motherhood.

Mother's identity and formulation of concept of motherhood

Raising her Deaf daughter revealed to mother #3 that motherhood is an attitude, something within:

"Motherhood is there from the day we're born." - #3

Regarding their role as a mother, mothers #1 and #2 frequently identify as *'simply a mother'* rather than a *'mother of a Deaf child'*:

"I'm just a mother ... I mean it's normal, it's my job. Even if any of my kids had any problem I would act the same way (...) I feel proud. So proud." - #1

"I describe myself as a strong mother. I don't see myself strictly as a mother of a Deaf child. I am a mother and that's it." [Long silence]. - #2

In the excerpt above, mother #1 expresses how proud she is of her *'exceptional boy'* but behind the strength she exposes to the world, there is a vulnerable mother who follows society's expectations:

"I am a very sensitive person. Anything can hurt me or move me but I NEVER show them. I never show my vulnerabilities to my children. They recall memories and recently told me that I am now more cautious or worried about him compared to when he was younger." - #1

As mother #2 puts it, being a mother of a Deaf child does not change her attitude or her behaviors, she describes herself as an *'obsessive mother'* and does not link it to her child's condition:

"I don't think it would be different, because I am like that. That's my personality. I am an obsessive mother. Even if my child wasn't Deaf, I would act the same way. I would be obsessive and worry a lot and inflict this on myself." - #2

The repetition of the word 'strong' in mother #2's narrative sounds like a self-fulfilling prophecy. It seems like she reminded herself that the efforts made are worth it:

"There was a lot of physical effort, exhaustion. But it was, sometimes okay, this thing is giving me experience, I am being strong." - #2

She confirms this way of thinking by describing how she would put her emotions on the side to always be available for her children:

"If I went back in time, I might have the same attitude and same perception. I look at my children. I am the way I am because of them and for them. For them, I have to put sadness on the side and each person has these things to be done to find a positive outcome." - #2

Similarly, mother #1 is adamant of not showing her emotions. The concept and notion of motherhood is clear to her: she is expected to be patient, cheerful, accepting, and warm. She is affected by people's comments regarding her temperament and way of being as a mother:

“I even didn’t want him to see me as the sad mother. I was the patient one. I was very patient. People would tell me “Ouf, you’re so patient”. Well shouldn’t I be patient?” - #1

Drawing from the excerpt in 4.2.1, mother #4 expresses feeling gutted and sad upon hearing her son’s diagnosis and how it affected her way of being and processing her emotions:

“I really have problems talking about my feelings, I don't know how to express myself. I just had to soothe myself.” - #4

Her idea of self-worth changed over time as her child is growing up. Mother #2 echoes and repeats how hesitant she would be with her decisions. And this reflects her negative and harsh self-perception:

“What changed... I don’t know... maybe it’s because I am more severe with myself, more often. I would blame myself by saying things like “I shouldn’t do this. No no why am I doing this?” And so on. Whereas before, if I thought this was the right decision, then I would take it, no matter what. But now, I would be more hesitant, less confident.” - #2

The effort, energy and their whole being are devoted to their child. Different dimensions of their existence are affected: physical, psychological and social:

“[Daughter’s name] took everything from me and took my whole life. My whole life revolved around [daughter’s name] (...) She really drained me, on every level. Psychologically, physically, financially, everything. I was really tired with her.” - #3

“It really isn't easy at first and even when I accepted it, I still need to fight for things and be resilient. It is draining psychologically and physically.” - #5

Mother #4 shares similar behaviors and attitudes about devoting herself to her Deaf child. She decided not to have children because she believed *he is a handful and too much to handle*. I wonder whether this decision comes from a sense of fear of having another Deaf child. She reveals she lost herself in the process and does not find the balance between two polarities: being a mother and being a woman. Her decision as a mother is to put all other aspects of her life on the side:

“I want him to be perfect. I dedicated my life to him. I stopped working when I knew about his diagnosis. I can't leave him alone with someone, so I decided to leave work and be with him. (...) The focus is on him totally. Everyone tells me to have another child/sibling for him, I really want to dedicate my time for him instead of having a child and maybe feeling guilty.” - #4

Similarly, mother #5's days revolve around her responsibilities of helping, teaching, empowering, and supporting her Deaf child. Her work-life balance does not seem healthy as it sounds like mother #5 puts her needs in second place after her child:

“I want her to be better and stronger on all levels. I don't mind skipping work to take her to her sessions for example. I am working on every weakness she has and want her to improve them (...) she might not do anything with her life but I would at least be assured that I did my best for her.”
- #5

Mother #3 went from feeling drained to realizing that she is creative, resilient and motivated. She explains that it took her 4 years to embrace her full potential:

“Before, I would see myself as a person...who is destroyed (...) But I felt that [daughter’s name] gave me motivation, energy and knowledge. She educated me in a way I never thought I would ever acquire. She pushed me to show skills I never thought I had (...) I discovered that I was intelligent and smart. I discovered that I was an exemplary mother. I overcame a lot of challenges thanks to her.” - #3

Mother #5 sees the different attitudes she holds and confidence she developed:

“First of all, she strengthened my personality, a lot. I was not very assertive (...) I needed to work on myself to accept and address my anxieties. I did not want to transmit this to her. I was very self-conscious.” - #5

The concept of motherhood according to mother #3 englobes being a woman first. She highlights the necessity to put her priorities and her needs first. This is contrary to what mother #4 is struggling with in balancing her life as a woman and as a mother:

“When I came back to Lebanon, I had to play the role of a woman (...) I said to myself that I have to reclaim my rights. My rights were in many ways taken away from me and I placed my daughter in the right place, in the center and then I had to find myself again.” - #3

In conclusion of this subsection, all mothers also share that they fear their anxieties would be projected and would affect their child, like some sort of enmeshment with their Deaf

child. All of them are aware and stated that the journey of acceptance and self-awareness is needed to be confident as mothers, regardless of their child's condition.

Normalizing and accepting deafness

The word 'normalizing' is used to denote the social process through which the mothers came to perceive and see their child's deafness as a natural aspect in their everyday life. Their behaviors around their Deaf child become almost automatic. They would take into consideration their needs, capabilities, struggles, and abilities. It is also about the identification of the Deaf person within the two social worlds: the hearing world and the Deaf world (Morse, Wilson & Penrod, 2000). For example, mother #2 noticed the school curriculum is not adapted to her child's academic levels. She thus acknowledges her son's delays and difficulties compared to peers his age. Her child is different and should be treated as such:

"I used to say: "my child is strong and he is exactly like any other hearing child his age". But now I think: "no he is not like a normal child because a hearing child has more capabilities". I really used to think that he was as capable as hearing children (...) I can't say that he processes things and understands things the way other children do. He needs more time for a lot of subjects and matters." - #2

A similar narrative is drawn by mother #5: acceptance of the hearing impairment also means accepting the child's differences and not bypassing the efforts needed for the child's adaptation:

“I cannot deny this difference and cannot deny that these delays are caused by her hearing. Also, there is a daily reminder that she needs to put the devices in the charger. If it falls, she needs to fix it and so on.” - #5

Mother #5 and #4’s journey towards acceptance started when they admitted to herself and others that there is a difference and this difference needs to be taken seriously. They went through the shock, denial, the anger of their child’s condition and realized that looking for solutions and better ways to adapt would be optimal for them and their child’s wellbeing:

“It was a shock, and that’s the moment I realized that this thing is not fun, it’s a problem in life. I then accepted it slowly” - #5

“Now I totally accept it. I see how much he does and how he adapted to children his age.” - #4

Mother #5 also demonstrates that people’s behavior and attitudes do not affect her because she knows that her daughter is capable of a lot of things, as other children do:

“Even when people come over to us, or even when they stare, I really am not affected at all. It really doesn’t affect me or bother me. Even when they say “poor girl”. It doesn’t affect me. Because really, she’s not a “poor girl” I know that she is doing great in school.” - #5

Mother #2 uses the word ‘Deaf’ with her child and people in her environment. It seems she wants to reduce the stigma related to that word. Acceptance plays a major role in mother #1’s meaning-making. She repetitively uses the word ‘normal’ to define her child’s condition and she highlights all his potential and how he overcomes any obstacle. I wonder if she holds onto these successes to accept him:

“It was normal, I don’t see it as something different. On the contrary, it’s an amazing feeling. Amazing. It’s like I have a deaf child and my son was able to do THIS and this this.” - #1

The employment of the word ‘normal’ is not an expression of denial, but is the mother’s way of accepting that she is capable of a lot of things. As previously mentioned, she is forcing herself not to attend to or ‘see’ the device. She then models the acceptance to her daughter:

“I was considering her as normal, I didn’t see the hearing aid anymore, and I considered her a normal girl and I would treat her like a normal girl. It tremendously helped not to see the hearing aid she wore. You know what I meant when I said that I didn’t see the hearing aid? It’s not that I was in denial or rejecting it and couldn’t see it. When we got the device, I would tell her that this hearing aid is her ear. And I would kiss it every day in front of her so she accepts it. And I would kiss it every day and love it myself.” - #3

Similarly, mother #5 considers the cochlear implant as much a part of her as any limb and does not feel the need to hide it. It is not always the case with mother #5:

“I now know that a lot of mothers nowadays remove their child’s cochlear implant (the outer part) when people come over for example. To me, I don’t mind it at all. I want her to accept it like I do. I don’t mind putting her hair in a ponytail and showing off the device. I really don’t want her to be embarrassed.” - #5

“I would first tell her no, your ears would look weird, but now I just don’t care, as long as she’s happy, I am okay with it. I accept it as it is. (...) She has nothing less than anyone else.” - #5

It seems for mother #5 that having a ‘solution’ changes the whole dynamic she has which makes it easier for her to accept her child’s hearing impairment:

“We really wanted her to hear, she was excluded and isolated from everything (...) I mean now, I don't care. What used to be a problem, a hearing problem is not there anymore. And even if she just heard in one ear, she still hears, other people can't see, can't walk and so on... and that's it.”

- #5

Mother #1 asserts on the relief of introducing an enhancement device which also helps normalizing deafness:

“I told you we were so happy to hear that he needed hearing aids. It was clearer. In Lebanon, the testing is so weak and we are not equipped. (...) I really wanted to know “why?”, “what were the reasons?”. But then I accepted that he was born this way. (...) But maybe here it's a bit different because it's a physical handicap, although I really don't like this term.” - #1

Aspirations and wishes for the future illustrate mother #3’s way of accepting her daughter’s deafness:

“My aim and wishes for her is to become a sign language interpreter, lip reading and oral one too.” - #3

In summary, normalization of the hearing impairment is a process of identification of their child in both the hearing and the Deaf world. The mothers work through their acceptance of

society's stares, remarks, and possible rejections. They all embrace their child's capabilities and needs and empower them. It is the balance between overcoming challenges and highlighting competences, while taking into consideration the factor of time, that help mothers accept their child's differences.

Mothers' assertiveness in making decisions

The mothers' assertiveness in making decisions regarding their Deaf child's medical, educational and lifestyle choices are depicted in this section. There is a sense of being completely responsible for their child's development and future and that their decisions and choices will affect them. For example, #5 decided to keep her full-time job to ensure a future for her daughter:

"I am buying my relief in the future. I am buying my relief and better days for her." - #5

Mother #1's decisions are taken as a family as a whole. She never feels judged regarding her choices and no one from her extended family or entourage makes any direct comment. She shares a conversation with her eldest daughter about her choice of not operating her son with a cochlear implant:

"I wish we went through it first. Even [her daughter] told me it would have been better for him. It would have facilitated him a lot of things and his hearing. But I always tell her, he's fine. I mean he's fine. And I told her that if I find him struggling because of his hearing, of course we'll do something to improve it. But he's fine." - #1

As she describes her experiences, I notice that mother #1 relies and listens to her gut feeling. This is also understood as a by-product of a lack of resources:

“So, clinicians told me: “these are the results”. They were straightforward. “Your son has this this, and it is preferable if you saw this doctor and he will most probably need hearing aids in both ears”. Believe me at the time we would be excited about a solution, this was the solution!” - #1

Making decisions for her child’s wellbeing revolving around his medical status are made solely by mother #2. She would consult the LCD for guidance and advice. I also understood from her narrative that she is expected to seek help from family members but does not rely on that:

“I am very assertive when it comes to decisions. I usually say: “I want to do this and that for my son and that’s it. That’s my decision”. My husband didn’t have a role or have a voice in this. I would always refer back to the LCD, with regards to my decisions.” - #2

Similar conclusions are described by mother #3 as she consults trusted professionals, especially at the LCD. It highlights the novelty of the world they were getting into. None of the mothers’ entourage had similar hearing impairments and they feel they were thrown (Heidegger, 1996) into the world and taking drastic decisions:

“Please note that with every decision I made, I always made sure that every doctor and every institution was perfect. Nothing was random, even for my delivery.” - #3

Realizing her choices are not always optimal, mother #2 takes responsibility and accountability for her actions and decisions:

“I took the decision that I didn’t want them to have it (cochlear implant). I regret it and I started thinking that their hearing would be better but then I remind myself that I took the decision and I will go all the way with it.” - #2

In conclusion of this subsection, participating mothers are keen on making decisions for their child. It is a combination of the lack of resources and robust information in Lebanon and the useful guidance from professionals at the LCD. Mothers are put under the spotlight by doctors when a decision needs to be made concerning the choice of hearing enhancement devices. This is part of their role and responsibility as mothers. They rely on their gut feelings as a decision-making mechanism. Gut feelings and intuitions are discussed in details in the Discussion chapter.

Empowerment, advocacy of deafness and gratitude as a lifestyle

Empowering themselves, their Deaf child, their other children, and others are clear goals. Their aim is to inform, raise awareness, support and empower others in the Deaf community, hearing circle and mothers going through similar experiences. For example, mother #1 is determined to talk and share her son’s story to empower others. Additionally, her son’s achievements and improvements constitute her motivation:

“If other people are going through the same thing, I want to share my story too to boost other parents. (...) I bring up the topic and I feel so empowered while empowering others! It feels like I’m flying (...) When I see all of his achievements and improvements, it pushes me even more and this is my motivation, right there.” - #1

Mother #2 recognizes the need to empower and raise awareness around Deafness. She believes society is harsh on people with disability and shared:

“I look at my children, I mean alright Thank God that psychologically they’re strong, I empowered their personality. This society is very... In this small society, my children are strong and have nothing wrong... [stays silent]” - #2

Similarly, mother #5 reports her perception of society’s reaction to her Deaf child’s accomplishment. She needed to prove to people that being Deaf did not necessarily stop the person from excelling and standing out. I wonder if her eagerness does not put pressure on her child:

“If she aces her courses in college for example, they would say that she is an excellent student WHILE also having a hearing impairment, so this would be what makes her stand out of other students. So, people would differentiate her to her advantage.” - #5

Promoting and raising awareness about deafness is a clear goal for Mother #1 and her son. She feels empowered by her son’s initiative and motivates advocacy activities:

“I really want you to note it too. So, they state the definition of ‘handicap’. So [her son] stood up in front of the whole class and said “Miss, they’re not called handicaps, they’re called people with disabilities!” So, she told him to change it and he told her that the whole class has to do it too.” - #1

The idea of always promoting, raising awareness, and empowering others is also present in mother #3's daily life. She says she 'adores' this community and this is highlighted in her response to mothers who do not seem to know how to interact with their Deaf child. She comments:

"I have a love that is out of the ordinary. I adore them. I am always ready to help and support. I keep all my notebooks and notes, I never throw any information, I still have everything. I get them out and re read them and help others (...) I would be sometimes furious if I witness a mother not trying to communicate with her child." - #3

Mother #4 shares similar concerns and explains that raising awareness around congenital deafness is crucial for the child's development as well as the mother's understanding of the child's behaviors and difficulties:

"I worry about those mothers who witness their 4-year-old or 5-year-old child not speaking yet and having no idea that it has to do with their hearing. I really get upset when I hear this, the child could have 50% hearing loss and can't speak properly because of this." - #4

The love, affection, understanding, and empathy that mother #3 feels towards the Deaf community is expressed. She is part of several groups of mothers of Deaf children and offers lectures and support groups. She dedicates her time and energy to help and interact with mothers going through similar experiences:

"I am now in 4 different groups of mothers, cochlear implant groups, and I am... I mean... can you imagine that I give my time from 1am until 4am in the morning (...) I leave the bedroom and

start attending the groups. I talk to this mother, I advise this mother, I hear this mother, I take out my notebooks and give lectures, whatever you would think of.” - #3

The idea that mother #3 is active and motivated to make it easier for her daughter and everyone around her is clear. For example, Mother #4 relieves the anxiety she feels, around her son being bullied, by informing the children and teachers:

“A lot of kids ask as they haven't seen any of this sort. I always talk to the teacher so he doesn't get bullied for that. The children's environment also says a lot and I like to raise awareness about this by talking to the teachers.” - #4

There is a general consensus among mothers that awareness and advocacy are specifically needed among the Deaf and hearing worlds. So, as shared by mother #3, her role to educate her child and children in the hearing world is needed:

“I first told them: "I want to introduce to you, your friend [daughter's name], I want you to protect her, support her, help her, don't let anyone hurt her". So, I removed the cochlear implant from her head and showed it to them. I said: "that's a hearing aid, touch it, hold it, look at it. This is where you place it, this is where [daughter's name] hears, this is where the sounds are translated, if anyone removes it, she wouldn't hear anymore, isn't it a pity that she stops hearing if you remove it?" I introduced it to everyone and everyone held it, I really didn't mind, to show where the batteries are, everything!” - #3

Mother #1 shows her support and encouragement in every endeavor her son makes. He advocates for the rights of people with disabilities in the presence of several ministers within

parliament. She feels it is her role as a mother of a Deaf child, to support and contest for the rights that are not being executed and well implemented by the government:

“Whenever there is a project about overcoming obstacles for example, [son’s name] is the first one to present! He was in grade 2 the first time he presented, and he wanted to tell his story and explain everything about hearing aids and his experiences. It was amazing.” - #1

There is a sense of being part of a community of mothers going through hardships in a world they barely knew. Mother #3 describes how advocating for Deaf persons fed her own knowledge:

“If anyone sent an invitation to anything, like a lecture, workshop, discussion for the Deaf, I would go! I would be the only mother who attends everything, everything they organize. Although I am aware that I already know everything they’re talking about but I always like to refresh my memory, and remember the old times with [daughter’s name] and go back to zero. I would remember how much I struggled, I also feel I really enjoyed the interventions.” - #3

By advocating to others and teaching her son to speak up and raise awareness, mother #4 believes her son would convey his milestones to others:

“It is the help and information he will give to others. I feel that he will advocate for people that were in our position when he was younger. He really loves giving hope to mothers, especially mothers. It is such a relief. He is really relieving. A lot of parents need this support, it is really needed.” - #4

Mother #5 mentions another mother of a Deaf child who came up to her in a supermarket. She is open to her and is also keen on assuring others that it gets better:

“I really wanted to be like this mother; Be open to whoever asks me about hearing impairments. I want them to know what we went through and that it goes well.” - #5

For four of the mothers, empowerment is also connected to the presence of God and spirituality. Mother #1 repeatedly thanks God for the blessings she and her family have. She is aware of her resilience and wholeheartedly conveys the strength she feels. She illustrates this idea:

“It was very hard at first but then when we got this news he got so excited and happy and said this is our new hope and thank God! (...) Because whenever I fail, I can stand up and continue my life and learn from my mistakes. Because thanks to God we are all in good health!” - #1

Gratitude towards God is expressed by Mother #3 throughout her narrative:

“I used to tell them my daughter is a burden, God sent me my daughter as a burden and challenge. Now what I say is that my daughter is God’s grant, God’s gift. She was a huge weight but I actually believe that she is a present. God gave me a present and I earned so much from her.” - #3

Gratitude is also echoed by mother #4 in the sense that it is God’s will. From her narrative, the aspect of time (in terms of early assessment), her son’s diagnosis and the acceptance of deafness are understood as a continuous presence of God. These processes are smooth thanks to God, according to mother #4.

“The positive thing, Thank God, is that [son’s name] can read lips. I know that there are so many cases that are much worse, I know that. I am glad and thank God we caught it quite early (...) I thank God that there was a solution to the problem. There was a solution and I thank God it wasn't something worse. It could have been worse.” - #4

Another illustration of being grateful is depicted by mother #5 who believes God gives her the ability to make the ‘*right choices*’ for her daughter:

“Maybe that's also an advantage with God. I don't know. Could be... Actually, I thank God for making all the process go smoothly, from finding the doctors, to the center and school and so on (...) I thank God, because of this job, I was able to get a huge discount for her and retirement plans are perfect.” - #5

In summary of this subtheme, the child’s hearing impairment puts things in perspective in the mothers’ life and they choose to convey this gratitude and empowerment to others. They turn what is supposed to be a negative endeavor into a healthy adaptation. All the mothers do not want to qualify themselves and their child as a failure and try to overcome the challenges.

The idea that God gives them the strength to attend to their child’s needs and that God gave this child as a gift is expressed. Being grateful and using this energy to empower their child and other people throughout their journey come from a place where they feel the need to be empowered. This idea is discussed at length in the coming chapters.

4.3 Theme 3: Societal and family reactions to deafness, guilt towards other children and informal support received

This section portrays the family's reactions to the child's hearing impairment and implications in their rehabilitation. The mother's reaction to their other children is also conveyed. The informal support received from mothers going through similar experiences are presented in the last section.

Reaction of family members to the diagnosis

In a middle Eastern family, talking about feelings is hard and it is usually expressed in other ways. Not everyone reacts the same to certain events or situations. The diagnosis may have come as a shock for the mother and could be received differently by different family members. For example, it seems that for mother #4's family, the diagnosis came as a shock but they were mindful of their behavior. They all embraced her child, accepted him as he is and did not differentiate him from other children in the family. Similarly, mother #1's husband and children's reaction felt a lot of sadness and concerns without including the mother much in the discussions. She holds a defensive stature such as *'so, what's the problem?'* towards her husband's trepidations and older son's reactions:

"They were affected but no one expressed it. They were all stronger than me, everyone in the family pampered him because he is the first grandchild. He was spoiled by everyone." - #4

"I once got back home and saw my husband and son in tears. I asked them what was going on and they said they were talking about [son's name]. My first reaction was to say: "What's wrong with him" but internally, I was very upset." - #1

Mother #2's husband's reaction helped her accept her son's condition. He was not upset and showed her he would treat his son like any other child. He thus modeled this behavior and attitude:

"My husband was the type of person that would say: "It's okay, so what? This is God's calling. I accept it, it's okay, my son doesn't have anything else". And this was helpful to me to accept what was happening, this was the support." - #2

The extended family members of mother #1 show support by including her son in their activities. His siblings are also always eager to find games and activities to improve his language acquisition and hearing:

"Friends and cousins all play with him normally. The interactions and so on are great! When they talk to him, they would make sure to tap on his shoulder so that he can look at them and focus. (...) They [his siblings] would get or always ask about things that would improve his development, like games, pictures and so." - #1

The search for improvement and support in the Deaf child's development is also apparent in the father's behavior:

"My husband was always on the go for [son's name] and we motivate each other all the time; "Let's go here, let's go there for him" this is what our life looked like. Our goals and objectives revolved around guiding [son's name] on the optimal track." - #1

For mother #3's father, the diagnosis came in as a shock and was hard on him. The lack of knowledge and information regarding deafness is also highlighted. He thinks that having a hearing impairment can be solved by implanting a person's ear as they would with a kidney for example:

"There's an anecdote, when my father got the news, he lost consciousness. It was a harsher shock on my father than it was for me. Imagine. And then he would tell me he would donate his hearing. I had no idea what hearing loss was, or what cochlear implants were, we all thought that hearing implant can be done like a kidney transplant or heart transplant. So, we would all say: "Can we donate our hearing?" - #3

The notion of education, geographical location and socio-economic status seem to play a major role in individuals' experiences of having or being surrounded by a Deaf person. Mother #5 articulates:

"My husband's parents for example are from the village and they all see her and look at her with pity. They don't know anything about it and I understand. I don't want her to see these stares and gazes." - #5

Mother #1 describes the children's awareness of their brother's difficulties. She believes these behaviors tremendously decrease her guilt and worries. She conveys the seamless efforts they make to create Deaf-friendly outings:

"Even if they have this age gap, they would take him wherever they would go, if it was suitable for him. Even now, whenever they go to the movies, they ask if there subtitles are available. I

mean they're all going out to have fun, so might as well make it pleasant for everyone. You see the details?" - #1

According to mother #2, her own mother does not understand that having a Deaf child means that a lot of things needed to be changed and adapted. Her frustration towards her mother's ongoing behavior was palpable during the interview and I wonder if she communicates her concerns:

"She didn't know what it was. She'd say things like "Yeah okay he's Deaf" and not talk about it or ask anything. She doesn't know, she's ignorant in this matter (...) She wouldn't respect that her daughter is sitting with her son. He has to work in silent, with no distractions and loud noises. But she isn't mindful or forgets about this." - #2

A recurrent experience between mother #3 and her own mother is also depicted. On several occasions during the interview she mentions her mother saying: you're a perfectionist, you're obsessing. She feels unheard and her feelings invalidated:

"My mother did not accept, not at all. And she was in denial more than me. Parents don't understand this. So, my mother would not listen to me at all, she would say: "that's just one thing in the ear, you're exaggerating, you're obsessional". It was a really hard time for me." - #3

In this account, mother #5 reports similar experiences where her mother rejected the idea of sign language and belonging to the Deaf world. Mother #5 is affected by her mother's reaction but also understands that the generational gap may be a factor explaining this rejection:

“When I told my mother about sign language for example, she didn't accept it. Parents from my own generations were really okay with it actually, they said it's their language, that's what they need to communicate. But for mom, it was hard and she would say: “she will hear, why would she learn sign language?”. She says my daughter shouldn't be part of them as she is not like them.” - #5

Mother #2 shares negative experiences with extended family members. There is a sense of uneasiness whenever they saw family members:

“Their judgments, their behaviors, their words, their comments and their looks toward a Deaf child would really upset me [pause] They sometimes say hurtful things to me. So, to avoid getting bothered and upset myself, I decided to take my distance. I stopped the contact completely. I only connected with my husband's family. I was much more at ease like this, away from them. I was in contact with my brother, father and mother only. They would be bothered with my son, they would think that since he is Deaf, he has some mental retardation.” - #2

On this note, mother #3 believes family members may be harsher than strangers and shares her conclusion:

“There are humanitarian people, and this humanity is not fueled by religion, race, culture or family” - #3

As stated by mother #2, family members judged her Deaf child as having no mental capacity. She took the decision to cut the cord with her side of the family:

“They never made him feel like there was something wrong. They never marginalized him. They love him a lot and they make him feel loved. They weren’t differentiating him. This was the support provided; they interacted with him very positively and never with pity of course. It was more about containment. Even now at this age, they treat him the same way as the rest. They even got to the point where they really saw them equally.” - #2

In summary, positive and negative experiences are conveyed by the participants. Some family members accepted and embraced the Deaf child’s differences. They showed their support and understanding by including the child in their activities and encouraging them in their learning. But for most mothers, close relatives such as grandparents did not accept the child’s hearing impairment and considered it a disability to either fix or reject. Sign language and the Deaf world are rejected altogether. The education, the lack of knowledge and the generational gap are apparent factors in these discrepancies. Grandparents living in secluded villages in Lebanon are not exposed to new technologies and medicine and are not knowledgeable that hearing cannot be transplanted for example.

The mother’s reaction to social situations

As part of the Lebanese society, all participants recall their encounters and reactions to people. For some, they are positive experiences where they find comfort in conveying their story to other parents who seem to be lost. In other instances, people’s reactions to their child’s deafness trigger negative emotions and defensiveness.

Mother #1 makes efforts to be ‘*strong*’ for her family. While thinking about solutions, her husband showed clear distress after the diagnosis. As previously mentioned, she had quite a

defensive reaction towards her family's anguish for her son and reports similar reactions to people around her. An overarching theme of defensiveness is thus highlighted in this section.

"You know, the environment would feel pity. And I would say "What's wrong with him?" (...) They once complained at school that [son's name] was very talkative so I told them I always dreamt of hearing his voice. Let him be. They were astonished, in a good way." - #1

The rhetorical question portrays her defensiveness to negative comments. Also, her reflection "*I dreamt of hearing his voice*", stated above, noticeably shows the disparities she experiences with her son's delay in language acquisition due to the hearing impairment. Nonetheless, she aims to trigger thought-provoking reactions from people. She describes an incident with a friend of hers and uses an analogy depicting her view of deafness:

"Once someone commented on his haircut and said: "oh this looks great now his hair would cover the hearing aids". I would usually give this analogy about wearing eyeglasses because of diminished eyesight and wearing hearing aids because of diminished hearing." - #1

Mother #1 justifies people's reaction by saying: *'In this world, we know that people are not that aware. A lot of stuff are not brought up in our society. To be honest'*. She thus tries to voice out the normality of the hearing impairment at every occasion she could.

Mother #2 describes her reaction to interpersonal experiences and compares her way of being with children and her stance with adults. It is harder for her to trust adults as they feel pity. She decided to take her distance from any adult relationship:

“It affected me with my interaction with children in general to be honest; other than my children. I am more able to understand them, connect with them more easily, in a lot of ways. But I took my distance with adults since I got a Deaf child. This is also part of my reaction to people. I feel that I took distance to avoid questions or curiosities. Things like: “Oh look! She has a child like that!”. I don’t want to feel their pity. So, I preferred to take my distance, it is better to stay far from people.” - #2

Society’s rejection in general also come up for mother #3. The notion of others feeling pity is recurrent in the mothers’ narratives and experiences of other people. Interestingly, as mentioned in previous subthemes, mothers were at first oscillating between wanting to overcompensate for their child and feeling pity for them.

“Our society is a tough one. They don’t know, they are uncultured, they see her and they feel pity. But alright, she has a hearing aid, why the pity?” - #3

Around the notion of pity, mother #5 explains not being affected by people’s stares and comments as she is aware of her daughter’s capabilities and abilities:

“Even when people come over to us, or even when they stare, I really am not affected at all. It really doesn't affect me or bother me. Even when they say "poor girl". It doesn't affect me. Because really, she's not a poor girl" - #5

Mother #4 also shares how she frequently experiences being taken advantage of by individuals in the professional world. She believes it is due to a ‘*lack of professionalism everywhere and it's all related to lack of awareness*’.

“I feel that people use those cases to put extra fees and use them to get money; they make use of children's conditions. I mean come on! They saw that my child has a hearing aid and can hear, why would they ask for a shadow teacher? If the child has an eyesight problem, wouldn't they simply put him closer to the teacher? I feel they wanted to take money from children with disabilities like my son.” - #4

For mother #5, when the school director knew her daughter's cochlear implants' worth, they denied her application. They did not want to take any responsibility if a damage ought to occur within the school premises. The mother was overwhelmed and worried about her daughter's future. She felt rejected and the director started crying with her.

Despite the defensiveness with some people condemning deafness, Mother #1 recalls two main situations where she was willingly available whenever any individual needed information or guidance regarding parenting and deafness.

“I once saw a woman in the supermarket, she passed by me and my son then came back. I think she saw the hearing aids. She said: “Mrs., can I talk to you?”. So of course, I turned towards her and she asked: “Which school is your son enrolled in?” I directly knew what she insinuated. I told her the school and she then bombarded me with questions such as if the school was inclusive, mainstream and so on. We talked for 30 mins in the supermarket and she told me her story.” - #1

The story resonates in her and she empathizes with the woman's frustration and indecisiveness. Strangers' support is also a contributing factor to their journey towards acceptance. Mother #4 is keen on highlighting positive encounters and recalls an incident:

“We were once walking in the mall and a man came to us and said he also has a hearing loss and he's doing very well; he travels, achieved so much in education, and he's a professor in a college. He approached us to show support and tell us his story. There is something about their world. They have their own world and they support each other [long pause] such a relief. So much relief. I really get better when I hear such stories and it warms my heart. I also get curious about children with hearing aids and I approach them. I get curious about what they go through and also share what we are experiencing.” - #4

Mother #4 highlights the relief felt when someone from the Deaf community approaches her, she feels contained and her son supported too. This is also echoed by all mothers. There is a need to connect with mothers going through similar experiences.

In conclusion of this subtheme, positive and negative experiences relate to their reactions to social situations in Lebanon are conveyed by mothers. For some, being defensive to people's pity and insensitive comments is needed but understood as the society's lack of knowledge. In other instances, the mothers are open to talk about their experiences to whoever reaches out. The overarching theme in this section is the concept of *being supported and supporting others in similar situations*. The mothers are often emotional and sensitive to other people sharing their experiences as their way of showing that things do get better with time.

Guilt towards other children

This theme highlights a salient issue concerning the idea of motherhood and the role as a parent of a Deaf child. A common notion for the guilt is related to the time spent commuting and visiting doctors, therapists, speech therapists and other professionals for their Deaf child. And

this in turn affects their quality time with other children in the household. A collective consensus is reported: the Deaf child is perceived as needing extra care and attention. For example, mother #5 is confident her hearing daughter can defend herself while her Deaf child could not.

Mother #1 is worried about her children's reactions towards their Deaf brother and does not know what to expect from them:

"I was more worried about his siblings' reactions at the time. I was scared for them and his father (...) I was scared not to be there for them. And this is what happened actually. There was a shortage but they were so understanding." - #1

Her family's reaction triggers a plethora of emotions: she discerns her husband feeling pity towards her son and her children did not understand her Deaf son's condition at first. She did not permit herself to *'feel weak'* and seems like she recognized her past feelings by talking about them during the interview in private:

"You know, I didn't cry because he was like that, I cried for them. I was so sorry for them. This was my reaction. When my husband started crying I thought to myself and told him: "Why are you crying? You're making me feel weak". I didn't cry at the time. Maybe now I'm emotional because it's been a while." - #1

Mother #1 feels guilty for not spending quality time with her other children, but with time she makes sure to allow an open communication. She makes sense of her children's behaviors by highlighting their 12 years age difference:

“I wasn’t giving the same amount of attention as I did with my son. I felt guilty and we were always on the go to see doctors all around Lebanon. Nonetheless, I talked to my children about this.” - #1

Twelve months separate mother #5’s Deaf daughter from her other child. She differentiates them and shares that her Deaf daughter is her ‘*weakness*’. She also notices dedicating most of her time and efforts to her Deaf child and is now trying to improve the dynamic with her younger daughter:

“I stopped breastfeeding the younger one when we started going to the doctors’ and so on. I would keep the youngest at my mother’s and go to the appointments with my daughter. I would go from place to place with her. I did not have the same bond I had with [daughter’s name]. I am trying to work on that now.” - #5

As time passes, mother #3 notices she not only does not spend much time with her children, her children feel alien to her and she does not know much about them as her focus revolves around her Deaf child:

“I neglected my four children. My mother would cook for them, feed them, do their homework and everything. So, the youngest of the girls, who was 5 years old at the time was neglected in a very harsh way. I know and I notice that this girl is different than her siblings because of me neglecting her. I did not know anything about her.” - #3

Mother #2 shares the constant effort needed to hold herself together and is aware her sadness is fueled by her children:

“For them, I have to put sadness on the side and each person has these things to be done to find a positive outcome.” - #2

In conclusion, the mothers report two main feelings: feeling sad for other children because of the time spent with their Deaf child, and not wanting to show sadness at all for their children. The idea of *staying strong* for their children is recurrent in the mothers’ narratives. One mother overtly shares ‘*neglecting*’ her other children to care for her Deaf child and this causes tremendous pain in the youngest child and hurt for the mother too. After self-reflecting, all the mothers share the need to reconcile the dynamic they have with their children and restoring the balance in the family.

Informal support received and finding comfort in mothers going through similar experiences

This subtheme seems relevant especially after the subtheme related to family members’ reaction to the Deaf child. As stated earlier, Mother #1 describes the confusion and lack of trust towards medical practitioners. In two instances during the interview, mother #1 clearly voices the help she receives and it is critical to find hope in her journey:

“My siblings are pharmacists and my brother told me: “Look, keep this in mind: You see this small hearing ability he has? That is the hope. It will be even better with a hearing aid and everything will be okay. Even if you wanted to do a cochlear implant or anything else, there’s hope”. He was right.” - #1

For mother #4, her husband's support is crucial and uplifting. Mother #2 similarly seeks support in her husband and shares with him all her thoughts and feelings.

"He's stronger than me. He was the one supporting me. I would crumble and he would help me get back up." - #4

"My husband. My husband was the person I would talk to about everything. When I feel (pause) Or whatever I felt." - #2

Not all family members were supportive and understood what the mother may have gone through. Mother #4 felt and experienced judgements from other family members:

"They always thought I was exaggerating and they made me feel that way." - #4

For mother #2, #3 and #4, their support system revolves around their family members. However, not all members provided the support needed. For example, mother #2 articulated that her mother would help her a lot with her children and the household chores. Nonetheless, she did not provide her with the emotional or psychological support needed. She believes the lack of knowledge from the mother's side constituted a barrier:

"There was no emotional support at all but the only thing she helped with me was when I got angry; I burst out and when things cool down, she doesn't hold any grudges and she tries to comfort me. So, my mom was a huge relief for me, really. And I would be sad to be honest, I

wonder why I don't have a mother who helps me or who knows and supports me emotionally.” -

#2

“My primary source of support was found in my mother and my sister.” - #3

All mothers found support and empowerment at the LCD and considered them like family. Mother #2 conveyed that the speech therapist offered constant support as she would confide in her:

“I used to take classes; they would teach us how to speak and communicate with our children. At the end of the class there was an empowerment section: the psychological support for mothers of Deaf children (...) They were such a support to me. So much. They would always encourage and praise me for being patient and things like “look how your son turned out thanks to you, look at the improvements he made thanks to you.” - #2

Mother #2 feels ‘blessed’ to have found the LCD when a mother approached her after her daughter’s audiogram. The participant is open to suggestions and welcomes other mothers’ experiences and recommendations:

“She told me that she signed up her daughter with a speech therapist in another neighborhood, because they’re very knowledgeable. So, I went. And since then, I am still holding onto the whole center.” - #2

Mother #3 also found support and motivation from mothers going through similar experiences, she shared one encounter when her mental health was low:

“When I have depression and my mood drops, I would want to cry all the time. When a mother called me few days ago and asked me to help her communicate with her son, wow... I had a surge of energy.” - #3

Finding comfort and support from mothers of Deaf children was similarly shared by mother #5. She asked her husband if his colleague could add her to a group of mothers raising children with hearing impairments:

“These amazing women shared their experiences and one of them had the surgery with the same doctor and was having speech therapy with the same therapist we consulted.” - #5

Mother #5 made the decision to be part of a support group when she realized the need to witness lived experiences of mothers and their Deaf child. She took decisions concerning her child’s hearing devices, choice of school and therapist and allowed space for guidance from mothers. She shared her previous experience before being part of the group:

“I asked a lot of people and no one would give me advice or guide me, I totally understand that because it is a lifetime decision. I needed to make a quick decision and it had to be made the earliest possible.” - #5

In conclusion of this subtheme, all the mothers in this study shared their experiences of informal support offered by family members and mothers going through similar experiences. Interestingly, financial support is not mentioned by the mothers, but they all conveyed the

psychological and even physical support they received. Tremendous relief is experienced by the mothers when they are encouraged to communicate their knowledge too.

4.4 Theme 4: Journey and challenges faced with the medical field: from diagnosis to rehabilitation

The highlight of the mothers' encounters with the medical body started with the initial screening of the hearing loss suspected. The journey with the medical professionals and the challenges faced are conveyed. They were all in Lebanon when they went through their child's hearing assessment and screening. They reflected on their experience throughout the diagnosis processes and choice of rehabilitation/interventions.

All mothers recall mixed feelings towards the medical community throughout their Deaf child's infancy and toddlerhood. They shared a plethora of experiences, both positive and negative, ranging from the screening tests, to the support available, and treatments proposed by medical doctors.

Trustworthiness of professionals questioned

A predominant word is articulated by all the mothers as they talked about their experiences with medical professionals: Trust. The idea of trust is questioned and I was mindful the encounters occurred more than 10 years ago. Science and Medicine evolved since then especially around auditory problems and congenital deafness. As all the mothers explained, none of them experienced a Deaf person and had no idea about this world. Mother #1 expected guidance and support from the medical field and shares her feedback:

“Even doctors, no one advised, no one suggested.” - #1

Mother #1 shares her experiences and first encounters with the medical community since the day her son was born and faced medical complications. She communicated the scarcity of support and absence of empathy within professional bodies. All of the doctors who reported a diagnosis of hearing loss directly proposed a medical plan that mainly consisted of hearing aids. No other options or routes are suggested:

“Let me tell you what happened. When [son’s name] was born, it was the 2006 war, the situation was really bad. He was placed in an incubator for 5 days. The doctor advised us to place him there as they were worried about him because apparently, he had fluids in his ears. This is almost what they told us and we got lost with their explanations. It was very vague, we didn’t know what was actually happening.” - #1

Doctors’ explanations were unclear and mother #1 was left with unanswered questions and wonderings regarding the fluid in his ears. She made sense of the incubation and tried normalizing it by saying: *‘Nothing much there, it happens’*. Besides providing her with unclear reasons for the incubation, the doctors were not transparent regarding the screening tests which made her doubt the medical field and question their reliability:

“Every doctor would give us a different result, drastically different. (...) The results from the specialized hospital showed he doesn’t have ANY hearing loss and that everything was perfect. Imagine, that’s a specialized hospital. How can I trust anything they say? How can I direct him and myself to a certain path and put hearing aids for example?” - #1

Similarly, the frustration is palpable during the interview when mother #5 conveyed her experiences with the doctors. They received several inconclusive results:

“We did all the tests and the doctors would tell us that her bone concentration was completely normal. I thought she had some dead nerves. Maybe her hearing affected her motor skills. So, the first MRI showed that she had black spots in her brain.” - #5

The trustworthiness of professional bodies was jeopardized with each encounter and with each contradicting result the mothers received. Not enough light is shed on hearing testing in newborns and babies even though tests were part of the medical records signed by the Ministry of Health in Lebanon:

“The problem is that hospitals don't offer or at least don't talk about the hearing tests. They directly ask for allergy testing, I don't care about that, we would know with time. I paid whatever they wanted right away and asked them to do ALL the tests, everything. And everything turned out related to his hearing.” - #4

Mother #4 noticed strange behaviors while observing her child and was worried about his delay in language acquisition around 9 months of age. She consulted doctors and felt there were major flaws in the tests done among pediatricians:

“The first thing was to check his hearing, and they made me feel that this was something I wanted rather than THEM, as professionals, asking to do it (...) I am not the professional, I am not the doctor, you're supposed to guide me. And when I opened my son's medical records, the first page

was about the child's hearing. I didn't even know. I would give the booklet to the doctor. I didn't even know what they would usually do with those records.” - #4

Mother #5 echoed this experience when she felt obligated to make the decisions as doctors were not assertive. She previously shared how hard the day was for her when she realized her daughter could not hear:

“I did not want to anticipate anything and we went home with the treatment prescribed for her. I had to see him 14 days later. I called him and told him that she is supposed to be a bit better as the fluids are supposed to be gone. I imposed myself and told him I needed a checkup. So, he did an assessment and it turned out that her right ear still had a bit of fluids and the left one had none.” - #5

Mother #1 conveyed the anger and frustration felt after several trials and consultations. She could not empathize with the doctors and describes them as ‘cold’. Mother #2 shared similar experiences of doctors not showing signs of empathy, especially during the diagnosis:

“I mean okay, “your son has a hearing problem, he needs a hearing aid” and that’s it (...) I felt like a customer; I am in a shop buying something and they suggest and bye. There was no communication or interaction.” - #2

Mother #1’s skepticism of the medical doctors was justified as the professionals did not support her nor her family and would not offer enough time to explain the steps for her son’s proposed interventions and clarifications of his condition. This was depicted in mother #3’s narrative as

she conveyed the doctors did not explain nor guide the mothers concerning the interventions and surgeries:

“They didn’t explain in a way that they were really trying to inform me and enlighten me. I didn’t understand anything at all. I would get the laptop and do my searches. I saw surgeries and checked exactly what they did. They don’t get it that it was my first time I ever hear about this thing. They just assume that when they say cochlear implant, I directly know what they are talking about (...) He gave me the device and he just showed me how it turns on and off. Other than that, nothing! He said: “There’s a manual inside, read it”. That’s it.” - #3

In summary of this section, the mothers’ encounters with the medical field is deceiving. They did not feel contained nor guided by the professionals. All the notions and information were new to them and the doctors seemed stringent on information and time. In the following section, the mothers’ clear reactions concerning the doctors’ lack of support and questioned trust are communicated.

Commitment to treatment and continuous search for improvement

Upon hearing the diagnosis and reflecting on their experiences with the doctors, most of the mothers felt the need to look up the best interventions. They did not fully trust doctors in Lebanon. They all spent additional time and effort commuting to doctors’ appointments and interventions to provide their child with ideal treatments and interventions.

Mother #1 was committed to finding a final reliable diagnosis for her son’s condition: *‘One day we actually went from North to South for doctors’ appointments’*. The lack of up-to-date technologies and testing added to the uneasiness:

“Bear in mind that the technology and medical equipment used weren’t up to date. They tried so many stuff, even at a hospital in Beirut, I got too tired and frustrated by so many stuff. We would go back and forth so many times.” - #1

The dedication and commitment to her child’s development and rehabilitation was expressed by mother #5. Effort and energy-consumption were also expressed as she showed how inextricably linked her everyday life was with her child’s development and treatment:

“I don't mind skipping work to take her to her sessions for example. I am working on every weakness she has and want her to improve it. I am keen on putting in a place that will cultivate all her skills and encourage her and motivate her. This is the environment I want her to be in. (...) I still need to fight my way through, I still need to make the effort to take her to the speech therapist and occupational therapist.” - #5

Looking for information and knowledge around deafness, interventions, parenting skills with Deaf children on the internet was a habit for mother #3. She found that the internet offered more information based on American doctors and practitioners. This in turn highlighted the scarcity of information in Arabic:

“I would go on YouTube, and there would be American professionals because they had the knowledge, not the Arabs. I am telling you these information that go back 10 years ago, and 10 years ago there wasn’t much on YouTube in Arabic. I would watch the videos and apply everything with her. In addition to the interventions she had at the center. I was very tough and I was very strict with her.” - #3

Mother #1 voiced her feelings and concerns regarding medical equipment several times. Her main go-to platform was basically the web, as she articulated:

“We look a lot on the internet for new stuff and innovations for my son (...) We got this microphone that the teacher would place during class. Although it was very expensive. I wanted him so have a smooth learning experience, with no distortions in sounds or distractions.” - #1

Mother #1’s family’s involvement and commitment to finding the best interventions and tools for her child’s language development also helped her persevere:

“The family really supported me AND supported him. I told you how much effort they would do to get him games or things to improve his development and build skills in language. Small anecdote, my husband once told me: “I read about this game and it apparently helps in acquiring better hearing; it is those Spanish musical instruments and apparently it boosts hearing on different levels and gross motor skills.” - #1

Despite having different reactions to the diagnosis, mother #1 and her family agreed on one point: finding optimal tools and activities to aid her Deaf child’s language acquisition and social skills. Thus, the frustration she felt during the first years of her son’s life decreased with time. Mother #3 also decided to take necessary measures and enrolled her daughter in EI programs. She was adamant in implementing the most suitable environment as soon as the diagnosis was conveyed:

“I swiftly enrolled her in the EI program, even before the implant. We first put hearing aids and then I asked them what would the next step be. And they told me about the EI program.” - #3

Similarly, mother #2 consulted different doctors to get the best treatment for her son’s development:

“We worked a lot in getting him the optimal treatment. We went to the hospital and we did a lot of tests. We went to a psychiatrist because they thought he might have autism. We needed to know: Did he just have a hearing problem? In order to get him the hearing aids. It was a LONG journey before we were actually clear it was solely his hearing.” - #2

Concerning the hearing devices, it was harder for mother #5 to accept the hearing aids because she could see it was irritating her daughter’ skin and the background noises were disturbing her. She reflected on the collaborative period between her and the doctors in finding the best interventions. She was relieved when the cochlear implant was decided:

“We had plenty of time to adapt and I needed this too. We started working with the speech therapist and fine-tuning the implant. We were asked to use pans for example to create noise to fine tune the device to the sounds. That’s what we would do all day. We really wanted her to hear, she was excluded and isolated from everything.” - #5

For mother #4, it sounded like the hearing aids were used as a statement. She wanted to show them off to the world and model to her son that they are part of him. She was mindful that her reaction and attitude towards the hearing device affected his compliance to the treatment:

“I cut his hair on purpose and his hearing aids are big like this (she shows the size with her fingers), like a turbo. I will later get something smaller and more refined but I gave him this for now on purpose, to show him that these are part of him.” - #4

As the mothers express it, there was a constant and continual search for improvement, optimal treatment options and interventions. This was also translated in their commitment to treatments, sessions, doctors’ appointments and commuting to different places for lectures, discussions, and related consultations. Concerning the hearing enhancement devices, all the mothers voiced their involvement in their child’s commitment and compliance to the devices. This was also part of the efforts made by the mothers to improve their child’s wellbeing and overall development.

4.5 Theme 5: The choice of education and communication strategies implemented

The choice of education and school system was intrinsically related to the mode of communication chosen by the mother. If the mother chose an inclusive or specialized school, the child naturally learnt sign language. Four of the five participants’ children were taught to sign. The narratives also presented the mothers’ suggestions for practitioners and professionals in Lebanon.

Communication strategies and employment of sign language

The concepts of communication and language are inherently covered all along the narratives. Language development and cognitive abilities were in the back of their minds when the diagnosis was conveyed. Choices needed to be made concerning the language and optimal interventions aiding the child in acquiring language. In the first few years of her Deaf son’s life, Mother #1 was keen on using oral/aural mode of communication with her children. She then allowed him to express himself the way he wished to but responded to him in spoken language.

“He would call his siblings, and around that period he would try really hard to use sign language by himself ... Yes, by himself. At first, I thoughts and felt I forced him to speak (...) I didn’t know how to respond in sign so I would talk to him normally. I was very open for him to speak. He’s expressing himself and I, of course, allowed him to express himself in any way he wished. It’s his mother tongue.” - #1

Mother #1 shared that all her children learnt sign language but she did not grasp the language and said she *‘forgets easily’* and finds it *‘hard to learn a new language’*. Her tone is assertive and she made it clear that this was the communication mode she made sure he adapted to:

“He doesn’t sign with me so he speaks normally. Whenever he asks me to raise my voice I ask him to focus more!” - #1

It seems Mother #1 strongly believes her Deaf child needed to belong to the hearing world as well as the Deaf world. The salient notion of sense of belonging portrayed the mother’s resistance in adapting to the Deaf world while her son tried his best to search for his own identity. She advocated sign language to everyone:

“I believe that sign language is crucial among Deaf people but also hearing people. Crucial! We must raise awareness. Awareness is key.” - #1

Mother #2 also accepted her son learning sign language. She nonetheless seems to differentiate between the hearing world (notably the household and external world) and the Deaf world (his school):

“He is very good at signing and he likes to express himself this way at home. But I also tell him: “I don’t understand and you have to speak with me, if you sign with me I won’t understand, so speak”. He only uses spoken language with me. His brother learnt too and it is great because they always sign.” - #2

Mother #4 acknowledges the need to make as much effort to understand her son’s world as she did with her other children. She is learning sign language with him:

“It is something that will help him communicate with people like him. This is how they interact. This is the special language they have. I am interested in everything related to this world.” - #4

Despite the difficulties in learning sign language, mother #2 was aware communication was key and the interplay between hearing world and Deaf world was their new reality. She was keen to learn sign as much as her son wanted to communicate and be understood:

“It’s very complex and it’s like learning Arabic, it has a lot of complex grammar. I wanted to learn it the proper way. Because in my mind, he’s learning how to speak well I can learn how to sign. I have to, anyone can learn it, not necessarily Deaf people only should sign.” - #2

At first, mother #3 held a different attitude to sign language and communication. She expressed her rejection of signing and believed speaking ‘normally’ is the oral language:

“We spent a while without hearing aids. I was rejecting sign language so she learnt how to lip read with the speech therapist. I didn’t teach her sign language at all (...) We speak to her normally, no one uses sign language and no one knows how to sign.” - #3

With time, mother #3 realized signing was her daughter’s way of being included in her own world. This motivated her to be open to the idea of teaching her child and learning sign language herself. She now believes it is part of her child’s identity:

“She longed to learn it. God is big, because regardless of how hard I tried to change her identity... She would say: “although I can speak, I am still Deaf”. She is passionate and adores this world, her world. When we’re there, it’s unbelievable, she feels home. She speaks really well and she motivated me to learn sign language.” - #3

Following this chain of thought and realizing that effort in communication and language acquisition was needed, mother #5 was keen on teaching her child sign language and help her attain the academic level she was expected to be at. The mother chose an inclusive school and highlights the interaction of both worlds as this was her daughter’s reality at home too:

“I can’t behave and interact with her as if she has nothing. This would show that I really didn’t accept it. But the thing is, I know that she understands everything and I also know that she is in delay in a lot of things compared to children her age.” - #5

In summary of this subtheme, a common consensus and theme is explored in the narratives and the shared extracts above. They all acknowledged with time that communication

was key in their child's development as well as their dynamic. An interplay between the hearing and the Deaf world needed to be highlighted and recognized. They all shared that learning sign language themselves as very hard but it nonetheless did not affect their child's learning experience. They all believe it was their mother tongue and if the Deaf child was making efforts to integrate their world, they also made efforts to communicate with them in their chosen language.

The choice of school

The choice of school depended on the mothers' exposure to the school system. No one ever suggested or recommended a school and all of them were not supported in this area. Specialized schools are scarce in Lebanon and are not part of the public sector. One of the participants enrolled her child in a specialized school associated with the LCD. Three mothers enrolled their Deaf child in inclusive schools and shared their choices and experiences. One of the Deaf children was in a mainstream school and mother #3 believed it was the optimal choice. Mother #2 was keen on including her son with people '*like him*' and decided to enroll her son in a specialized school. She found that being in a mainstream school would affect him psychologically as he would always be differentiated from his peers. She acknowledged that his spoken language would be negatively affected but she thoroughly held herself accountable for her choices:

"I wanted him to be with friends and children like him. I didn't want him to be psychologically affected by this. Although I know that in terms of spoken language, he would have benefitted more. I have some regrets at times then I take it back, this is the best decision." - #2

As a school teacher, mother #1 enrolled her son in the same inclusive school she works at. From her previous experience at the inclusive nursery, mother #4 drew positive conclusions. For example, she conveyed that her son adapted easily and was accepted by the children. She did not see the need to differentiate him from other children and was aware that he was well supported by his speech therapist and other therapists along his developmental milestones:

“I don't want to differentiate him from others. In the nursery, he was in a blended environment and it went very well.” - #4

Mother #1 was keen on her Deaf child adapting to the hearing world and acquiring auditory-oral skills. The school's admission process compensated for the frustration felt towards the medical field. The family as a whole was implicated in searching and finding possible options for their Deaf child's continuing education:

“We are even planning for it. His siblings are also planning and suggesting: “[Son's name], if there are no university that would encourage to prove yourself, there is this one and this one and this one!”. His sister for example is really encouraging him and pushing him to go to Canada. But I am scared.” - #1

Mother #1's incongruent thoughts and feelings regarding her son's future were salient in this section. Although she saw a bright prospect and was aware that Lebanon may not be a convenient choice. She is enmeshed with her son and did not want him away from her. The word normal was prominent in all the mothers' narratives concerning the choice of school:

“I want her to be with normal children. I don't want her to be differentiated from the other groups.” - #5

On another note, mother #3 shared that being in a specialized or inclusive school is a daily reminder of her child's differences. She enrolled her daughter in a mainstream school and noticed that her daughter got to an advanced level in language and communication:

“I am keen in having her live and be treated like a normal child. If I placed her in a school for the Deaf, she would be treated differently in the real world” - #3

In summary, all the mothers interviewed are keen for their child to prosper in their environment and based their choices depending on the language and communication available to them. For one mother, being in a specialized school seemed like the natural choice. For other mothers, being treated as ‘normal’ was their aim. They desired their child to be part of the hearing world as much as they were part of the Deaf world.

Suggestions for professionals in Lebanon

All participants expressed the need for improved equipment in Lebanon, for testing, assessments and most importantly awareness among societies. Throughout the interviews, the medical sphere and social sphere were expressed as part of the larger theme of inclusion and support.

In the following statement and as expressed by all the mothers in the subtheme related to their experience with the medical professionals, mother #1 highlighted the need for updated medical equipment:

“The equipment here needs to be updated. We lack so much stuff here to improve testing and diagnosis.” - #1

Regarding societal views in Lebanon and specifically Beirut, all the mothers shared the same experiences and suggested raising awareness. All of them, in their own ways, advocated for deafness and empowered the community through empowering their Deaf child.

“Awareness for parents of Deaf children, regarding the cochlear implant, more support from professionals, more guidance, improvement of the educational system, and things like that (...) For example, there are no kindergarten specifically for Deaf babies and toddlers, and Deaf children should integrate the society and mingle with other children. They have to be in contact with others, but it’s not available here. Few pre-schools are inclusive. The education level is low. It’s very low.” - #2

In the above statement, mother #2 shed light on the school systems in Lebanon. She not only found difficulties finding an inclusive and affordable school, she also noticed that the school curriculums needed improvement. This highlighted the differentiation between Deaf and hearing children. It was not about their intellectual and cognitive abilities, it was really about adapting to their communication, language development and individual competences.

The notion of awareness was further accentuated by mother #5; she found the education in Lebanon ‘*not fair for everyone*’:

“I really hope to have more awareness in this country. You cannot imagine the amount of uncultivated people here. Awareness and knowledge is much needed here. Concerning education

for example, I wish easier things and processes could be available and of course cheaper stuff and options.” - #2

Mother #4 was keen in conveying her experiences with people’s stares and attitudes towards her Deaf child. She noticed the use of demeaning words that defined Deaf children with an impairment:

“There is no acceptance and tolerance in this society. The bullying, the pity looks. "Oh, poor child" they say. They think this is how they should talk to you, the Deaf child or those with special needs. In Saudi Arabia, they stopped using the word "disabled". They use terms like: with special needs or additional needs.” - #4

She suggested few ways to improve knowledge and raise awareness among the population. She said it was a shame people have no clue what deafness was unless they have a Deaf child or relative.

“I would use marketing and ads for people to be exposed to the Deaf culture. Not a TV program because people won't watch it. Ads would catch attention in a fast and concise way and they would present information about the cochlear implant. Then, a year later for example, they would show some new advances and so on. Exposure is key. A lot of people, even educated people still can't accept differences and see Deafness as if it was a developmental and intellectual problem. We should shed light on this. A school director once told me not to enroll my child because the hearing aid would scare the children. I was appalled. I told him: "If I put a hat on my daughter's head, I can bet you whatever you want that you won't know she's Deaf, because she's smart and can do everything!". He wouldn't accept.” - #4

The lack of commitment and execution of plans from the government and specifically the Ministry of Public Health frustrated mother #4:

“Information is really needed in Lebanon, it's a simple matter; someone from the ministry can very well go on TV and advocate for the screening tests for newborns. Or at least making the tests for free, parents are already paying a lot of money for the hearing aids. It's not a lot and the least they could do is early screening.” - #4

Summary

In summary of the findings, there is a common consensus among mothers following their rich experiences of over 10 years of raising a Deaf child. The mothers repeatedly mentioned the fear they felt regarding their child's future and reflected on the long journey they have already been through with pride. They all felt empowered by the challenges they overcame and shed light on the importance of having the support needed. Things were not easy for them because of the community they live in was not aware nor knowledgeable of hearing impairments. Three mothers felt the need to clarify around them that a hearing impairment was not an intellectual nor developmental problem. The child was often considered a lost cause as if nothing can be improved. All the mothers were upset during the interview when asked if any improvement or suggestions in Lebanon can be implemented. The overall mood changed because they felt appalled and rejected by society and could not understand it.

Chapter 5: Discussion

The purpose of the research study is to explore the lived experiences of mothers of Deaf children in Lebanon. The main research question guiding the study is: “What are the parenting experiences of hearing mothers who have a Deaf child in Lebanon?”. A greater depth of understanding from hearing mothers parenting Deaf children in Lebanon would assist professionals. For instance, clinicians, psychologists, counsellors, pediatric doctors and other helping professionals in contact with this population would thus offer optimized interventions for the mothers and their children.

Interviews were arranged with five participants who met the inclusion criteria. I conducted individual semi-structured interviews with each mother either face-to-face or video call. I decided to revert to video interviews for two participants when the pandemic affected Lebanon and the country was in lockdown. The participants and researcher’s safety are of utmost importance. Interview data included around six hours of recorded interviews. Each interview was transcribed immediately after the encounters and unraveled one hundred and twenty pages of transcription.

Following an interpretative phenomenological analysis of the data collected, the findings identified the mothers’ experiences of parenting a Deaf child. The superordinate themes and subthemes illustrated in the study are: **The mothers’ reactions to their child’s deafness; *their initial reaction*** is highlighted by denial, *as well as the role of crying in the coping process*. They shared the *guilt* they felt that was translated into *Finding an etiology and overcompensating for deafness*. A common subtheme is the *Worry about the future and comparison with other children*. At the beginning of their journey, mothers were keen on *Finding solutions to their child’s hearing impairment*. The second theme identified is: **The mothers’ meaning-making and acceptance of**

deafness which lead to the examination of the *Mother's identity and formulation of concept of motherhood*. The identity formulation and way of Being are highlighted through *Normalizing and accepting deafness* and translated as the *Mothers' assertiveness in making decisions, Empowerment, advocacy of deafness and gratitude as lifestyle*. The third superordinate theme depicted is: **Societal and the family's reactions to deafness, guilt towards other children and informal support received**. The following subthemes grasp a deeper understanding of the theme: *Reaction of family members to the diagnosis, Mother's reaction to social situations, Guilt towards other children, Informal support and finding comfort in mothers going through similar experiences*. **The Challenges faced and journey with the medical field** are expressed throughout their experiences **from the diagnosis to the rehabilitation**. This section includes the mothers' input on their *Trustworthiness of professionals and Commitment to treatment and continuous search for improvement*. **The choice of education and communication strategies implemented** is the fifth theme discussed in depth through the *Communication strategies and employment of sign language and Choice of school*. The closing of each interview ended with the mother's input and *Suggestions for professionals in Lebanon*.

The purpose of this chapter is to convey the analysis and interpretation of the findings, which includes implications in knowledge generation, clinical relevance with psychologists, pediatricians, physicians working with this population, and probable social change. The chapter also includes suggestions for counselling mothers of Deaf children.

5.1 Interpretation of findings

The study focused on mothers as primary caregivers of children as shown in research studies on parenting and disabilities (Calderon, Bargones & Sidman, 1998). All the mothers interviewed conveyed their experiences of raising a Deaf child openly and readily. As depicted

in this study, from the first tests done at home to the identification of the hearing loss, mothers go through a roller coaster of emotions (Opoku et al., 2020). The diagnosis itself generated a plethora of feelings such as guilt, denial, and loss. But, initial responses gave space for adaptation and acceptance (Zaidman-Zait, 2007). Mothers are faced with challenging tasks and decisions as their child grows among the hearing and Deaf world. Some of these challenges include: being involved with professionals in a multitude of fields, the choice of interventions, communication strategies, schools, choice of using technological hearing devices, and dealing with added expenses and pressures (Meadow-Orlans, 1994; Zaidman-Zait, 2007). Several studies found that individuals of socioeconomically low status and with poor educational levels, did not have access to information regarding deafness and did not have access to hearing enhancing devices (Meadow-Orlans, Sass-Lehrer, & Mertens, 2003; Steinberg et al., 2019; Whyte & Ingstad, 1995); Zaidman-Zait et al., 2015).

The diagnosis is a tipping point for the mothers; a label is officially placed by medical professionals. Nonetheless, the mother's point of view and embodiment of Deafness also affect their attitude towards the diagnosis. Is the child treated as living with a disability or as a fully functional child that may need few adjustments to communicate with? The narration and discourse used at the time of diagnosis affect the mothers' reaction as also depicted in the studies by Fjord (2001) and Meadow (1975). For example, one mother stated her doctor presented the diagnosis without empathy, in a cold and direct manner. They reflected on the medical professionals' fixation on the problem and finding solutions rather than trying to adapt to the hearing loss and the family context.

The following sections describe each theme presented in the introduction in depth as part of the findings' analysis and understanding of the concepts following thorough literature exploration.

1.1.1 The mothers' reactions to their child's deafness: from denial to finding solutions

The first superordinate theme relates to the mothers' reactions to their child's deafness. Each mother reconstructed the first few instances when they were suspicious about their child's hearing..

All the mothers depict their experiences at the time of the diagnosis as if they happened only yesterday, in details and thoroughly. Also, professionals' communication of the diagnosis is vividly expressed. One mother shared that a family member once told her she is '*overly protective and too concerned*'. The diagnosis validated and confirmed the parents' observations. The time after the screening and doctors' appointments felt like a 'bomb' dropping without prior knowledge of the Deaf world and medical terminology related to it. The establishment of the hearing loss constituted a turning point; a label is placed and the child seems objectified as a deaf child needing to be fixed by the medical field.

Grief is highlighted as a first reaction to the diagnosis. The experiences of grief in this study relate to the death of the baby the mothers hoped for, longed for and the future expected. This also includes the death of the mother's identity. Denial, anger, bargaining, depression, acceptance and growth are part of grief and the mothers expressed these emotions in their on-going journey. This finding is validated by previous research such as Kurtzer-White and Luterman (2003) and Kara and Harvey (2017).

The subsequent sections follow the results' structure laying the superordinate themes and subthemes. The findings are discussed in light of the literature with the aim of relating studies in

the literature to the current findings. In the last section, I show how the project's findings inform practice and research.

Mother's initial reaction: denial

The mothers' experiences highlight the non-linear stature of grief. When the diagnosis was placed, the mothers did not want to hear about it or accept it from the first try. As discussed by Luterman (1999), there is this idea of fluctuation between accepting or digesting the news and then getting back in the cycle of disbelief and avoidance.

Three mothers went to several doctors hoping to receive a different outcome. The mothers were then faced with the choice of hearing devices as depicted in other research studies (Anagnostou, Graham & Crocker, 2007). This added to the anxiety and anger felt towards their child's condition; it is apparent, people can see it, they can see it. It is official.

Following an existential conceptualization of motherhood relating the findings to the literature, mothers' mental representation of their relationship with their child, their sense of Self and identity formulation changed (Arnold-Baker, 2020; Stern, 2020). Drawing on the definition of a mother, the conceptualization of motherhood in a Middle Eastern country such as Lebanon was fluid and ever-changing. Motherhood is perceived as the total devotion of the mother to her child, the unconditional maternal love and the idealized image of the women's "raison d'être" (Bernard, 1974; Shloim et al., 2020). Over time, traditional expectations of motherhood and motherhood myths add to the stress and uneasiness felt by women (van Engen, Vinkenburg, & Dijkers, 2012).

The participating mothers felt destabilized and their inner world shaping differently. In support of this finding, previous studies highlighted denial as the apparent emotion and reaction of mothers of cochlear implanted children (Anagnostou, Graham and Crocker, 2007). One of the

mothers was in Bad Faith for over a month upon placing the hearing aids. She persuaded herself that the devices are not there and as Sartre (2001) described it, this highlighted the mothers' refusal to confront reality, and was thus living in Bad Faith. She bypassed them to perceive her daughter as 'normal'. The hearing device, once again, makes the hearing impairment visible and hard to digest.

The participants, in Heideggerian (1962) terms, are *thrown* into an unknown world on one hand and on another hand, they are *thrown* in the unpredictable nature of birth (Arnold-Baker, 2020). The new role destabilizes and affects the mother's worlds, as described by van Deurzen (2012): the physical (Umwelt); the social (Mitwelt); the personal (Eigenwelt) and the spiritual (Uberwelt). They are confronted with the unknown and the grief of the life prior to the child and prior to the diagnosis. Following the denial felt by the mothers, these feelings are translated into emotions through crying. The following section presents the role of crying in the mothers' journey.

Role of crying in the coping process

As the person grows, crying shifts from a look to signal the caregiver as a baby to a cathartic emotional release of tension and negative emotions (Efran & Spangler, 1979). Crying is considered a coping strategy when psychologically induced (Sharman, Dingle & Vanman, 2019). The literature defines crying as part of idiosyncratic characteristics of the crier (Sharman, Dingle & Vanman, 2019). Thus, the appraisal of crying is related to the person's gender, age, personality, coping strategies, and their openness to crying (Vingerhoets et al., 1993). For a couple of mothers, crying is their way of expressing their sadness. One participant embraced this feeling as she expressed self-compassion. For another mother, crying is an apparent reaction to the pain she felt for her Deaf child; she anticipated the future and picturing the difficulties her

child may experience. For all the mothers, the doctors' consultations triggered tremendous sadness communicated through crying. All of them, with no exception, remember that day vividly with heightened emotions.

The participants experienced crying differently over time. It is firstly their way of expressing distress, the loss of the baby they longed for, the worry and the constant need for adaptation. Grief is tremendous for all the mothers and the roles were changed as one participant describes crying on her mother's shoulders when she would be the one supporting her. Crying was ongoing and present. One mother clearly said: *'I used to cry a lot. I still cry a lot until this day, a lot a lot. The only thing that, I mean I would cry all the time. If a person asked me how is your son, I would cry'*. It seems like an automatic behavior as the grief for her son was a long process. The mothers need to make sense of the new responsibilities, the transition to motherhood – let alone raising a child with a disability – which highlights uncertainties and our finitude (van Deurzen, 2012). The plethora of emotions are highlighted in the coming sections that led to the mothers' acceptance of their child's deafness.

Guilt: finding an etiology and overcompensating for deafness

Upon hearing the diagnosis, mothers rejected the hearing impairment and were in denial. Then, as they felt responsible for their child, they were all keen on knowing the causes and etiology of deafness. In other words, instinct led to finding the causes of the child's hearing impairment (Bøttcher & Dammeyer, 2013).

As mothers holding their child during the course pregnancy, they feel responsible for any complications that came ahead (Arnold-Baker, 2020). As reflected in their narratives, they reflect and wonder if they were not cautious enough during their pregnancy. One mother highlights the significant effort she put to monitor her mental and physical health. For one mother, she even

asked herself if it was engendered by ‘*some kind of neglect*’ from her part. For another participant, knowing that consanguinity could be a reason for her child’s impairment, tremendous blame and guilt took over her. For example, one mother stated she would blame herself if her son had a bad grade as she feels responsible for it.

Kobosko and Zalewska (2011, p. 53) shared that “the representation of the mother-child relationship in mothers of adolescents who are deaf is predominantly behavioral”. The findings from Polish mothers’ coping and adaptive strategy may not reflect cross-cultural differences (Kobosko & Zalewska, 2011). For example, Lebanese mothers of children with chronic illnesses “tend to dramatize and exaggerate their sufferings” (Zahr, Khoury & Saoud, 1994, p. 400). However, a shift in attitude from the medical perspective to a more sociocultural formulation of deafness is depicted in empirical studies in the 1960’s (Munoz-Baell and Ruiz, 2000; Roumanos, 1998). This transition seemed to take time to be adapted among laypersons given that 90% of Deaf persons are born to hearing parents.

In the current project, all the mothers’ behaviors reflect the guilt they feel as they are overcompensating for their child’s deafness. They treated their child as a baby and devoted their time and energy to them. This finding is also reflected in Meadow-Orlans’ (1997) study with parents of Deaf children. The mothers’ implication with their child seem like a burden that needs constant rehabilitation and efforts.

Guilt also exposes an underlying feeling: pity. The literature exploring mothers’ experiences of having a child with a physical disability validates this finding (Opoku et al., 2020; Oppenheim et al., 2002; Rivadeneira, Silvestre & Laborda, 2015). One of the mothers looked at her child’s hearing aid and feels bad for him. Johnson (2000) explains the theory of parental straddling: mothers oscillate between the past, the present and the future. Mothers in the current

study internally strive to view their child without a disability hence normal. Thus, the overcompensation comes from a combination of guilt and pity (Ebrahimi et al., 2015).

Finding an etiology and overcompensating for their child's condition is apparent in the participating mothers' daily life. According to them, the reason behind the deafness would remove the blame and guilt off their shoulders. Also, it is their way of understanding the hearing impairment which in turn highlights the efforts needed for their child's cognitive, emotional and social development. Overbearing worry about the future is experienced as the child is growing up.

Time: Worry about the future and comparison with other children

Time is a core theme in all the narratives. Cultural and social norms play a role in the attitudes and possible stigma experienced when having a child with a disability (Alsulaiman et al. 2014). In *Being and Time* by Heidegger (Heidegger, Macquarrie, & Robinson, 1962), Being-in-the-world is in part defined in relation to others, Being-with-others, and in relation to oneself. In Mueller's (1946) writings, experiential and existential time are explored. Time and space are considered entities: flowing or stagnant according to the individual's experiential views. Thus, time is experienced in relation to external entities.

According to Aristotle, time is defined as "a number of motions in respect to before and after" (Mueller, 1946, p. 424). As with the initiation to adulthood with puberty, the diagnosis seems like an initiation to another state of personhood. Women's transition into motherhood also underscores a plethora of changes and crisis: the re-formulation of beliefs, values, sense of self and the world (Arnold-Baker, 2020). The social construction of the state of personhood before the diagnosis may drastically change after the diagnosis (Fjord, 2001). The child's embodiment and mother's experience of that body is given another meaning compared the to the Time before

the diagnosis. Embodiment is understood as the amalgamation of the person's experiential view of their own body and the social constructs related to that body (Merleau-Ponty, 2013). In other words, the way all the mothers in this study viewed the Deaf body engendered worries around society's acceptance of the 'disabled' body. The Deaf person is not reduced to his deafness. The body is a combination of entities and worlds, and this is conveyed by the mothers' experiences of their Deaf child. The idea of embodiment englobes binary oppositions that some may deem as paradoxical (Landes, 2013): Deaf worlds and the hearing world, oral versus sign language, the medical perspective versus the sociocultural perspective.

With time, the participating mothers started comparing children the same age and could see the behavioral and linguistic differences. They attribute the discrepancies to the time 'wasted' before the diagnosis. Comparison with other children implied and highlighted their child lacked something others had (Mapp & Hudson, 1997). It was a constant reminder that their toddler had an impairment and it is visible in their language acquisition, learning abilities and communication (Burger et al., 2005). In the study by Mapp and Hudson (1997), parents accepted their child's disability within 12 months of the diagnosis and this was also highlighted in this project.

As previously mentioned in the section around guilt, mothers are overcompensating for their child's impairment by spending added energy and time with them (Rivadeneira, Silvestre & Laborda, 2015). The idea of the child they longed for needed to be fixed. All the mothers shared the pressure they feel for their child to have a '*bright future*'. This term is accentuated and repeated in all the narratives. One participant expresses her gruesome worry of dying before her child and before making sure she relies on herself. That is part of empowering the child but they could be painting a picture the child may not be envisioning for themselves. Another mother

articulates being present with her daughter every step of the way and will be ready to let go when her daughter ‘*becomes somebody*’. It seems like the mothers feel responsible for their child successes as much as they are responsible for their failures. And this finding was highlighted by the descriptive phenomenological study conducted by Mostafavi and colleagues (2017) with Iranian mothers expressing the responsibility they hold towards their child’s success. The awareness of their inevitable responsibility, freedom and unknown future triggered *existential angst* (Heidegger, 1962; Sartre, 1943). In other words, the existential angst or dread the mothers experience refer to the negative feelings felt upon realizing their inevitable freedom and responsibility.

There is this overall worry that their child will be rejected by society’s attitudes deeming them as ‘handicapped’ and this is highlighted in several studies of parents of children with impairments (Combaz, 2018; Ebrahimi et al., 2015). One mother keeps repeating the word ‘everything’ to point out the extent of the hardships a Deaf person may encounter. It sounded like the person’s worlds are affected in their entirety. Personal worlds and identity are questioned: the physical world is affected by the impairment and the social world is in turn disturbed by other people’s views and attitudes. Finally, as in other themes, their spiritual worlds may be the only world where they find refuge (van Deurzen, 2012). These positions may be deterministic and only concern the mother’s views of their child and not what the actual circumstances entail.

Worry of the future and the worry of the Deaf child not getting married is expressed by the two mothers of Deaf daughters. This finding is reflected in the study by Alsulaiman and colleagues (2014) after investigating Saudi mothers’ attitudes towards termination of pregnancy (TOP) and the detection of a possible impairment in the fetus. One mother longed for her

daughter to be with a man who understands her and accepts her. Another mother told her daughter that she will find a man like her. Her daughter rejected the idea and told her '*I don't want to see a hearing aid*'. Ebrahimi et al. (2017) also highlights Iranian mothers' concerns related to their Deaf daughter's future that is related to finding a husband. This is compared to mothers of Deaf male's concerns that are related more about worries about finding suitable jobs. These narratives confirm that the mother's image of their child's future may not match their child's vision. I noticed that the two mothers of Deaf daughters reflected on future relationships whereas mothers of Deaf boys highlighted prospective jobs. Lebanese mothers report higher rates of distress when raising a boy with chronic illness compared to mothers of girls with a chronic condition (Zahr, Khoury & Saoud, 1994). This is explained in many Middle Eastern families of children with chronic illnesses (Patai, 1983). In the study with Hispanic parents, the parent's reactions and stress is reportedly more intense when the child with a disability is a boy compared to a girl (Mapp & Hudson, 1997). Thus, gender roles' expectations may affect the mother's reactions and process of adaptation to her child's disability; more pressure is put on Middle Eastern boys compared to girls.

There is a general consensus that a child with any difference is an easier target for bullies, and this is expressed by the study's participants and in the literature (Mishna, 2003). Four mothers worry their child would not defend themselves while one mother is adamant her child will have the tools and strength to fight back. In the literature, mothers' characteristics and parental style influence the child's victimization and bullying experience, regardless if the person lives with an impairment (Georgiou, 2008). Thus, bullying and victimization are learnt at home (Patterson, Reid, & Dishion, 1992). For example, when mothers are overprotective and/or

experienced maternal depressiveness, their child showed higher risks of victimization and are target of bullying behaviors (Georgiou, 2008).

In summary of this subtheme and linking the findings to existential views, there seems to be similar patterns of worry related to their child's future and the constant comparison with other children. This supports the notion of the future being unknown and anxiety engendered by the child's diagnosis (Johnson, 2000). The mothers are *thrown* into this role and the future seems uneasy (Heidegger, 1962). Additionally, awareness of their freedom of choice and responsibility of these choices regarding their child's future creates tremendous distress for most mothers in the study (Cooper, 2016; van Deurzen, 2012). This illustrates how embedded the impairment is in their daily life. Worry about the present and the future is overbearing. As Kierkegaard (1967, p. 61) expressed it, "anxiety is the dizziness of freedom". Mothers are aware of the infiniteness of their choices and own possibilities - looking down into the abyss - which in turn brings about guilt and anxiety; dizziness.

The following subthemes describes the mothers' coping process. They all experienced denial, bargain, anger, worry about the future, and noticing the differences to actively trying to find interventions for their child's condition and ease the uneasiness.

Finding solutions to their child's hearing impairment

Relating the process of grief, worry of the future and comparison with other children, mothers in this sample directed their energy to obtaining practical solutions. The lost time between the birth and the diagnosis needs to be regained by offering suitable and optimal interventions. Part of finding solutions to their child's deafness relates to the hearing enhancement devices and mothers share they are pressured by medical teams to make the choice. For one of the mothers, thinking about solutions is her way of coping with the difficult news.

Looking for solutions reduces the uneasiness felt and avoids feeling them and sitting with them. This is also highlighted by Iranian mothers of Deaf children who felt guilty for their child's deafness and wanted to understand the cause (Ebrahimi et al., 2015).

A sense of relief is highlighted in this group of participants since their child were candidates for cochlear implants or hearing aids. They feel their child was less alienated by the hearing world given that they can 'hear', to a certain extent. However, this reflects some kind of denial of the situation and the child's condition. The ideal child imagined needs to be fixed and finding relief in hearing devices could be deceptive. Seeing the hearing aid, for a couple of mothers, is still hard to digest and accept. According to them, it makes the impairment tangible and seen. For one mother, her daughter's experience of the hearing aid is very hard and they both rejected it as it looked bulky. They reverted to the cochlear implant few months later and it seemed 'easier to accept', as the mother expresses. Another view of enhancement assistive devices is conveyed by Al-Makharmeh' (2016) study: the rehabilitation approach advocated independent living and empowerment. However, for the mothers in this study and the sample of Iranian parents in the study by Mostafavi et al. (2017), parental stress increases with increasing duration of rehabilitation. The mothers share their struggles with the financial constraints, time constraints as well as the responsibility they hold.

In the literature, parental stress is reportedly high upon hearing the diagnosis (Burger et al. 2005). But, as hearing assistive devices and interventions are chosen, parents' acceptance of their child's condition and quality of life was improved (Cagulada & Koller, 2019). These changes are explained in terms of the mother's time of adaptation, and the use of optimal resources improving the child's integration in society and development. This in turn help the mother's adjustment to their child's hearing impairment and improve the family's quality of life

(Meadow-Orlans & Steinberg, 1993). There is also *angst* around the freedom of choice among mothers (Sartre, 1943). The decision significantly impacts their child's life and family's life and the outcomes cannot be predicted. Thus, choices and outcomes become the mothers' responsibility (Arnold-Baker, 2020). *Thrownness* seems like an impediment again (Heidegger, 1962). One mother expresses: '*I was first shocked and then I had to adapt and think about the solutions*'. The word '*had*' does not seem to have a positive connotation. Thinking about practical matters is their way of accepting the situation and adapting to a sense of 'normalcy'. Different measures need to be put in place to help the children adapt to a world that is predominantly able-hearing.

In conclusion of this subtheme, finding solutions is the mothers' way of intellectualizing their feelings following the diagnosis. Exploring the experiences of mothers who did not choose or were not able to employ hearing enhancement devices may have different narratives. Following the mothers' search for solutions and interventions, acceptance and meaning-making of their child's hearing impairment seem like a prominent matter among all participants. The following theme presents in-depth exploration of the findings.

5.1.2 Mothers' meaning-making and acceptance of deafness

Being a mother of a Deaf child brings about perspectives, attitudes and ways of being associated and influenced by social norms, constructs and backgrounds (Arnold-Baker, 2020; Kara & Harvey, 2017). Thus, mothers of Deaf children cannot be taken in isolation of their society.

In the study by Lampropoulou and Konstantareas (1998), Greek mothers reporting more stress, spend more time with their Deaf child. Therefore, the frequency of involvement with their child reflects more stress in mothers. In this study, for two stay-at-home mothers, their day

revolves around their Deaf child. I understand this degree of involvement as the mother's duty for care and as a chore. As mentioned in previous sections, mothers feel obliged and guilty if they do not attend to their Deaf child's needs (Zaidman-Zait et al., 2018). Mothers are keen on participating in every step of their child's activities, doctor's consultations and maintaining contact with professionals. One of the mothers reports longing to be portrayed as a 'good' mother but could not stop blaming herself that her pregnancy may be the cause of the impairment.

All the mothers interviewed felt guilty for not attending as much to other siblings and felt guilty if they did not solely attend to their Deaf child (Bosteels, Van Hove & Vandebroek, 2012). Siblings of a Deaf child seem to have more responsibilities, made greater efforts to communicate with their Deaf sibling, and a lot of compensations are made to understand deafness (Tattersall & Young, 2003). This section explores the mothers' formulation of motherhood and parenting a Deaf child. Their process of normalizing and accepting their child's condition is conveyed in their narratives. And, their role in advocacy, empowerment and awareness are highlighted and presented in the subthemes below.

Mother's identity and formulation of concept of motherhood

As described in the previous section, mothers feel guilty for raising the child who turned out to have a hearing impairment: they are the ones who held the baby throughout the pregnancy (Bosteels, Van Hove & Vandebroek, 2012). There is little research on women's lived experiences of motherhood and the social transition proclaimed by society: from women to mother (Shloim et al., 2020). In the Middle East, women are put on a pedestal when they raise a child (Tabchi et al., 2000), and their worth is elevated. This said, the definitions of motherhood seemed ontic and almost reductionist (Heidegger, Macquarrie, & Robinson, 1962). What about a

mother raising a child with a disability? How does the mother perceive herself? The pressure of being a ‘good mother’ is highlighted (Bowlby, 1973). An ontological meaning is thus added. There is a distinction in the meanings given by the mother concerning her Being and her essence (Heidegger, Macquarrie, & Robinson, 1962).

The woman’s self-esteem and self-worth is affected by the cultural views of motherhood she is exposed to (Falk & Heine, 2015). This research study does not look into mothers’ self-esteem per se. Nonetheless, participants shared their concept of motherhood, their attitude towards raising a child with a disability and their idea of selfhood. For example, one participant described motherhood as an instinct. The conceptualization of motherhood endorses the value the woman put to herself, her role, and expectations that are in-turn expressed in her interaction with her child (Lecciso, Petrocchi, & Marchetti, 2012). Their personal and social worlds are affected. The woman is *thrown* in her role of mother (Heidegger, Macquarrie, & Robinson, 1962).

The expectations of a mother’s behaviors and attitude are clearly conveyed by three mothers. They adapted and shaped their identity with time. One mother expresses her way of Being as projected by society: patient, cheerful, accepting, and warm. This consequently affected her authentic Self and denied her own feelings and behaviors; she put her sadness apart because it was not accepted by people around her. She holds a certain status and wants to preserve it. It was also hard for another mother to express her feelings openly, as she shared during the interview. These experiences are paralleled in the subsection related to the role of crying in the mother’s journey. According to them, a mother needs to hold onto a certain image to be considered ‘a good mother’. She could not voice out the worries she felt as it was not tolerated nor accepted. It seems like her conscious mind rejected it too.

The notion of grief mentioned in previous sections pertains to the crisis of motherhood the participants went through upon hearing the diagnosis (Arnold-Baker, 2020). In other words, an existential crisis is highlighted as they reformulate their life, values, beliefs, attitudes, expectations, freedom of choice, meaning and purpose in life (van Deurzen, 2012; Stern, 2020). Each participant highlighted their ‘maternal insightfulness’, which referred to the mother’s sensitivity to her child’s behavior (Koren-Karie et al., 2002, p.534). In other words, maternal sensitivity is reported according to their expectations of their child. Improvement in their child’s social functioning and communication skills decrease the mother’s anxiety (Fadda, 2011). Also, communication, plays a major part regarding the mother-child connection (Vaccari & Marschark, 1997). This phenomenon will be discussed in details in the section related to the communication strategies. Learning and building synchrony and reciprocity between the child and the mother leads to a gain in behavioral, improvement in cognitive strategies, knowledge of self and other as well as a sense of being part of the world (Singleton & Tittle, 2000; Vaccari & Marschark, 1997). However, mothers are not entirely recognizing their child’s motives, desires, emotional needs and complex worldview but rather impose their own expectations (Lecciso, Petrocchi, & Marchetti, 2012; Oppenheim & Koren-Karie, 2002).

All the mothers shared how tired and drained they feel: psychologically, physically, socially and financially. Their perception of motherhood is associated with their wellbeing (Shloim et al., 2020). A common consensus is expressed about devoting their life and energy to their Deaf child. In the previous section around guilt, overcompensation is emphasized and linked to putting their needs on the side. In hindsight, and over time, the mothers’ conceptualization of motherhood and their view of their past experiences changed. For one mother, raising a Deaf child affected her negatively; she lost confidence in her abilities and

capabilities and felt *'more hesitant, less confident'*. For other mothers, their experiences boosted them. One mother expressed: *'I discovered that I was intelligent and smart thanks to her. I discovered that I was an exemplary mother thanks to her. I overcame a lot of challenges'*. Additionally, for three mothers, challenges turned into strengths. This is also highlighted by Korean mothers (Park & Yoon, 2018) where the mothers share that raising a Deaf child changed their values in life and they feel more serene.

In conclusion, self-reflection directed the participants to conceptualize their journey into motherhood. Despite going through an existential crisis following the transition to motherhood, they are all aware of how resilient they actually are. One participant realized how creative she was when she was helping her daughter with her homework. Another mother highlights accepting and perceiving herself as a woman first and then a mother. She takes care of herself and empowers herself as a priority and as part of self-care. One mother articulates that she reclaimed her rights as a woman. This transitional period alongside the adaptation to their Deaf child aided all the mothers to normalize and accept deafness with time.

Normalizing and accepting deafness

As previous sections depict, in the mothers' narratives, the 'solution' to their child's hearing recurrently comes up. It is about accepting they can adapt to both worlds. Three factors affected Deaf persons' perception of themselves: the family's acceptance and normalization of their disability, the society's attitudes and the means of communication (Munoz-Baell and Ruiz, 2000). According to Morse, Wilson and Penrod (2000), normalization refers to the identification of the person with disability with both the dominant culture and their culture. So, the mothers normalizing deafness in their everyday life take into consideration their child's needs, capabilities and risks. After a while, they are aware of their child's limitations and are confident

about their abilities. For example, one of the mothers was appalled by the school curriculum and subject materials not being adapted to her child's capabilities. Another mother shared: '*I cannot deny this difference and cannot deny that these delays are caused by her hearing*'. While she acknowledged her child's differences, she also shared: '*She has nothing less than anyone else*'. She included and identified her child in both worlds.

As stated earlier, one of the hardest parts of the mother's journey towards acceptance is the inclusion of hearing enhancement devices: they are expensive, need extensive maintenance, and are a reminder of their child's condition. As Mostafavi et al. (2017) also depicts the mothers' frustration with the added financial needs pertained to the information required and retained throughout the rehabilitation process. In a study in Poland, Kobosko et al. (2021) referred to parental burnout as an indicator of parenthood difficulties and hardships with coping with the condition. One mother said she often used the word handicap as a way to normalize her son's deafness instead of advocating '*he has nothing*' and being in Bad Faith (Sartre, 2001).

Acceptance and normalization of deafness is apparent in social settings. All the participants articulated that people's stares, pity, and curiosity do not affect them anymore. Part of their process of acceptance relates to people accepting their child. They also realized the need to accept their child before society is able to fully accept them (Oppenheim et al., 2009). As mentioned in previous sections, the mothers' personal world is questioned throughout their journey. Society followed through this way and their social world is thus balanced with their other worlds (van Deurzen, 2012).

This sample of participants solely included mothers of children with hearing enhancement devices. I wonder if they had profound hearing loss without implementing hearing devices, would the mothers hold similar narratives? Nonetheless, with time, children showed that

their cognitive and intellectual capacities are not affected and that they needed help and assistance regarding language comprehension and acquisition. This engenders apparent relief and empowers the mothers through the process of acceptance which is also related to the mothers' decision-making.

Mothers' assertiveness in making decisions

Concerning decision-making, mothers shared different experiences in making choices for their child's medical, educational and lifestyle possibilities. Social and cultural views of a child's disability influence the mothers' attitudes, ability to cope, their approach to interventions and motivation for communication (Lane, 1995).

For one of the mothers, the family as a whole makes decisions after extensive research online and gathered information from different sources. For two other mothers, the LCD offered significant support and guidance in making informed decisions. Additionally, gut feelings played a major role in two of the mothers' decision-making processes. One mother kept her full-time job to claim benefits for her daughter. Another mother shares her experience with the medical professionals, and trusting her gut feeling. Gut feelings and intuitions that most mothers convey seem to lead to their optimal decisions they account for (Gigerenzer, 2007). According to the literature, concerning decision-making, mothers in the study oscillates between *maximizers* - those who explore the exhaustive list of options – and the *satisfiers* – those who settle with the first alternative that seems satisfactory (Gould, 1992, p. 469). Thus, the unconscious mind serves as guidance at first, and it is most of the time the path the mothers takes. For example, when they needed to search for professionals, three of them went to several doctors before they felt comfortable. For others, they went directly to the 'best doctors in Lebanon' and stuck with this

decision. They all rely on their gut feelings and intuitions that lay in their unconscious mind (Gigerenzer, 2007).

As mentioned earlier, “constructive action” is highlighted by all mothers when they digested the diagnosis and decided to search for ‘solutions’ (Fadda, 2011, p. 105). For example, when the mothers are in denial of their child’s condition, the hearing enhancement device is perceived as a ‘cure’. This constitutes an additional disappointment and misunderstanding since the device would not treat the hearing loss. But, when the mothers understood that technological hearing devices have benefits and limitations, their parental expectations were more realistic and maternal anxiety concurrently decreased (Koren-Karie et al., 2002). The literature found this in turn improves the mother-child interactions, maternal sensitivity, shared attention, and social functioning (Fadda, 2011; Oppenheim et al., 2009).

In conclusion of this subtheme, all mothers do not regret any decision made regarding the education, communication, and the hearing devices. Most of the mothers are guided by their gut feelings with the combination of their freedom of choice. However, the inevitable freedom and unpredictable outcomes may create worry (van Deurzen, 2012). They hold worries and guilt towards their other children and this matter is discussed extensively in a subsequent theme.

Empowerment, advocacy of deafness and gratitude as lifestyle

Empowering others is the mothers’ way of showing that raising awareness and encouraging Deaf people and individuals in the community to speak up are essential. Empowering others came from a place where mothers projected their own needs as they were going through similar experiences. There is a lack of information and support and all the mothers expressed that the support among people in the community was needed (Roumanos, 1998). Roumanos (1999) shares that in Lebanon, the lack of planning, lack of professional personnel

and lack of adequate funding are all factors affecting available care and service provision for Deaf communities. Over 20 years since the publication of Roumanos' findings and the situation remained the same (Bakhos et al., 2022).

Disseminating and conveying information that could benefit other mothers is the goal for four participants. One of the mothers prepares and shares lectures, notes and information that may be of great use to the micro-community. She stays up all night on WhatsApp groups as part of support groups for mothers in the Arab world. Additionally, awareness among educators is needed. This is an added reason for the mothers to continue advocating and empowering their child to do so. For example, one mother is aware the teachers' lack of knowledge around deafness could constitute a barrier to the child's optimal learning experience. Two mothers are keen on staying up to date with information concerning hearing impairments. They also feel the need to belong to a community as their motivation is fueled by their own experience of not being supported nor informed. One mother expressed: *'I would remember how much I struggled, I also feel I really enjoyed the interventions.'* So, by taking part in workshops, conferences, meeting or discussion regarding Deaf children, these mothers showed eagerness to empower themselves and others.

To decrease anxiety, all mothers express fear around the idea their child could be rejected by their peers. The intersectionality theory explained that people's identities and way of Being are shaped as they engage with other people. That is what mothers aim to do by advocating Deaf identities in the hearing world (Kusters, De Meulder & O'Brien, 2017). Two participants explained to classmates about the hearing device and answered all possible questions the children asked. One mother shared that the children were given the task to *'protect'* the Deaf child and her cochlear implant. Another mother got a teddy bear with a cochlear implant and

showed it to the class. Removing the children's curiosity relieved the mothers. The objective is to model tolerance and acceptance of the differences among younger generations. The mothers and their child's mental health and wellbeing thus improved (Van Eldik, 2004).

Being grateful to God is also a way to relieve stress associated and triggered by the freedom of choices and unavoidable responsibilities (Arnold-Baker, 2020). Gratitude to God is recurrently articulated by all mothers as a coping mechanism (Steinberg et al., 2019). It is their way of giving meaning to their experiences too as the outcomes of their choices are only assessed in hindsight (Kierkegaard, 1967). It is a cultural matter to say 'thank God' in a sense. One participant sees her daughter as a *'gift from God'*; a challenge of life. In other words, God is challenging the mother with a Deaf child. According to the literature, deafness and disability are accepted as gifts of God fueling mothers with even more motivation and willingness to empower their child towards a prosperous future (Kara & Harvey, 2017; Opoku et al., 2020).

Mentioning God may is not directly related to the participant's closeness to God and their Faith although three mothers wore the veil at the time of the interview. I could not make any assumptions about their religious practices as it was not the scope of the study. This may need to be looked at in future research. Nonetheless, as in the study by Kara and Harvey (2017), Black South African mothers of Deaf children do not rely solely on their faith in God and traditional healers. They believe Western medicine, notably doctors such as audiologists, surgeons and specialists have the Deaf child and the family's best interests and optimal solutions at heart. This is also apparent in mothers in this study as they all look into interventions and technologies to improve their family's quality of life.

In summary of this subtheme, each mother witnesses their child's achievements and abilities and want to show the world they do not lack anything *'despite being Deaf'*. This is also

their way of empowering themselves as mothers of Deaf children. Empowerment is conveyed through advocacy to mothers, educators and from other mothers too. Empowerment is also fueled by their gratitude to God and the meaning they give to their child's deafness according to their Faith. The mothers' social world is thus highlighted and further exploration presented in the following theme.

5.1.3 Societal and the family's reactions to deafness, guilt towards other children and informal support received

Mothers of Deaf children experience pity and discrimination from people around them (Opoku et al., 2020; Steinberg et al., 2019). This stigma affects their mental health and wellbeing (Combaz, 2018; Ebrahimi et al., 2015). Social constructs follow stereotypes and judgements around disabilities deeming people with disabilities as helpless, in need of constant assistance and care (Hyassat, 2012; Roumanos, 1998; Sajjad, Saleem, & Aziz, 2016). Deaf people are thus marginalized by social barriers preventing them from participating in social activities (CESCR, 2016; Kara & Harvey, 2017). In turn, these attitudes engender in mothers and their child a sense of disempowerment.

Contrary to what the literature depicts, mothers reject pity and empowered themselves and their child (Kumar and Rao, 2008). Thus highlighting their acceptance and recognition of the child's differences. This section illustrates the family's reactions to the diagnosis, the participants' experiences of other people and the guilt they feel towards their other children. The narratives also highlight the importance of informal support received, notably from family members and mothers going through similar experiences.

Reactions of family members to the diagnosis

The dynamic, the structure, the ease of adaptation, communication modes, the openness between members and shared values are elements constituting a family (Seligman, 1991).

Participants in the study are encouraged to portray and define their family through each member's dynamic with their Deaf child. These dynamics and interactions influence the mothers' adaptation and attitude towards the child's condition (Park and Yoon, 2018).

Concerning the family's reaction to the child's hearing impairment, participants shared various responses and experiences. As shared in a previous section, mothers feel guilty for having a Deaf child, and this feeling was exacerbated by other people's reactions. The Iranian mothers in Ebrahimi et al. (2016) study felt taunted for being blamed for having a Deaf child. In a study conducted in Canada by Jamieson, Zaidman-Zait and Poon (2011) with parents of Deaf children, the social domain affected. The parents in the study shared that the support and reaction from sibling was overlooked by professionals. One mother reflected on her experiences and noticed family members are harsher on her and her child compared to strangers. One participant caught her husband and son crying on various instances. She took it in a defensive way and her reaction is discussed in the subsequent subtheme. Her family did not tolerate the condition and expressing themselves in front of her seems taxing. This underlined their sensitivity to the mother's reaction but also the disparity in time needed to accept the diagnosis among different family members. According to another participant, cousins and family relatives included their child in their activities and siblings buy toys supporting the Deaf child in their learning. However, for three mothers, several family members did not accept the child. In one of the narratives, the Deaf child's grandmother was clearly not mindful of the child's needs. For example, during homework, complete silence is needed to ensure full attention and avoid any distracting sounds the hearing aid may detect. The grandmother nonetheless walked around, moved, and made unsolicited sounds. It is not clear whether the grandmother does not understand the additional needs but it seems like there was not enough communication between

the participant and her own mother. Similar experiences are shared by another mother: her own mother did not accept her granddaughter's diagnosis and accused her daughter of exaggerating. Would questions such as "how can I help?" be useful? Could the mothers have taken the grandmothers to one of the doctors' appointments or speech therapy sessions? For another mother in the study, extended family members poked and hurt the child emotionally and physically. They thought he would not be able to express himself and assumed he was not intellectually capable of complaining to his parents.

Generational gap, educational and socioeconomic status are also factors affecting the family's reactions. For example, one grandmother rejects sign language and feels it is their way of alienating the person from the actual world. Thus, she dismisses her Deaf grandchild's world. For one Deaf child's grandfather who came from a village in Lebanon, hearing is believed to be donated and transplanted. It was a shock as he never encountered a person with a hearing impairment. The grandfather does not reject the child but the lack of knowledge explained his uneasiness.

In summary, the high levels of stress and rejection of the diagnosis reported by some family members is linked to the pressures and expectations emphasized on the mothers (Brubaker & Szakowski, 2000). Mothers clearly do not get enough support from few family members (Calderon & Greenberg, 2000) and this is particularly highlighted in Lebanese families (Roumanos, 1995). Additionally, education and lack of knowledge around hearing impairment are factors taken into consideration. This includes the rejection of the mode of communications employed by the Deaf child and rejection by grandparents from rural areas with little to no access to information (Mapp & Hudson, 1997; Park & Yoon, 2018).

Mothers' reactions to social situations

The concepts of embodiment Being-in-the-world are highlighted in this subtheme (Heidegger, Macquarrie, & Robinson, 1962; Merleau-Ponty, 2013). From the mothers' narratives, the perception and experience of the Deaf child's body is in-of-itself an alien experience. The body as a physical entity seems deprived of one of the senses belonging to the hearing world. However, mothers' experiences of other people's acceptance of this 'alien body' bring relief and contentment. The Body portrays a phenomenon of inter-sensory entities rather than just the Self (Csordas & Harwood, 1994; Landes, 2013). The Deaf child's 'otherness', as seen by society, is the mothers' daily reminder (Bosteels, Van Hove & Vandembroeck, 2012).

As mentioned earlier, participants report being highly distressed when family members reject their child. However, with time, the child's condition is embraced and understood by most of them. This echoed the mothers' reactions to their child's hearing impairment in the first few months. Interestingly, two mothers shared that siblings and children's peers accepted and included their Deaf children in their daily activities. Hearing peers play with and including the Deaf individual although they are not sure how to communicate with them (Opoku et al., 2020). Mothers' anxiety and worry around their Deaf child being isolated thus decrease. In other instances, in-laws' acknowledgements and acceptance directly soothed two participants and helped them readily accept their child's condition.

A defensive stance is held by three of the mothers who did not tolerate particular family members that showed sadness and pity towards their child. One of the mothers, as previously mentioned, do not accept her husband and son crying for her child. The participant made the parallel between someone needing a hearing enhancement device and someone needing eyeglasses for their diminished eyesight. Another mother reacted behaviorally and stopped seeing several family members who bully her son and think he has an intellectual problem. For

another mother, relatively drastic measures were taken towards friends and family. The pity they expressed affected her and her child negatively and she decided to stay away from them. Her behavior around children changed. She became more patient, understanding and found it easier to communicate with them. Yet, she could not tolerate adults' reactions. One Deaf child's school application was rejected because of the pricey cochlear implant. This rejection validated the mother's fear and worry about the future: because of her hearing impairment, her daughter will be rejected by society and will not be able to prosper in life. Nonetheless, the mother found motivation to persevere and look for other schools that would embrace and support her daughter.

In summary of this subtheme, most mothers are defensive at times with people when they pity their child and, for one of the mothers, when hearing comments on their child's hair length (not being too long to cover the hearing aid). But at other times, mothers are more contained and understanding of people's reactions. They all explain that the Lebanese society is not exposed to information and knowledge about deafness. This is also echoed in empirical studies addressing Middle Eastern countries such as Saudi Arabia and Lebanon (Alsulaiman et al., 2014). Accordingly, their reactions portray this understanding as they try to convey information to people (Kluwin & Gaustad, 1991) which links back to the previous section of advocacy. Also within the mothers' social realm lie their other children. The following subtheme illustrates their reactions and behaviors towards them.

Guilt towards other children

This section depicts mothers' feelings and attitudes towards their other children. Most express guilt, with the exception of one mother who only has one child. The subjects all thought and conveyed their devotion towards their Deaf child. They are sorry for the times they did not spend with them and decided to dedicate time to their Deaf child such as in sessions, commuting

to practitioners and teaching them. Interestingly, no other study depicts the parents' dynamics with their children when a child with a certain condition was also in the household.

As echoed in previous sections, overcompensation is noticed. For one mother, the differentiation is apparent even in breastfeeding. She stopped breastfeeding her younger child although one year separated the two children. The decision is '*naturally taken*' as she dedicated her time and energy to her Deaf daughter. For another mother, she went as far as saying she '*neglected*' her other children. She said she deprived them of her presence, warmth, and attention. She in turn does not know much about them and even noticed rivalry and hatred from one of the siblings towards her Deaf child.

When the mothers reflect on the feelings and behaviors experienced towards their children, each of them shares their own way of improving their dynamics and reduce the guilt. For one mother, having an open communication with her older children helps in keeping a contained and safe space for everyone. She is mindful of the age difference between the siblings that may have helped in reducing the existing challenges. They are more understanding as they reach a certain age where they claim independence. Another mother puts her sadness aside to attend to her other children. She feels tremendous guilt for not spending much time with them. So, she tries her best to be motivated, energized and most importantly positive around them. As mentioned earlier, the mother raising children who are one year apart tries to improve the dynamic with her hearing daughter. She implemented a systematic schedule with her husband to share their time equally with both children. Her husband is thus helping the mother give the reign to someone else when she needs to spend time with her other child. Concerning the mother who has one child, a determined decision is taken not to have other children. She says she still feels guilty and spends most of her time with her Deaf child. She believes having another child would

not be fair for both of them. Also, she acknowledges and accepts that raising a Deaf child took up a lot of her time and energy, and decides to focus on herself before thinking about having another baby.

In summary, the mothers in this study feel guilty for their Deaf child and wondered if they are to blame for the hearing impairment. With time, they all notice that the devotion and over-compensation affected their dynamic with their other children. This leads to also feeling guilty for them. Mothers correspondingly acknowledge that the children need time to adapt to their Deaf sibling. Nonetheless, as their child grew up, the mothers' dynamic and quality time with their other children improved as strategies were set in place. With this in mind, while receiving nebulous information and support from the medical field, all the mothers find comfort and support elsewhere.

Informal support received and finding comfort in mothers going through similar experiences.

All the participants highlight the need for emotional support. For one of the mothers, parents helped her in the house chores but did not know how to offer psychological and emotional help. As mentioned, the generational gap, the education and geographic location of family members are factors taken into consideration in their understanding of deafness. The mothers feel they are not supported for two reasons: Parents do not know how and are not knowledgeable of the mother's needs. The other possible reason concerns the judgment they hold, which is in part related to the lack of knowledge and culture. The aim of the involvement is to inform the family members about the Deaf child's abilities, capabilities and needs. This in turn eases the communication between these two parties (Poon and Zaidman-Zait, 2014).

Social and emotional support are considered the most needed among mothers of children with a hearing impairment (Lecciso, Petrocchi, and Marchetti, 2012; Meadow-Orlans, 1997). An array of studies reinforces this finding, as mothers' wellbeing and ease of adaptation significantly improved when the needed support is provided (Meadow-Orlans, Sass-Lehrer, and Mertens, 2003; Zaidman-Zait et al., 2018). This form of help and encouragement also help mothers accept their child's diagnosis and motivate them to be more active in their rehabilitation (Ingber, Al-Yagon, & Dromi, 2010). They all explain their choice to seek informal support as a by-product of their negative encounters with doctors in Lebanon which is discussed in details in the next section. For one of the mothers, information and suggestions regarding interventions are discussed with her brothers who are pharmacists. Spencer (2000) also shares the crucial role of family support and explained that this form of support increased the parents' ability to obtain and evaluate information and increased their confidence in their own general parenting skills. For two mothers in this study, their husbands empower them and support them through their tumultuous journey. One mother shares that the speech therapist and psychologist were referred by other mothers rather than professionals. Mothers are praised for all the efforts which in turn motivates them to take accountability for their choices .

An existential twist to the sociocultural perspective of deafness views the body as a tool the person employs to shape and understand the world they live in (Lévi-Strauss, 1987). Hence, the concept of embodiment being proper to each individual (Merleau-Ponty, 2013). Society's experience and view of the Deaf person may reduce the disabled body to a disabled Self. For example, several family members rejected the diagnosis and deemed the child intellectually flawed. In other experiences, the body and 'self' were not necessarily judged as defective and the mothers, as well as society, embraced the child's 'bodiliness' (Csordas & Harwood, 1994). A

parallelism between the Deaf children's world and the mothers' worlds is witnessed; each member of different communities finds emotional support and belongs to a group that empowers them and embraces them with open arms.

4.1.4 Challenges faced and journey with the medical field: from diagnosis to rehabilitation

As mothers shared their experiences of the diagnosis, they also disclosed their experiences with the medical field. This section presents the challenges and journey with the medical professionals. All participants were in contact with practitioners and doctors when a diagnosis and interventions were needed.

Trustworthiness of professionals questioned

As mentioned in previous sections, to make informed decisions, mothers did not find comfort nor proper guidance from professionals in the medical field. They found themselves getting useful support from lay persons including mothers who went through similar experiences. The mothers' trustworthiness of the medical professionals is discussed in further details in this section.

A powerful and expressive wondering is shared by one of the mothers concerning her experience in the first few weeks of her son's diagnosis. No two doctors gave the same diagnosis or explanation to her son's hearing loss and she wondered if she can trust any doctor with treatment suggestions. Similar experiences are described by another mother: she received unclear, inconclusive and at times contradicting results. Furthermore, one participant is appalled by the nonexistent systematic testing for newborns and babies. Two other mothers lost confidence in the medical field for not highlighting the importance or systematically conducting neonatal hearing screening. Opposing procedures are depicted in other countries. For example, in Flanders, babies between four and six weeks old systematically undergo neonatal hearing

screening and parents of every newborn are encouraged to book a consultation with their neighboring public childcare organization (Bosteels, Van Hove & Vandebroek, 2012). This reinforces the importance of early detection and EI for babies with hearing impairment.

Concerning doctors' interactions and communication, most of the participants described them as '*cold*', '*not empathetic*' and do not share much information. Medical terms are alien to all the mothers and they feel the doctors did not make any effort to clarify them. Two mothers felt like customers in a business transaction as the doctors directly talked about hearing aids and procedures. Mothers are expected to make choices concerning hearing enhancement devices without much information nor guidance. This is understood as the medical doctors' views of deafness as an impairment to fix (Roumanos, 2000) which is not the case in Denmark for example where doctors articulate that the child does not need the enhancement device to be 'fixed' (Fjord, 2001). Additionally, Bakhos and colleagues (2022) reports the Lebanese physicians' lack of awareness of Deaf culture and health needs which lead to misconceptions and misinformation about deafness that affect the provision of care. For example, lip reading and note writing are considered an effective health communications by practitioners although proved ineffective and misleading by Deaf people (Bakhos et al., 2022). Regarding the sociopolitical system in Lebanon influencing the doctors' exposure to Deaf culture and health, not much funding is offered to practitioners to have access to resources from more established nations (Combaz 2018). Yet, improvement in hearing enhancing devices and technologies is a prominent sector in Lebanon (Global Survey Report, 2008). This highlights the type of resources practitioners offer to children who are deaf that may seem at times focused on the biological basis of hearing loss rather than on a holistic view of the human experience (Bakhos et al., 2022).

Binary oppositions between the medical view and sociocultural model of deafness is apparent among healthcare professionals in Lebanon. On a positive note, one mother shares the positive experiences she had with a doctor who humanely treated her and her child and guided her throughout the surgeries and rehabilitation.

The participants' experiences with the medical doctors come across as pejorative and almost accusatory. However, there are complex elements that could contribute to the doctors' behaviors such as the medical education, the medical culture and medical environments. It is clear that the audiologists consulted by the mothers in this study, opted for enhancement devices, but this may not be the case for all the audiologists in Lebanon.

In summary of this subtheme, all the mothers highlight that the quality of resources and technologies for screening needed updating. This is reflected in other studies in developing countries (Störbeck, 2012) which lead to the mistrust of the medical field. Nonetheless, as previously mentioned, all the mothers devote their time and energy to improve their child's wellbeing and learning experience. This is discussed in the following section.

Commitment to treatment and continuous search for improvement

As depicted in their narratives, most of the mothers thought about solutions and interventions when the diagnosis was conveyed. For others, looking for solutions was a way of coping with the unexpected news. The scarcity of information provided and the lack of reliance and trust in the medical equipment and testing fueled the mothers to seek help and consult several doctors. The section entitled *Finding solutions to the hearing impairment* differ from this section in that the mothers' willingness to find solutions is explored. In this section, the mothers' active participation and commitment to treatment and search for improvement is conveyed.

As this research showed, mothers of Deaf children are keen to advocate resources and information about their experiences to other mothers. According to various studies, mothers of Deaf children spend time advocating awareness around deafness and encouraging their child to advocate too (Brubaker & Szakowski, 2000). The mothers in the research by Meadow-Orlans (1994) report and describe their child as hyperactive, needing constant attention, and easily distracted. These findings are reflected in this study: two mothers report asking educators if their child's '*excess energy*' is related to their hearing impairment. Another mother shares the need to attend to everything her child does even as an adolescent. These comments reflect the mothers' representations of their children (Kobosko & Zalewska, 2011).

In addition to the knowledge provided by the doctors, information and explanations are searched for on the internet or through other mothers' experiences. These experiences are different in countries such as the United Kingdom, where technologies, testing and professional services are up to standards (WHO, 2020). Commitment is much needed to attend sessions, stay up-to-date with schools, therapists, doctors' appointments and follow-up with audiologists. One mother does not mind skipping work to accompany her child to sessions and another mother genuinely explain the '*draining*' efforts needed. The by-product of this commitment is explored in the section 'Guilt towards other children'.

There is a sense of urgency in gaining back the time lost since the birth and the diagnosis. For example, one mother says she '*swiftly enrolled [daughter's name] in the EI program, even before the implant*'. This is comparable to other mothers consulting different doctors to confirm the next steps of treatment and/or rehabilitation. The continuous search for improvement is also encouraged by family members such as one participants' husband who found educational games

for language development. Also, siblings take their sibling to arcade games to be exposed to other children.

Concerning hearing devices, two mothers share different but comparable experiences. One mother is in continual search for the optimal hearing device for her daughter. She did not accept them as they look bulky and itching her daughter's skin. She nonetheless attends appointments and speech therapy sessions to fine-tune the hearing device. Another mother takes her time to love and embrace the hearing aids and modeling her daughter to love and embrace them too. Compliance, for her, is quite important and she makes an effort to also use this motivation to improve her child's language acquisition. One of the mothers said she is proud of her son's deafness explicitly shown with the hearing aid. This is also echoed earlier when mothers were sensible to their reactions and would model tolerance to their child. Their aim is to guide the child in accepting, normalizing their own condition, and adapting to the hearing device.

In summary, participants are aware the devices are part of the child's identity formation (Arnold-Baker, 2020). If they reject the child's deafness they know the child would also have difficulties accepting themselves. As Bowlby's (1973; 2008) theory of attachment suggests, infants and babies are modelled by their primary caregiver's attitudes and behaviors. Thus, normalizing deafness while also finding the optimal and individualized treatment is needed to attain independence and acceptance of the Self by both the mother and the child. So, rehabilitation, fine-tuning the device, attending speech therapy sessions are meticulously attended by all mothers.

As this section depicts the mothers' commitment to their child's rehabilitation and treatment, it is also important to develop EI programs while considering the active participation of parents of Deaf children (Ahmad & Brown, 2016). The parents' knowledge of Deafness, the

different communication strategies, and the time spent with their child are assessed to better establish the families' needs (Ahmad & Brown, 2016). Observing the mothers' interaction with their Deaf child is important to work on their competences and employ adequate strategies (Zaidman-Zait et al., 2018). Individualized plans and interventions improve the mothers' knowledge, and confidence in dealing with their Deaf child which in turn enhance the mother-child communication and reduce maternal stress (Lederberg & Prezbindowski, 2000). The following superordinate theme discusses in details the mothers' decisions related to the schools and communication strategies employed.

5.1.5 The choice of education and communication strategies implemented

This section presents the participants' experiences in choosing communication strategies with their child related to their choice of language and school. As Fjord (2001) depicts, mothers are expected to make major decisions on the spot, such as the choice of language models in preparation for a possible cochlear implant. This adds to the sense of loss, confusion, stress and anxiety mothers experience upon hearing the diagnosis. It seems mothers take the responsibility to regain the time wasted before the diagnosis.

The amount of reciprocal communication between Deaf children and hearing mothers is less significant than hearing dyads (Carey-Sargeant & Brown, 2005). Developing techniques to ease the communication between Deaf children, their hearing parents and educators are crucial. The aim is to enhance parental communication, reduce maternal stress, support the child's language development that would improve mother-child dynamics (Calderon, 2000). For example, two mothers highlight the importance of pausing while interacting with their Deaf child as it allowed them to understand their utterances while showing the efforts made (Carey-Sargeant & Brown, 2005).

Doctors in Lebanon do not necessarily encourage sign language learning and encourage the development of auditory-verbal programs (Broughton, 2018). Deaf identity is indirectly constructed by doctors' views of deafness. The mothers' choices are thus limited and sense of freedom restricted (van Deurzen, 2012). Nonetheless, mothers in this project pondered on the employment of sign language as introduced by the practitioners at the LCD. Their experiences and choices of communication are presented in the following subthemes.

Communication strategies and employment of sign language

Various factors affect mothers' choices of mode of communication employed in the household (Meadow-Orlans, 1997) such as the attitudes and beliefs towards sign or spoken language (Kluwin & Gaustad, 1991; Mindel & Vernon, 1971). Parent-child interactions and linguistic stimulations, especially during the Early critical years, affect the child's attachment patterns and are indicators of the child's emotional and social development in adulthood (Roumanos, 1999; Vaccari & Marschark, 1997; Van Eldik et al., 2004). Humphries et al. (2019) found that the mode of communication determined how the Deaf child functions within the family. The debate between sign and speech was a cultural one. The literature shows that Deaf children in hearing families tend to experience a significant degree of isolation in their families and community (Calderon & Greenberg, 2000).

Mothers interviewed want their child to be an integrated part of the hearing world. Nonetheless, all the mothers acknowledged that sign language is their instinctual language (Kara and Harvey, 2017). Roumanos (1999) strongly believes that the solution is laid in sign language in the household. As their child grew older, the mothers seem to compensate for their language delay by gesturing more. Among Hispanic and African American mothers of Deaf children, communication showed to affect the relationship (Mapp & Hudson, 1997). They found that

mothers were more likely to be intrusive, less flexible and less consistent in their interactions which in turn affected their stress levels. Studies also showed that improving synchrony and reciprocity modeled the child's cognitive and linguistic development as mothers made active efforts to communicate (Lederberg & Everhart, 1998). In other words, fluidity and turn-taking is not typically seen in hearing mother and Deaf child dyad, thus does not arise naturally but is learnt (Swisher, 2000). All participants find it hard to learn sign language as also portrayed in most studies of parents of Deaf children (Brubaker & Szakowski, 2000; Napier, Leigh & Nann, 2007; Vaccari & Marschark, 1997). Three mothers share that their child is very well observant of their lips and are adepts of lip reading. However, studies show that Deaf individuals are only able to understand 30% of the conversation when lip reading (Ingber, Al-Yagon, & Dromi, 2010).

Developed countries such as Australia established and developed detailed teaching curriculums of Australian Sign language to parents and children (Napier, Leigh & Nann, 2007). Necessary tools, knowledge and support are offered to learn sign language and communicate with their Deaf child consistently. The project in Australia aimed to standardize resources around the regions in the country, for example by using universal signs and teaching them in elementary schools. Lebanon has yet to establish a nationally-recognized sign language (Bakhos et al., 2022; Broughton, 2018). Thus, doctors may not suggest its acquisition (Article 19, Lebanon: Disability and Access to Information, 2015). In comparable circumstances, the Netherlands has an extended system of education but has no legal recognition of sign language (Knoors, 2007). They believe that a child is a little linguist. They encouraged establishing a shared language between the parents and child.

Three mothers in the study are curious about sign language as they chose the intervention modes. One mother describes easier interactions when her child signs '*water*' for example rather

than uttering the words. In contrast to this, according to one participant, her son was not eager to learn sign language and she wanted his identity to develop around hearing people solely. A comparable experience is shared by one mother as she rejected sign language at first. According to her, communicating normally means acquiring oral language. As time passed, she reveals that despite how hard she tries to change her daughter, she was '*still Deaf*'. This illuminates her daughter's identity and sense of personhood. She is now looking for sign language courses at the LCD and hopes to take part too.

Different depictions concerning the choice of communication is reported. All mothers noticed that extended families favor oral communication over sign language whereas siblings are motivated to learn and have access to their sibling's language. This finding is echoed in the study by Lederberg and Everhart (1998) where the findings show that the Deaf child's communication seem to improve when siblings learnt to sign. In one participant's neighborhood, children acknowledged her child by playing with him as they try communicating accordingly with him (Opoku et al., 2020). There is a lack of understanding that bilingualism needs to be highlighted in their child's development and world (Alfano, 2019)

In summary of this subtheme, there is an understanding that the hearing world is represented in the household, and the Deaf world belongs to their school and peers. However, this is clearly not representative of the real world and the participants acknowledge the need to understand their child as much as their child tries to balance and integrate both worlds. According to Swisher (2000), mothers are expected to be skilled in communicating in the visual mode and to provide accessible language input to their children from the beginning of life. All mothers value using oral language and preferred employing assistive devices to improve the child's hearing. Children are encouraged to vocalize and develop their lip-reading skills while

also learning sign language. This is consistent in other research' findings (Ahmad & Brown, 2016). They also all recognize the interplay between the hearing and the Deaf world, that communication is key and constitutes their new reality. This choice is also translated in the school chosen for their child. Making the choice to place hearing aids or make the child go under surgery for an implantation is reported as the hardest and most stressful decision for parents (Zaidman-Zait et al., 2015). The child's deafness engenders many challenges including communication difficulties and the acceptance of both parents and child of the new device, if chosen.

Choice of school

The previous section and the literature depict the mothers' readiness to support their children in optimizing their learning environment while adapting to the Deaf child's needs (Jean et al., 2018; Paradis and Koester, 2015). Mothers share affirming and disaffirming experiences related to their child's education and school system. Four mothers enrolled their child in inclusive schools. Their argument revolves around including their child with '*everyone*'. They do not want to marginalize them in a specialized school as it is not representative of the real world.

For the mother who enrolled her child in a specialized school, her sole purpose is to expose her child to '*people like him*'. She is aware his oral skills are limited but she maintains her decision (Lederberg & Everhart, 1998). She believes a mainstream school would break him psychologically and he would have been rejected and differentiated from his peers.

Similar thought processes are shared by participants who enrolled their child in inclusive schools. One mother longed for her daughter to be treated like a *normal child* because in the real world, she was seen as different. The parent is determined to expose her to real-life situations

and empower her to defend herself and be assertive. This idea is also echoed by other mothers, who recall their experiences in the nursery and found that being in a blended classroom was not problematic. These experiences encouraged them to take the decision. The mothers' choices are also facilitated by their Deaf child's easiness of adaptation in an inclusive classroom.

Advocacy additionally helps them feel contained in their micro society. This micro society is constituted of deaf people. They are part of the wider community in Beirut for example but also have a widely different language, their proper communication needs, art, and values. As shared earlier, one mother explained to classmates about the cochlear implant and allowed everyone to touch it to feed their curiosity. Another noticed the teachers did not know how to interact with a Deaf person and thought about enrolling her child in a specialized school. She realized this would not be beneficial nor constructive and instead tried to give the teachers the benefit of the doubt and guided them.

In conclusion of this subtheme, three mothers enrolled their Deaf child in inclusive schools and wanted their child to be part of the *real world*; they constituted a minority. For one mother, the choice of a specialized school seemed natural as she longs for her child to be treated as 'normal'. For one of the mothers of a child who has a cochlear implant, enrolling her in a mainstream school was evident. She did not want to differentiate her child from her peers in any way. For one family, higher education and a career are also part of their plans. There are no limits to what they picture for their child and they encourage him to do what he wishes, as any other teenager. All the mothers share their aspirations that their child will '*be someone*' and achieve great things in life. These desires and choices do not come without anxiety or worry and this can be referred back to the section: '*Worry about the future*'.

Suggestions for professionals in Lebanon

At the end of each interview, participants are encouraged to share what they thought could help improve Deaf people's lives in Lebanon. All of them refer to suggestions to professionals. They share the incredible need for improved equipment for congenital testing and screening (Störbeck, 2012). The theme of support is also highlighted and is reflected in a previous section where mothers did not trust medical professionals. They all express feeling more contained by mothers and persons going through similar experiences.

Society's reactions and attitudes are underlying themes: They all share that exposure and awareness are key. Societies should be exposed to people with hearing impairments, cochlear implants, hearing aids and any information feeding their curiosity. They also notice that people in Lebanon, even if they were educated, do not know that Deafness or hearing impairments may not relate to the person's intellectual abilities (Bakhos et al., 2022; Broughton, 2018). This is highlighted by their own experiences as all participants did not hear or know about Deafness before they had a child with a hearing impairment. They all share that awareness is needed and their advocacy may not be enough.

Concerning formal support and guidance from professionals, parents are not given enough time, information and the relationship is not collaborative. Various parental needs are not met by the medical field. The choice of hearing amplification technologies depends on the information provided, availability and family's financial capacity (Zaidman-Zait, 2007). According to the Law 220 on *the Rights of Disabled Persons* referred to as Law 220/2000, people with physical and developmental difficulties have the right to have facilitation and assistance in their admission to various medical services and education (Article 19, Lebanon: Disability and Access to Information, 2015). However, regarding the implication for persons with disabilities in Lebanon, there are "major failings in the contents, implementation and enforcement of public

laws, policies and practices” (Combaz, 2018, p. 30). This is not portrayed by the participants who found that the cost, access and support are lacking. Additionally, the definition of disability in the Law 220/2000 does not conform with international standards and does not provide enough information around inclusion in Lebanon (CESCR, 2016). Jamieson, Zaidman-Zait and Poon (2011) shed light on financial resources needed for parents of Deaf children for provisional services over time including the cost of hearing devices, batteries, consultations, therapy sessions and other services.

Social support is underscored in varied studies and further reinforced in the participants’ interviews (Calderon & Greenberg, 2000; Roumanos, 1995). The WHO (2020) also emphasizes the importance of early identification, optimal interventions, and the availability of suitable professional and informal support. The conceptualization of social support closely relates to the stress and coping theory of parents that would form a basis for family-centered care (Poon and Zaidman-Zait, 2014). Significant social and emotional development are noted by parents when the child’s path and future endeavors are clearer. Additionally, in the literature, parents assisted by professionals report an improved state of well-being and effective ways to cope (Cagulada and Koller, 2019). However, societal attitudes, stigma and discrimination of Deaf individuals seems to cause major concerns for family members, despite the implementation of policies and inclusive practices (Article 19, Lebanon: Disability and Access to Information, 2015; Bakhos et al., 2022; Broughton, 2018).

All participants share that the government and professionals play major roles in implementing contained and tolerant attitudes towards people with disabilities. For example, concerning the educational system, they share that inclusive schools need funding to improve teachers’ training and provide optimal material to integrate children with additional needs. The

curriculums would be more adapted to each child's capabilities. Three mothers are appalled by the differences noticed in school curriculums and the relatively low levels at specialized schools. One mother is adamant that Ministries are not providing nor executing basic Human Rights of Deaf people or people with disabilities in general (WHO, 2020). For example, providing free hearing screening tests for newborns or babies is a start. Another example relates to sharing campaigns to a larger number of hearing and Deaf individuals with simple terminologies and information around deafness.

In summary of this subtheme, mothers encourage the execution of the laws protecting and facilitating Deaf individuals' quality of life in Lebanon. They also relate this to society's stigma and discrimination. If people are exposed to more information, marginalization of Deaf individuals would decrease. Suggestions for practice are laid in details in the next section.

5.2 Implications

Participants in this project are considered co-researchers contributing to the literature. Their challenges, experiences, self-reflections, worries, empowerment and other lived experiences are at the basis of the interpretation and phenomenological analysis. The following sections present the study's implications in the field: its clinical relevance, influence in social change, and knowledge generation for this particular population and practitioners in contact with this population. Finally, a discussion of the findings regarding the importance of counseling for mothers of Deaf children is offered.

5.2.1 Clinical relevance

Concerning clinical relevance, this project highlights the mothers' needs and necessities to be contained by practitioners. The findings help practitioners shed light on the importance of

examining individualized plans and interventions for mothers' specific needs to provide suitable and optimal psychosocial support.

A shift of attitude from the pathological and medical perspectives to a sociocultural view of deafness in the 20th century reveals a more inclusive view (Mendel and Venon, 1971). Deaf awareness, Deaf studies and the implementation of sign language in school systems in developed countries contribute to that shift (Roumanos, 1998). But, this approach and application are not witnessed in Lebanon, as Deaf awareness is still in its early stages (Broughton, 2018; Roumanos, 1999; 2008). Accordingly, Bakhos and colleagues (2022) reports and confirms the lack of unified consensus regarding Lebanese sign language to this date. Nonetheless, the implementation and use of Lebanese sign language among deaf communities, the media, academia and interpreters bring a sense of cohesion (Broughton, 2018). The literature and this study emphasize the need for richer information around the Deaf community and the inclusion of parents of Deaf children in the exploration too. Psychiatrists in Lebanon conducted a review of laws related to mental health in Lebanon and found that these laws do not conform to international standards such as those in the UN Convention on the Rights of Persons with Disabilities (Kerbage, El Chammay, & Richa, 2016). There are no clear legislations that would guide psychiatrists and practitioners faced with clinical dilemmas in their practices that would protect patients from abuse for example (Combaz, 2018).

The diagnosis of a hearing impairment is reported by a multitude of studies as an emotionally charged period for hearing mothers (Zaidman-Zait et al., 2018). Participants in this project confirm the rollercoaster of emotions when raising their Deaf child in Lebanon. They are bombarded with thoughts, worries, and wonderings about their life, their child's development and next steps around rehabilitation and interventions (Meadow-Orlans, 1994; 1995). All the mothers

searched or are offered support by non-professionals mostly, as well as health professionals such as doctors, technicians and audiologists. The availability and easy access to support at the LCD relieved the mothers in crucial decision-making and improved their wellbeing. They also rely on their gut feelings when a decision needs to be made (Gigerenzer, 2007). This information sheds light on the drastic need for trained counselors and practitioners working with individuals with hearing impairments. The aim is to ensure improved access to families and parents to beneficial counselling services.

In the study by Steinberg and colleagues (2019), mothers are considered active in their decision-making when they enquire, constructively question, and investigate information conveyed by medical professionals in Lebanon. The decision-making process of passive mothers portrays the acceptance of suggestions and guidance at face value, without questioning (Bosteels, Van Hove & Vandebroek, 2012; Gould, 1992). Mothers in this study are active in their decision-making when they receive informal support from family members and other mothers going through similar experiences.

Gaining deeper insight and better understanding of the mothers' lived experiences and meaning-making through ongoing dialogue assist practitioners in providing adapted services and interventions. Improved counselling services to better assist mothers and parents are needed upon hearing the diagnosis and when decisions need to be taken. Support and counselling are also required throughout the child's development, until adulthood, to become healthy and productive members of society, similarly to their hearing peers.

5.2.2 Social Change

Motherhood and deafness are socially constructed concepts. Thus, mothers cannot be taken in isolation from their environment. Lebanese communities living in Lebanon are

influenced by a combination of Arab values and Western attitudes. Also, decision-making and personal goals are subordinate to collective goals. A crucial window of time for language acquisition is apparent in children for optimal cognitive and emotional development. It is also important for mother to convey that intellectual delays associated with hearing impairments are debunked as these views are unfortunately still among common misconceptions.

The participants show that the micro-community, formed by the parents, children and mothers of Deaf children matter the most. This is also apparent among the Deaf community constituting a micro-society of its own. The formulation of the Self and personhood is related to a combination of cultural views and collective selves in connection with the language learnt.

Colloquial Arabic is the language employed in Lebanon, and Arabic has a proper ontological aspect to semantics (Ayyash-Abdo, 2001; Parkes, Schneider & Bochner, 1999). Stemming from a collectivistic orientation, in an Arabic sentence, the 'I' is usually dropped. Thus, the Self is removed from the focus of attention. Using Arabic as a main language may reinforce the collectivistic orientations and this is witnessed in the participants' narratives. But, what do collectivism, language, social change have to do with Deafness and motherhood? Deaf individuals have their own language - that is mainly visual - their own art, cultures, way of being, and way of experiencing the world (Meadow-Orlans, 1994). As this study depicts, mothers must make decisions related to language and communication during a time typified by a plethora of emotions. With these information in mind, the web of interwoven interactions succumbs to social and cultural views. Whether the society is collectivistic or individualistic, whether they view deafness as a disability, a gift of God, or a different way of being-in-the-world, each individual has their own needs, aspirations, abilities, and competences. (Fjord, 2001). This study thus sheds

lights on the mothers' views and attitudes towards their Deaf child that in turn highlight the uniqueness of their experiences.

The study conveys the mothers' conception of Deafness, who clearly do not perceive their child as disabled but rather shaped by society's attitudes. All of them went through hardships and took the time to grieve the child they longed for, but they also all empower their Deaf child, themselves, and other mothers going through similar experiences. They do not want to be in the shadows as the case for many Deaf individuals in Lebanon. The aim is to show the world that they are capable of anything and everything when offered the opportunity.

Roumanos (1999) shares four levels of difficulties institutions in Lebanon face that are still relevant nowadays: 1) provision of basic need including personal health, healthcare, personal safety; 2) Institutional practices including qualification of teachers, availability of needed materials, equipment, books and tools; 3) Provision of adequate number of qualified personnel targeting special educational teachers, language specialists, and social workers; 4) Goal of the full integration of Deaf people into society by offering vocational training, independence, autonomy and protection from exploitation. There are no enforced measures supporting and ensuring vocational, social and health-related rehabilitation programs for people with disabilities. Also, there is a lack of inclusion of persons with disability in labor markets despite that the law 220/2000 recognizes their right to work (Combaz, 2018). The mothers' concerns around their child's future is thus valid. Also, the main reason explaining the inaction related to the crisis and impasse in the formal political system in Lebanon and this includes shortage of budget to address the basic needs of persons with disabilities (Lakkis et al., 2016).

5.2.3 Knowledge Generation

The current study contributes to the literature and scientific knowledge by disseminating the lived experiences of mothers of Deaf children living in Lebanon. Following the literature search, a limited amount of empirical studies and research related to the population targeted are depicted. Most existing research are focused in developed countries in Europe and the United Kingdom for example. Scientific research is thus not subsidized in countries in the Middle East. The scarce Deaf studies existing in Lebanon primarily focus on the medical perspective and technologies of hearing impairment. This leaves no attention to parents of Deaf children or the Deaf community. The mothers' acceptance process, meaning-making of their role, challenges with the medical world, advocacy and empowerment plans and communication strategies are among the themes this study conveys to enrich researchers and practitioners' knowledge. Additionally, reports highlight the confusion among populations in Lebanon about the difference between physical and intellectual disabilities as well as physical and mental health problems (Combaz, 2018). Prejudice, stigma, negative attitudes and behaviors towards deaf people are worsened (Bakhos, 2022). In turn, persons with disabilities receive inadequate levels of assistance and are left facing stigma and isolation.

5.2.4 Counseling for mothers of Deaf children

This subsection focuses on the discussion of the findings regarding the importance of counseling for mothers of Deaf children in the light of the literature.

Family dynamics, language, cultural backgrounds, mental health problems and the Deaf child's temperament and characteristics are among the factors influencing maternal stress (Rivadeneira, Silvestre, & Laborda, 2015). In Lebanon, support to mother and families of Deaf children is limited to a specific area in Lebanon (Article 19, Lebanon: Disability and Access to Information, 2015). The support needed comes in the form of concrete informational and

emotional support from professionals (Zaidman-Zait et al., 2018). Counselling services should be developed to gain access to prenatal diagnosis and allow access to information and support to families (Alsulaiman et al., 2014). The aim of counselling is to guide mothers in promoting their child's optimal development and psychological adjustment and improve the mother-child communication (Sajjad, Saleem & Aziz, 2016). Counselling is positively correlated with the mothers' general sense of relief, confidence, and coping strategies. Interestingly, the amount of informal support from friends and family do not significantly affect the mothers' engagement in their Deaf child's interventions programs and rehabilitation (Zaidman-Zait et al., 2018). It is thus important to differentiate between formal and informal support offered and their impact on the mother's coping, wellbeing, and involvement in her child's development.

In the study by Sajjad, Saleem and Aziz (2016) and as reflected by the mothers in this study, information concerning assessment, diagnosis, rehabilitation, communication strategies and the choice of schools are specifically required and needed. A complex and eclectic position between social and medical models of disability is needed. The aim is to acknowledge individual differences, the family dynamic and the context the parents are embedded in. The audiologist responsible for the child is on the frontline to provide information about the hearing loss, strategies applicable and the effects for the family (Luterman, 1999). Also, a multidisciplinary team including social workers, educators, psychologists, therapists, physicians, speech therapists, are effective in providing their services to mothers and their Deaf children.

In conclusion of this section, understanding the characteristics of families and mothers of Deaf children seem almost impossible because of the heterogeneity and diversity of families encountered (Calderon, Bargones & Sidman, 1998). Nonetheless, individualized and systemic

interventions are appropriate for the child's development while taking into consideration diversity and other factors proper to each family.

5.3 Study limitations

There are several limitations to this research project. As a hearing person interested in Deaf studies and actively conducting workshops and awareness sessions, several persons asked me about the reasons behind wanting to delve into this community. The answer is not evident. Additionally, being a childless young adult investigating parenting experiences can be a limitation. Parents might not view me as capable of understanding how stressful parenting is, let alone parenting a child with a 'disability'. Nonetheless, I am conscious of the preconceived ideas and assumptions people might have and I maintained this self-awareness during the research and kept a reflexivity notebook. Also, since I have a certificate in child and adolescent mental health and currently training as a psychotherapist, I am confident about my skills in approaching parenting concepts and parent-child dynamics with an open mind.

Another limitation concerns the representativeness of the sample and transferability of findings, mainly due to the sample size and purposive sampling. Participants do not share similar demographic information although they are all recruited and in contact with the LCD. The mothers come from cities all across Lebanon and have different journeys enriching the data conveyed through this research. Nevertheless, the size of the sample limits the potential for applicability to mothers of Deaf children in Lebanon despite in-depth analysis engendering prolific findings.

All interview data is understood and highlighted from the mothers' self-reports and recordings. Data is therefore subjective and possibly influenced by my presence, attitudes, body

language and the interaction between the participating mothers and I. For two of the mothers in the study, interviews took place through video call. This means of communication may play a role in the mothers' ease and readiness to share personal information. Furthermore, I interpreted the data and transcripts and may thus be subjected to bias and influenced by my own subjectivity.

Despite the limitations communicated, the study validity, reliability and the possible biases are rigorously kept in mind throughout the research execution. The value of the study's findings is explored in the following section and the dissemination plans are conveyed.

5.4 Value of findings and dissemination

As the first research project in Lebanon around mental health of mothers of Deaf children, I hope this would be the start of a series of studies on Deaf Mental Health in Lebanon. I plan to publish the manuscript in journals tackling parenting, education and counseling psychology. The main purpose is to raise awareness on parenting a child with hearing loss to enable change and facilitating parents' guidance in the best-fitted programs and interventions.

This study's findings, as other research support it, paint a clearer picture to what hearing mothers of Deaf children might see as useful and on the contrary, hinder their involvement in their child's life (Zaidman-Zait et al., 2018). Mothers are readily and actively looking for available information and meaning about deafness to better integrate them in their new role as a mother of a Deaf child (Bosteels, Van Hove & Vandebroek, 2012). Thus, professionals would better understand and develop suitable support and services. Doubt and low self-confidence are prominent when mothers are exposed to medical terminologies, auditory tools and life-changing decisions.

I also intend to disseminate the findings on public platforms on social media to spread the data and hopefully influence mothers dealing with parenting a Deaf child. Additionally, I am planning on presenting the study to the ministry of Public Health in Lebanon and shed light on the importance of support from professionals and implementing clear-cut national guidance in Deaf-friendly services among the medical field and mental health sector.

I would like to prospectively work on a self-help book dedicated to Lebanese parents of Deaf children that includes information on what to expect, how and where to get help as well as few guidelines and materials on the importance of communication and sign language among family members.

Maternal identity, the mother' self-representation when parenting a Deaf child and the mother's representation of her Deaf child need to be highlighted in future research. These would constitute grounding points for psychotherapy and psychological support.

Chapter 6: Conclusion and recommendations

This project is the culmination of the doctoral research. The literature review presents the main and crucial information around deafness. According to the mothers in this study, the medical perspective defines deafness as a hearing impairment needing to be fixed. In their narratives, their encounters with the medical professionals seemed brief and information insufficient. However, this sample of participants encountered doctors who opted for enhancement devices. Thus, this conclusion regarding the provision of care by the medical doctors such as audiologists and family doctors were proper to the five participants in this study. Nevertheless, forging the partnership between parents and professionals was highlighted in the literature across cultures. The social and cultural perspectives of deafness and ‘Deafhood’ defined it as a cultural minority. The word ‘Deaf’ with a capital ‘D’ portrayed the communities with their proper language, art, literature, and way of Being. In this study, a third model in the conceptualization of deafness is highlighted: the social constructionist model. Society’s perceptions, attitudes, misunderstandings, barriers implemented all affect the mothers’ perception of their child’s condition. The narratives touch on the medicalization of deafness. So, the parents’ aim is to diminish social and structural barriers faced in the Lebanese system.

The aims, the research question and rationale behind the study are presented. The chapter on methodology describes the research methods used to form a concise, rigorous and trustworthy qualitative research study. Five mothers are subsequently recruited: three interviews are held face-to-face and two over video. Ethical considerations, confidentiality matters concerning the recordings’ transcription and data storage are explained. Following an interpretative phenomenological analysis, transcripts are analyzed and the findings presented: the clusters of themes and subthemes relevant to the study are grouped. My reflexivity throughout the project is

presented to ensure transparency. Finally, a discussion of the findings and incorporation of the research implications are refined and presented.

Following the WHO (2020) recommendations, the primary healthcare system in Lebanon need to provide adequate training and resources to healthcare professionals to better support parents and people with hearing loss. The aim is to develop and implement useful information around prevention, interventions and rehabilitation. As mentioned by the participants in this study, advocacy and Deaf awareness sessions to all social classes and people of diverse educational levels need to be offered. The findings show the need to encourage slowing down in crafting appropriate intervention practices from families. The challenge is to embrace unpredictability at the beginning of the child's life and creating space for reflexive professionalism. It is also up to professionals, in liaison with the ministry of Health or Social Affairs, to rigorously identify and disseminate reliable statistics, prevalence, causes and outcomes of hearing loss among the Lebanese population. This in turn promotes inclusion and reduction of stigma related to hearing loss, which leads to societal changes lessening discrimination. The family and the Deaf child's wellbeing would improve as their needs are being met. Additionally, service providers need to target less-educated mother with regards to communicating with their child.

To summarize, Lebanese Sign Language essentially needs to be recognized as a national language and taught in schools. The promotion of social inclusion of people with disabilities reduces the stigma through exposure and community-based programs and events such as the global advocacy alliance by organizing the World Hearing Forum, or including World Hearing day in the annual advocacy calendar of events. Also, prospective studies are recommended to examine family-care frameworks in terms of formal and informal support. Family-centered

approach is recognized as cornerstone to effective EI. The key words to this approach include: provision of care, guidance, support and collaborative partnership.

6.1 Existential paradigms

Concerning the study's findings, existential paradigms are reported. In line with the view taken by van Deurzen (2012), the mothers' four basic dimensions of human existence were highlighted. They encounter the worlds and shape their values, attitudes and beliefs. Regarding the personal dimension, known as *Eigenwelt*, expectations of motherhood are questioned and reassessed. The mothers went through internal struggles and ambivalence between the hope to be heard and the fear of having to recognize the impairment. A search of identity and conceptualization of motherhood are explored by the mothers as they are adapting to their child's needs. All the mothers, with no exception, went through periods of denial upon hearing their child's diagnosis. The motherhood crisis is translated from the existential crisis of the woman questioning and recalibrating her views, values, and attitudes of the world and Self.

As for the physical dimension (*Umwelt*), the mothers relate to their environment and tried to make sense of the world around them. The hearing impairment seemed alien and their coping strategies and processes differed in many ways. The mothers are aware that the individual's body is not reduced to their senses as they would think before raising a Deaf child. For some of the mothers, crying is their way to grief the child they longed for. For others, finding solutions and support are conveyed as their utmost goals. As the mothers' time and energy are dedicated to their Deaf child, they feel guilty towards their other children. There is a sense of overcompensation for their child's hearing impairment. Time is a predominant theme in the narratives: the time *wasted* between the child's birth and the time of diagnosis, the time spent crying, the time spent commuting to doctors' clinics and therapy sessions. The worry about the

future as well as binary oppositions the child is faced with between the hearing world and the Deaf world are also expressed. The difference in language development is highlighted as they are apprehensive about their child's future and compared them with their peers.

Regarding the social dimension (*Mitwelt*), the mothers' experiences of relating and interacting with Others around them are highlighted. Their sense of belonging extended to the way they relate to their child and reaction of others. For two mothers, they feel that their interaction with the medical doctors was more about a business transaction rather than considering the person's needs and thinking about individualized plans. Here, the sense of isolation is apparent. In paradox, informal support is offered by family members and all the mothers felt a sense of belonging. However, this support is at times encouraging but at times the mothers are blamed for not shedding enough light on their child's ability to speak. This difference is explained by a generational gap and lack of information provided. For example, grandparents believe that the more the mother trains a child to hear and read lips the more their disability fades in the crowd. The mothers are clear about not normalizing the disability, and help the children blend in but rather shed light on accepting their differences and abilities. The recognition of Lebanese Sign Language (LSL) is encouraged among practitioners in Lebanon but speech is the dominate communication means.

Van Deurzen's (2012) fourth dimension, the spiritual dimension (*Überwelt*) is of utmost importance in the mothers' narratives and way of being. It is through this dimension that the individuals find meaning by putting all the pieces of the jigsaw together. All the mothers create their values in search of meaning and understanding in relation to their personhood and motherhood. All of them share their gratitude towards 'God' in bringing strength and perseverance when they are faced with challenges in the conceptualization of deafhood. In their

narrative, the paradoxes of purpose and absurdity, hope and despair are apparent throughout their journey of acceptance. All the mothers mention their aim of advocating for Deaf children and empowering their child towards independence by acknowledging the reality of their own death. This in turn surpasses mortality: the mother would have contributed to something valuable to humankind, to their community.

6.2 Recommendations for future research

The contribution of this investigation relates to the mothers' personal and emotional narratives, experiences and the mothers' challenges in their child's education and rehabilitation. A number of strong and promising foundations to build upon are presented in the thesis. For example, continuing to draw from theoretical frameworks of support capturing the multidimensionality of support. Further research could also be made with a pool of participants from varied background such as from the South or North of Lebanon and social differences could be drawn out. The focus of future research relates to the mode of communication, sensory devices (rehabilitation), formal and informal support available in Lebanon and a directory of inclusive schools and family orientation. This section presents recommendations for prospective research within the area of interest.

Deaf mothers of Deaf children or Deaf mothers of hearing children

The research population is refined to this sample of data from hearing mothers of Deaf children. Therefore, further research could explore the lived experiences of Deaf mothers of Deaf children in Lebanon for example. Research studies in this area need to assist professionals in developing a better understanding of Deaf individual's experiences (and their families) and develop a deeper understanding of the Deaf Community in Lebanon.

Single mothers or divorced parents

Participants in this study are married and part of a two-parent family at the time of the interview. Further research is recommended to explore the lived experiences of single mothers, divorced mothers sharing custody (or not) of their children, or unmarried mothers. Further study among this population may assist professionals from different fields develop a deeper understanding of mothers' experiences not living with a partner or part of a two-parent unified family. The aim is to explore potential influences and factors that may contribute to the different experiences, whether relational or environmental, in raising a Deaf child.

Sexuality – Parents or children from the LGBTQIA+ (Lesbian, Gay, Bisexual, Transsexual, Queer, Intersex and many other terms) community

Participants in this study identify as part of a heterosexual married couple and sexuality is not discussed. Future research may recruit and explore the narratives of mothers and/or their Deaf child identifying as members of the LGBTQIA+. The aim is to gain deeper understanding of the lived experiences, the challenges, the ways of Being-with-others and the sense of personhood of Deaf persons identifying with the LGBTQIA+ community in Lebanon.

Mothers who choose not to employ hearing assistive devices

Executing similar research to explore experiences of Deaf children (and adults) in Lebanon is crucial in Lebanon. All the mothers in this study decided to employ hearing assistive devices for their children. I did not have the opportunity to recruit and explore the lived experiences and meaning-making of mothers of Deaf children without any assistive devices. Therefore, further research in this area may need to form a better discernment of this population

and assist professionals working with hearing mothers of Deaf children with and without hearing devices.

Sign language

The findings pave the grounds for the development and the implementation of EI which are essential for Deaf children's language and cognitive development. Also, there is a need to provide and teach family-based sign language for all family members rather than solely focusing on the Deaf child. For the development of appropriate sign language curriculum for typically-hearing parents of Deaf children, several components of each family need to be taken into consideration. Individualized modules need to be integrated in teaching curriculums where parents are taught skills and strategies to communicate, play, read and attend to their Deaf child's needs and abilities.

6.3 Recommendations for practice

In this subsection and after thoroughly presenting and discussing the findings, the implications and suggestions for practice for health and education professionals who work in the field of study are offered.

On the basis of this dissertation's findings, parenting stress is highlighted and this included: 1) the hearing mother and Deaf child's communication difficulties; 2) The mother's concerns regarding the child's education and future; 3) The mother's choice and availability of hearing enhancement devices aid and rehabilitation and 4) The mother's several roles taken including being a language teacher and interpreter to the child. As depicted in the narratives and in the literature, mothers and caregivers also emphasize the need to simply being a mother rather than an interpreter for their child. Thus, communication difficulties and improvement are of

utmost importance in service provision. There is a significant need in sensitivity to the way service delivery is provided. Despite the structural issues in Lebanon that affect accessibility and availability of tools, varied number of organization in Beirut, the capital, have been working since 2005 in providing the necessary support to parents and Deaf children. Few recommendations for practice are presented:

- Interventionists need to engage in community education and outreach as well as provide direct services by making resources available and accessible to wide range of communities in Lebanon.
- Trained counselors and practitioners need to work with this particular population to ensure improved access to families and parents to beneficial counselling services. Practitioners and medical doctors need to master the use of Lebanese sign language.
- More emphasis need to be placed on working with the entire family system and context by the practitioners and clinicians in contact with this population. Support for siblings need to be highlighted in the service provision.
- Counselling services should be available for parents as soon as the diagnosis is given. Follow-up with mental health professionals is essential in the rehabilitation process.
- Bimodal-bilingual approach needs to be emphasized among family members. The Deaf child's identity would thus be valued, recognized and respected.

The final statement is a quote by Maurice Merleau-Ponty (2013; p. 214): "Our view of man will remain superficial so long as we fail to go back to that origin [of silence], so long as we

fail to find, beneath the chatter of words, the primordial silence, and as long as we do not describe the action which breaks this silence. The spoken word is a gesture, and its meaning, a world.”

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Appendix A



Existential Academy
61-63 Fortune Green Road
London NW6 1DR



Middlesex University
The Burroughs
London NW4 4BT

Participant Information Sheet

“Exploring the lived experiences of hearing mothers of Deaf children in Lebanon: A phenomenological study”

**Conducted by
Reem El Baba**

As required for the Doctorate in Counselling Psychology
from NSPC and Middlesex University

Date: October 2019

This is an invitation to take part in a research project reviewed and approved by Middlesex University Ethics Committee and the NSPC research ethics sub-committee. Before deciding whether to participate or not, take your time to carefully read and understand the aims behind this research and what it involves. If anything is unclear or if you wish further information and clarifications, you are encouraged to ask me.

What is the purpose of this research study?

The goal of the study is to examine the experiences of hearing mothers who have a Deaf child between 10 and 15 years of age. The aim is to shed light on mothers' everyday lives with a Deaf child. Motherhood experiences such as the challenges, interactions and communication experiences will also be covered.

What happens if I take part in the study?

If you wish to participate, here are the steps and information to keep in mind:

- You will first send me your contact details so I can get in touch with you and arrange a mutually convenient time and location in Beirut for an informal interview.
- The interview will be digitally recorded and will last around 60 minutes and not more than 90

minutes.

- Before the interview, I will administer to you a short questionnaire to collect some demographic information and check your eligibility for the project.
- You are free to stop the interview at any time and withdraw your participation without giving any reason for doing so.
- All information retained will be destroyed after 10 years.
- A list of centres and hospitals offering psychological services will be handed out to you if you wish to seek further support.
- During the interview, you are encouraged to speak openly and reflect on your parenting experiences with your Deaf child.
- You can express yourself in any language you feel comfortable with (Arabic, English and French).
- Once the interview is over, time is provided for debriefing and I will re-explain the objectives of the project and clarify the next steps of the project.
- All information you provide is strictly confidential and, as far as is practically possible, your data will not be identifiable.

What will you do with the information I provide?

I will follow the Data Protection Act 2018 to handle all information and personal data you present. A project code will be assigned for each mother and I will attempt to protect anonymity by changing identifying information. All data provided will be transferred to an encrypted USB stick and all personal information that you present will be kept in a locked drawer separately from the other files and will be destroyed after 10 years of the study submission.

You have the right to access any of your data collected by making a request to the address provided on this form. Please note that data will not be transferred via email as it is not a secure method of communication. If the research study is published, I will make sure that no identifying details nor names provided will be employed. The research will be carried out according to the ethical code of the *United Kingdom Council for Psychotherapy* and the *British Psychological Society*.

There are specific circumstances in which I am legally required to break confidentiality. Under the Children's Act 2004, I will report any information that associates you with risk. Under the Terrorism Act, 2000, I am obliged to report any information that ties you with terrorist activities. Additionally, if you or another person are at risk, I will take necessary measures to keep both you and any other parties safe.

What are the possible risks of taking part in this study?

Due to the sensitive nature of the research topic, it is possible that painful memories/emotions will arise during the interview, but you will be able to discuss this in a confidential and respectful setting. I invite you to openly notify me if you feel any distress at any time. You have the right to not answer questions and terminate the interview at any point in time.

What are the possible benefits of taking part in this study?

Reflecting and talking about your experiences could have a cathartic and therapeutic value. As a counselling psychologist in-training, I will mindfully listen to your experiences in a safe space and sensitively respond to any sign of distress you might express. Upon completion of the project, I will establish a support group for mothers of Deaf children and you will be welcome to be part of this community at your own pace. Also, you will contribute to a body of literature in this area which will help individuals and professionals alike to deepen their understanding of the experience.

Is there a consent form?

A copy of this information sheet will be provided and if you wish to participate, you will be asked to sign a consent form before the start of the study. I will personally go through the consent form with you before the interview to ensure you have understood what you are consenting to before we begin. You have the right to change your mind at any stage of the interview process and request that the interview be terminated.

Who can I contact if I have any questions?

If you have any further questions, you may contact me at:

Reem El Baba

Email: RE267@live.mdx.ac.uk

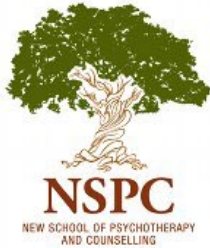
If you have concerns about the conduct of this project, you may contact my supervisor at:

Pam James

Email: office@nspc.org.uk

Thank you for taking the time to read this information sheet.

Appendix B



Existential Academy
61-63 Fortune Green Road
London NW6 1DR



Middlesex University
The Burroughs
London NW4 4BT

Written Informed Consent

Study title: Exploring the lived experiences of hearing mothers of Deaf children in Lebanon: A phenomenological study

Academic year: 2020/2021

Researcher: Reem El Baba

Supervisor: Pam James

- I have understood the details of the research as explained to me by the researcher, and confirm that I have consented to act as a participant.
- I have been given contact details for the researcher in the information sheet.
- I understand that my participation is entirely voluntary, the data collected during the research will not be identifiable, and I have the right to withdraw from participating in the project at any time without any obligation to explain my reasons for doing so.
- I understand that I can ask for my data to be withdrawn from the project until the transcripts are anonymised during the summer of 2020.
- I further understand that the data I provide may be used for analysis and subsequent publication in a scientific journal, and I provide my consent that this may occur.

Print name

Signature

Date: _____

N.B: Data may be inspected by the Chair of the Psychology Ethics panel and the Chair of the School of Science and Technology Ethics committee of Middlesex University, if required by institutional audits about the correctness of procedures. Although this would happen in strict confidentiality, please tick here if you do not wish your data to be included in audits:

Appendix C

Demographics Questionnaire

Research title: Exploring the lived experiences of hearing mothers of Deaf children in Lebanon: A phenomenological study

Researcher: Reem El Baba

Email: RE267@live.mdx.ac.uk

Supervisor: Pam James

Email: office@nspc.org.uk

Please feel free to ask me if you need any of the questions explained to you.

1. What is your age?
 - Under 18 years
 - 18-29 years
 - 30-49 years
 - Over 50 years

2. What is your marital status?
 - Single
 - Married
 - Separated
 - Divorced
 - Widowed

3. Do you have a Deaf child between 10 and 15 years of age?
 - Yes
 - No

4. If you answered Yes to question number 3, please specify the age and gender of each of your children and whether they have been diagnosed with a neurodevelopmental disorder (e.g., Autism Spectrum Disorder, Attention Deficit/Hyperactivity Disorder, Learning Disorder, etc.) and/or chronic illness (e.g., Asthma, Diabetes, Cancer, Crohn Disease, Cystic Fibrosis, etc.) in the following table:

Age	Gender (Male)	Deaf/hard of hearing	If yes, does he/she have a hearing aid or cochlear implant?	Has he/she been diagnosed with a neurodevelopmental	Has he/she been diagnosed with a chronic illness? If
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	or Female)			disorder? If yes, please specify.	yes, please specify.
		Yes/No			
		Yes/No			
		Yes/No			
		Yes/No			

5. What is the highest level of education you have attained?

- No schooling completed
- Lower than high school
- High school
- Technical school
- Undergraduate
- Graduate/Masters
- Postgraduate/Ph.D.

6. Have you or any of the members of your family consulted with or sought services from a mental health professional?

- Yes
- No

7. Have you or any of the members of your family been diagnosed with any mental health problems by a mental health professional?

- Yes
- No

Appendix D



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London NW6 1DR



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London NW4 4BT

Interview Schedule

as presented in the research protocol

Study title: Exploring the lived experiences of hearing mothers of Deaf children in Lebanon: A phenomenological study

Topic	Sample Questions
Parenting experiences	<ul style="list-style-type: none">• When did you know your child was Deaf? Who did you talk to about it?• What did you feel when you first noticed your child was Deaf?• What feelings come up when you talk about it?• What is it like to parent a Deaf child? How do you describe your relationship with your Deaf child?• “What does it mean to have a Deaf child” (Park and Yoon, 2018, p. 446).
Prospective experiences	<ul style="list-style-type: none">• What future do you see to your life?• What worried you about having a Deaf child?• What is it in your child that makes it different?
Family interactions	<ul style="list-style-type: none">• Did your child’s deafness affect the relationship with your family? How?• How do you communicate with your Deaf child? And with your other children? Has your child’s deafness affected your interaction with him/her?• What are the advantages of having a Deaf child in Lebanon?• What do you think are the difficulties you are facing with having a Deaf child?• In your opinion, how could things be improved?

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