

**A FRAMEWORK FOR HELPING MUSLIM PARENTS OF CHILDREN
WITH HEARING LOSS IN A SPECIAL EDUCATION SCHOOL IN
MALAYSIA**

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DEDICATION

I dedicate this thesis to all learners, helpers and truth seekers.

My special dedication to all parents of children with hearing losses.

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In the name of Allah, Most Gracious, Most Merciful.

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ABSTRACT

Parents of children with hearing loss (CHL) face a myriad of additional challenges, on top of the ordinary parenting challenges. In the Malaysian Muslim context, educating children is of prime importance and the family is considered the building block of the society, however, issues related to parenting CHL seem to be neglected. Thus, the objective of this qualitative study which is to develop a framework for helping Muslim parents of CHL in Malaysia is both timely and befitting. Prior to the development of the framework, the parents' experiences were explored via the lenses of Islamic and Bio-ecological perspectives. Phenomenology and Grounded Theory approaches were also utilized. Eleven parents and four teachers were involved in 32 interviews. Data from the interviews were triangulated with observation. In addition, questionnaire for parents, a research journal and memo were used as instruments to collect additional data. ATLAS.ti Version 7 software was used for data analysis and general data management. From the process of open, axial and selective coding, four main categories and 18 categories emerged. "Lack of authentic information" stood out as the core category and transcended into three domains, namely "hearing loss and related issues" "parenting and related issues" and "Islam". The framework addresses the issues of lack of authentic information within these three domains. Based on the findings, several recommendations have been proposed to assist parents and each party in the parents' microsystem, as well as to the Local Education Authority, helpers and future researchers. Anyone associated with parents of CHL would benefit from this study by understanding the complexity and challenges of parenting CHL, and using the framework as a guide to help them.

ABSTRAK

Ibu bapa yang mempunyai anak-anak bermasalah pendengaran (CHL) berhadapan dengan pelbagai cabaran, di samping cabaran biasa sebagai ibu bapa. Dalam konteks Muslim di Malaysia, mendidik anak-anak adalah sangat penting dan keluarga dikira sebagai asas pembinaan masyarakat, namun, isu berkaitan keibubapaan CHL nampaknya terabai. Oleh itu, objektif kajian kualitatif ini, iaitu membentuk satu kerangka untuk menolong ibu bapa Muslim yang mempunyai CHL di Malaysia adalah wajar dan tepat pada masanya. Sebelum pembentukan kerangka ini, pengalaman ibu bapa diteroka melalui lensa perspektif Islam dan Bio-ekologi. Pendekatan-pendekatan Fenomenologi dan *Grounded Theory* juga digunapakai. Sebelas orang ibu bapa dan empat orang guru telah terlibat dalam 32 temu bual. Data daripada temu-temu bual itu telah ditrigulasikan dengan data daripada pemerhatian. Di samping itu, soal selidik untuk ibu bapa, satu jurnal kajian dan memo telah digunakan sebagai instrumen untuk mendapatkan data tambahan. ATLAS.ti Versi 7 pula telah digunakan untuk menganalisis data dan menguruskan data secara amnya. Hasil daripada proses *open, axial and selective coding*, muncul empat kategori utama yang mengandungi 18 kategori. “Kurangnya informasi yang autentik” tertonjol sebagai kategori tunjang dan merentasi tiga domain, iaitu “masalah pendengaran dan isu-isu berkaitan” “keibubapaan dan isu-isu berkaitan” dan “Islam”. Kerangka ini menangani isu-isu berkaitan “Kurangnya informasi yang autentik” dalam tiga domain tersebut. Berdasarkan dapatan kajian, beberapa cadangan telah diutarakan untuk membantu ibu bapa dan setiap ahli dalam mikrosistem ibubapa, juga Pejabat Pendidikan Daerah, pembantu dan pengkaji akan datang. Sesiapa sahaja yang terlibat dengan ibu bapa CHL akan mendapat manfaat daripada kajian ini kerana dapat memahami betapa rumitnya cabaran menjadi ibu bapa CHL dan dapat menggunakan kerangka ini sebagai panduan.

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LIST OF ABBREVIATIONS

ACPT	-	Axial Coding Paradigm Template
ANOVA	-	Analysis of Variance
ASL	-	American Sign Language
BMKT	-	Bahasa Malaysia Kod Tangan
CBCL	-	Child Behaviour CheckList
CCM	-	Constant Comparative Method
CES-D	-	Centre for Epidemiological Studies -Depression
CHL	-	Children with hearing loss
CMV	-	cytomegalovirus
CSS	-	Critical Social Science
dB	-	decibels
D	-	Deaf
D/HH	-	Deaf and/or Hard of Hearing
DI	-	Deaf Infants
DemoQ	-	Demographic Questionnaire (for parents of CHL)
ECHI	-	Early Childhood Home Instruction
EVAS	-	Enlarged Vestibular Aqueduct Syndrome
FQoL	-	Family Quality of Life
HH	-	Hard of Hearing
HL	-	Hearing Loss
IQ	-	Intelligent Quotient
ISS	-	Interpretive Social Science
JKM Department)	-	Jabatan Kebajikan Masyarakat (Welfare Department)
LPP-PV	-	Language Proficiency Profile-Parent Version
LSD	-	Least Significant Difference (Fisher's)

LUCT	-	Limkokwing University of Creative Technology
MANOVA	-	Multivariate Analysis of Variance
MFD	-	Malaysia Federation for the Deaf
MCM	-	Manually Coded Malay
MSL	-	Malaysian Sign Language
OKU	-	Orang Kurang Upaya (A Disable Person)
PHL	-	People with Hearing Loss
PLS	-	Preschool Language Scale
PSI	-	Parenting Stress Index
RJ	-	Research Journal
SMTS	-	An acronym for a secondary school near SEPS
SEAI	-	Social Emotional Assessment Inventory
SES	-	Special Education School
TERA-D/HH	-	Test of Early Reading Ability-Deaf/Hard of Hearing
UNICEF	-	United Nations Children's Fund
USA	-	United States of America
WHO	-	World Health Organisation

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CHAPTER 1

INTRODUCTION

1.1 Introduction

The family is important (Gestwicki, 2007) because it is the most fundamental and basic social institution (Dickinson and Leming, 1995). As the basic unit of a society (Luqman Hakim, 1992; Chong and Cho, 1994; Myers-Walls, 2001; Jalaludin, 2007), families form a society and societies make a nation (Haji Lamin, 1998). Thus, without the families there would be neither society nor nation.

The family continues to be the crucial and enduring human social institution (Ingoldsby and Smith, 2006), providing many functions (Sasse, 1994) which are critical to the preservation of the human society (Ingoldsby and Smith, 2006; Mustafa, 1989). One of the family's functions is to nurture children. If a society is to persist, adults must not only bear children, but also provide them the basic needs during the long years of dependency (Lamanna and Riedmann, 2006). As infants cannot survive without being nurtured by caring adults, society will eventually diminish without families and communities to nurture (Berns, 2007; Mustafa, 1989).

Strong, DeVault and Cohen (2008) maintain that the family performs four important functions, namely: (1) providing a source of intimate relationships; (2)

acting as a unit of economic cooperation and consumption; (3) produce and socialize children, and (4) assigning social roles and status to individuals. Along similar ideas, Berns (2007) lists five family functions namely: (1) reproduction; (2) socialization/education; (3) assignment of social roles; (4) economic support, and (5) nurturance/emotional support. Through the fulfilment of these vital functions, the family ensures the continuity and survival of society (Berns, 2007; Hoghughi and Long, 2004). No institution other than the family institution provides such an intricate but fitting system; so basic yet elegant (Bohannan, 1985).

The long duration of dependency of the human infants to their families is a strong pointer to the crucial role of families as the critical medium for the survival of the human offspring. Ding and Littleton (2005) argue that this long period of dependency of children on their caregivers as one of the striking and distinguished features of human development. It is also during this dependency period that phenomenal and crucial development takes place, be it physical, psychological, cognitive or spiritual.

The most important members of the family are the parents (Nik Azis, 2002). That is why Bohannan (1985) believes that the ultimate purpose of the family is parenting. Ironically, this most important task of adults in the families is also the task that is the most poorly prepared for. In addition, parenting tasks become more difficult when the child has an extra challenge, such as a disability (Martin and Clark, 1996). This is a point of concern because disabilities affect 10% of the world population and is now a common phenomenon (WHO Media Centre, 2010). Thus, the most important purpose of the family, that is parenting, is at stake with the presence of children with disabilities.

1.2 Background of the Study

One of the disabilities that profoundly affect one's life is hearing loss (HL). It is a disability common among the general population (Backenroth-Ohsako, Wennberg and Klinteberg, 2003); it is everywhere (Andrews, Leigh and Weiner, 2004).

According to an estimate by the World Health Organisation (WHO), the number of people having moderate to profound HL in both ears is 278 million (WHO Factsheet no. 300, 2005). However, the number of people with HL worldwide could be higher—more than 500 million (Widex.com, 2009).

The prevalence of HL does not differentiate between developed or undeveloped countries. For example, between 2000 and 2004, the number of people having hearing difficulty in the United States of America (USA) was between 28.6 to 31.5 million (Kochkin, 2005). Similarly, in Europe, 71 million adults aged 18 to 80 years were hearing impaired (Hear.it, 2009). In fact Davis, Davis and Smith, (2009) state that one in six European has a HL, and this figure is expected to increase to one in four by the year 2050. A comparable data appears in the United Kingdom, where one in seven people experienced hearing difficulty or suffer from deafness (Davis, 1995; Morgan-Jones, 2001).

Under the American Disability Act (ADA) hearing impairment is a disability because the condition fulfils three criteria; namely, (1) the disability substantially limits a major life activity, (2) the disability substantially limits a major life activity in the past (3) the employer regarded (or treated) the individual as if his or her hearing impairment was substantially limiting (U.S Equal Employment Opportunity Commission, 2009). HL fulfils all three criteria and is thus a disability.

Further, WHO declares that hearing impairment is a serious disability which inflicts social and economic burdens on the individuals, families, communities and nations. HL not only makes it difficult for adults to obtain employment, to carry out the job designated tasks, and to maintain employment (WHO Factsheet no 300, 2005) but a condition, if untreated, affects nearly all dimensions of human experience (Better Hearing Institute, 2008). HL is not “just” the loss of hearing but impacts the very crucial aspect of a person, that is the “sense of self”, which includes self-concept, self-esteem, self-worth and self-efficacy (McDevitt and Ormrod, 2007). It is indeed a serious disability.

On the issue of self-concept, English (2002) contends that many CHL and PHL do not have positive self-concept. This phenomenon can be understood by looking at

how self-concept develops and the challenges faced by a CHL when communication is greatly impaired by the loss of hearing.

Self-concept is a person's perception of his or her identity being different and distinct from others (Berns, 2007 page 44; English 2002)). So important is the formation of self-concept that it is considered as one of the aims of socialisation (Berns, 2007). As the self is both a cognitive and social construction (Harter, 1999), self-concept emerges from the experience of separateness from others. Thus, the development of self-concept does not come from within the self but is learned by assimilating the input, feedback and reactions from those around us (English, 2002). Hence, self-concept is a learned concept built from the impact of the social experience and social interaction (Bauer and Shea, 2003; Scheetz, 2004); then becomes the blueprint of the person (Schmidt, 2006).

Since the family is the primary agent of socialization and education (Berns, 2007; Tuttle and Paquette, 1996; Scheetz, 2004), providing the most important relationship and the first connection to the world (McDaniel and Tepperman, 2007), for the first few years, children are mainly influenced by their parents and what goes on in the home (Hildebrand, 1994; Ding and Littleton, 2005). In other words, self-concepts are being first shaped at home, by the parents and family members.

Central to the development of self-concept is communication, and via communication parents convey to their children the sense of caring and acceptance (Scheetz, 2004). English (2002) contends that many CHL do not have positive self-concept. This phenomenon can to be understood by looking at how self-concept develops and the challenges CHL face when communication is greatly impaired by the loss of hearing.

The heart of communication is language (Makin and Whitehead, 2004; Olson and DeFrain, 2006), and this becomes the foundation of everything else; enabling humans to create and share meanings. Hearing children born to hearing parents or children with hearing loss (CHL) born to parents with hearing loss (HL), have a shared communication system through which the "feedback loop" for the development of positive self-concept is established (Scheetz, 2004). Because parents and children of

both categories have the same mode of communication, the children in these types of families experience a sense of inclusion from the very beginning (Schlsinger, 2000).

On the contrary, for hearing parents with CHL, the “taken -for- granted” and shared communication system accessible to other parent-child relationship is not available (Meadow-Orlans, 1996; Bouvet, 1990). Hence, with the absence of the shared communication system, the CHL are not able to recognize their parents’ voices, not able to hear the sounds of comfort from their parents (Mackelprang and Salsgiver, 1999); what more to understand the language of acceptance and inclusion from parents and family members. To further aggravate the already stressful situation, the inexperience hearing parents may feel a sense of rejection toward the CHL (Harris, 1978 in Mackelprang and Salsgiver, 1999) due to the lack of reciprocity from the CHL. Therefore, the parent-child communication system is greatly impaired or scarcely available.

As a result, the CHL born to hearing parents became aware of their HL through the painful experience of not being able to access the family communication (Scheetz, 2004). The development of CHL’s self-concept is thus impaired due to the challenge in communication between the hearing parents, family members and the CHL. Consequently the CHL grow up into adults with self-concept that seems to be more negative than that of the general population (English, 2002; Vernon and Andrews, 1990). Thus, HL affects not only communication but the most crucial aspect of a person, which is the self-concept (Bakenroth and Ahlner, 1997; Bakenroth and Ahlner, 1998).

In addition, as 90% of CHL are born to hearing families (Hall and Hill, 1996; Graham and Baguley, 2009; Kail, 2007, Scheetz, 2004) by default, superiority is usually given to the verbal mode of communication. This is because, humans are naturally auditory-vocal (Bochner and Albertini, 1988, in Strong 1988). Therefore, if verbal communication is the sole mode of communication in the home, then the CHL would infer that their HLs are being rejected (Bat-Chava, 1994). Even if the hearing parents of CHL decide to use signing as the mode of communication, they do not use signing consistently due to lack of training or feeling uncomfortable using signing in public (Marschark, Lang and Albertini, 2002). For example, in a Malaysian study by

Siti Zamratul Maisarah et al., (1999), among the parents of CHL who used *Bahasa Malayisa Kod Tangan* (BMKT), only a small percentage of the parents (3.9% mothers and 1.8% fathers) were considered proficient. Therefore, most CHL of hearing parents grow in homes where many indirect language learning situations are lost as the hearing parents of CHL only sign when they are communicating directly with their CHL (Marschark, Lang and Albertini, 2002) or not at all. Thus the CHL are left out from familial exchanges and feel isolated (Scheetz, 2004).

The CHL continue to feel isolated until they go to school, where the CHL meet similar people like them (Scheetz, 2004). However, going to school does not solve the feeling of isolation issue among CHL because there are myriad of other contributing reasons. For example, in a school environment where the teachers and administrators are not fluent with sign language (such as in a mainstream school), CHL who depend on signing as the main mode of communication will continue to feel the isolation (Smith, 2007). That is why Sheridan (personal narrative in Mackelprang and Salsgiver, 1999) cautions sending CHL to hearing school without the proper communication and education support.

In addition, Smith (2007), Gregory, Bishop and Sheldon(1995) and Antia et al., (2011) report that CHL attending the mainstream school are often excluded by their hearing classmates and usually fail to build close relationships with hearing peers. As a consequence, the CHL continue to experience isolation and loneliness (Foster, 1998; Mertens, 1989; Nunes, Pretzlick and Olson, 2006; WHO Factsheet No 300, 2009) even when they reach school-going age.

Isolation, a perennial issue for most people with HL (PHL), is often the precursor to mental health problems (Graham and Baguley, 2009). For example, in the United Kingdom, deaf and deaf-blind individuals suffer higher rates of mental health problems compared to hearing individuals (Kvam, Loeb and Tambs, 2006). In addition, three out of four parents in the USA indicate that their children experience minor to serious problems due to their HL (Better Hearing Institute, 2008). Similarly, van Eldik et al. (2004) report that Dutch CHL have emotional/behavioural problems nearly 2.6 times higher than the Dutch normative sample.

There are further problems associated with HL; for example low academic achievement. Even in countries where there already exists a Deaf culture, such as USA (Smith, 2007), the abundance of data related to PHL's academic achievement, is worrying and alarming (Johnson, 2001-2002; Moores, 2001). For example, Blanchfield et al. (2001) report that 44% of severely and profoundly deaf population over the age of 17 years in the USA did not graduate from high school, compared to 19% of the general population. Even after they leave school, deaf students' reading levels are low compared to the general students' population reading levels. In the USA, deaf and hard of hearing students leave school with a third-grade (Marschark, 1997), or around fourth grade level (Traxler, 2000; Goldin-Meadow and Mayberry, 2001) of reading skills.

The low reading level achievement of CHL can be appreciated by understanding what literacy is and how literacy develops. Literacy is not only reading and writing, but much more, including verbal communication and non-verbal communication. In fact, the root of literacy is the ability to communicate (Makin and Whitehead, 2004). Therefore, literacy does not start when children go to school, but at home (Makin and Whitehead, 2004). Thus, parents determine whether children's literacy foundation is strong or otherwise. That is why Fox (2001) contends that the first day of school is almost too late to learn literacy.

The interactions and shared experience between the parents and the baby not only provide the emotional bonding (Marschark, Lang and Albertini, 2002) but become the roots of literacy (Makin and Whitehead, 2004). Activities such as cooing, singing nursery rhymes, playing peek-a-boo and motherese (Hoff, 2009; McDevitt and Ormrod, 2007; Kail, 2007; Hetherington et.al, 2006) are thus part of literacy activities (Makin and Whitehead, 2004).

Ordinary parents, especially mothers, feel encouraged to do all the literacy-enhancing activities because parents/mothers receive reactions from their babies. So for hearing parents/mothers and hearing babies the experiences are an enjoyable and thus co-actions (Bouvet, 1990) and reciprocity loops occur (Andrew, Leigh and Weiner, 2004).

However, for hearing parents with CHL, it would be very hard to ignore the impact of knowing that their children have HL. Knowing that their babies have HL destroys parents' initiatives to keep talking to their babies as partners in conversation (Bouvet, 1990). It is indeed a great challenge for hearing parents of CHL, especially mothers, to stay positive and do communication- promoting activities while knowing their babies have HL (Bouvet, 1990). Thus, the CHL had a bad start with literacy and the consequence is low reading level achievement compared to hearing students (Traxler, 2000; Goldin-Meadow and Mayberry, 2001).

Acquiring adequate language skill is a problematic area for CHL (Hoff, 2009). This is because hearing is crucial to the development of language. The problem with CHL can be observed as early as during the babbling stage, when babies with HL start to differ from babies with normal hearing (Marschark, Lang and Albertini, 2002). However, due to the absence or limited amount of auditory feedback, infants with hearing loss do not produce well-formed syllables (Koopmans-van Neinum, Clement and van den Dikkenberg-Pot, 2001). Babies with HL do not babble the complex form of babbles as compared to hearing babies (Oller and Eilers, 1988). If hearing does not play a major role in language development, babies with HL should babble like babies with hearing. This shows that hearing plays a major role in language development and thus, HL affects all aspects of life because language, the tool for communication and socialisation, is severely impaired. The problem starts very early in the life of CHL, which is since during babbling stage.

Reading skills, academic achievement and the types of jobs obtained by people with HL (PHL) are closely related. PHL who have higher reading abilities are more likely to graduate from college and to obtain higher-paying jobs in the workforce (Cuculick and Kelly, 2003). Hence generally, PHL are employed in unskilled or semiskilled jobs (Furlonger, 1998) due to their lower academic achievements. As a result, PHL make less money than people with normal hearing (Better Hearing Institute, 2007) and more likely than not, have to live life with difficulties.

How people with disabilities, such as PHL, are treated by others around them is a reflection of how people with disabilities are being perceived (Smith, 2007). HL and related issues itself may not be the problem in itself, but the perception of the

people around PHL, or disability in general, may be the real challenge. According to Guadalupe and Lum (2005) “disability” as a concept is not given to individuals, but is the result of an interaction between an individual and a specific environment (Corbett, 1994). Thus, a disability such as HL is socially constructed (Stokoe, 2001) and the perception of hearing people towards PHL affect the way PHL are being treated.

Ableism has common history with prevalent forms of oppression and discrimination (Hehir (2002), where by people with less than optimal capabilities, such as having HL, encounter discriminations even by the most civilised society (Schmidt, 2006). Myths regarding people with disabilities, such as “people with disabilities are draining the economy” (Sue and Sue, 2013 page 528), continue to be rampant and thus maintain the negative attitudes and prejudice of hearing people towards PHL.

Another reason that hearing people tend to have prejudice towards and tends to stereotype PHL is due to the difficulties that hearing people encounter when communicating with PHL (Bouvet, 1990; Nikolarazi and Makri, 2004). This is especially true when communication is limited to speaking and listening (Nikolarazi and Makri, 2004). Gregory (1995) believes that it is not the HL which is the basic problem, but the communication between PHL and hearing people. Because HL is a hidden disability (Backenroth-Ohsako *et al.*, 2003), the CHL or PHL are perceived “normal”, but the different mannerisms and behaviours of PHL are often misunderstood (Scheetz, 2004). So, in their attempts to interpret the behaviours of PHL, and to simplify understanding of the world (Scheetz, 2004), the hearing people tend to stereotype the PHL.

However, stereotyping – a simplistic and fallacious characterisation of a particular group (McDevitte and Ormrod, 2007), is often negative (McDevitte and Ormrod, 2007; Guadalupe and Lum, 2005). Thus, more often than not, PHL are being perceived negatively by hearing people. That is why Ajuriaguerra (1972 in Bouvet, 1990) contends that having HL is worse than being blind because the blind person is seen although s/he cannot see; but the PHL not only cannot hear but are not being heard. Therefore, the seemingly “normal” PHL tend to be viewed with prejudice by the hearing people. HL is a disability which is real and with far-reaching consequences (Gregory, 1995)

The prejudice towards PHL is not limited to the laypersons but also to professionals. Bouvet (1990) believes that prejudice may be the hidden motivation of many hearing people, including professionals, insisting on giving speech as top priority; thus perpetuating the communication barrier loop between hearing people and PHL.

People with hearing (PH) tend to hold negative attitudes and prejudice towards PHL (Lampropoulou and Padeliadu, 1997; Parasnis, DeCaro and Raman, 1996; Parasnis, Samar and Mandke, 1996; Bouvet, 1990). One reason is due to the tendency of hearing people to view HL as pathological (Lott et al., 2001). Although this pathological view of HL is less dominant now compared to the past (Bat-Chava, 2000), the pervasive belief system of ableism is hard to let go. Therefore, the concept of “normalcy” is still pervasive and thus having a HL is generally considered an abnormality (Andrews, Leigh and Weiner, 2004).

The obsession with “normalcy” affect the parents of CHL too, and consequently many parents of CHL have difficulty accepting their CHL as the children are considered “different” (Leigh, 1999a) or not “normal”.

After the diagnosis of HL, Mapp (2004) reports that many parents react with shock, disbelief and disappointment when they realised that they have “less than perfect” child (page ix). In fact, Yoshinaga- Itano and Abdala de Uzcategui (2001) show that parents express the full range of “turbulent” emotions when their newborns failed a hearing screening test, namely, shock (42 %), anger (22 %), confusion (42 %), fear (52 %), sadness (16 %), frustration (31%), depression (37%), loneliness (16%), and blame (16%). These intense emotions during the diagnosis period were similar in Jackson, Traub, and Turnbull’s study (2008). In addition, Luterman (2006) reports that parents of CHL also have the feeling of loss after diagnosis. Thus, for parents of CHL, the additional challenge is not only having to cope with children with special needs, which is hearing loss, but also to cope with their own numerous and intense emotions (Mapp, 2004).

Being parents is challenging enough. That is why that Evans (2004) and Martin and Clark (1996) believe that parenting is the hardest job around. Stress is common (Strong, DeVault and Cohen, 2008; Mc Daniel and Tepperman, 2007) as this challenging career (Scheetz, 2001) demands nothing less than hard work (Syed Ali, 2007). Under the best of circumstances, parenting tasks that can make the best people feel uncertain (Gestwicki, 2007) and overwhelmed (Hoghughi and Long, 2004).

On top of the ordinary parenting challenges, parents of CHL's difficulty in accepting their children's hearing loss is only one of the myriad challenges that the parents of CHL face. Truth be told, having children with disabilities impact the family in major (Wright, Stegelin and Hartle, 2007) and numerous (Olson and DeFrain, 2006) ways; in fact, the parents' entire lifestyle (Hall and Hill, 1996). The multifarious impact includes financial, family activities, parental self-esteem, wellness and sense of competence (Bauer and Shea, 2003).

Thus, parents of children with disabilities are very likely to be susceptible to problems associated with emotional and psychological stress (Fiedler, Simpson and Clark, 2007). For example, Quittner, Glueckauf and Jackson (1990) and, Lederberg and Golbach (2002) found higher levels of stress among the parents of CHL compared to the parents of hearing children. It was found too that mothers of CHL were more depressed, interpersonally sensitive, anxious, and hostile than mothers of hearing children (Quittner, Glueckauf and Jackson, 1990). Similar to other parents of children with disabilities who often feel insecure (Gestwicki, 2007), mothers of CHL's emotions tend to be like roller coasters, coupled with fear and uncertainty of the child's future, and feeling inadequate (Jackson, Traub, and Turnbull, 2008). Feelings that affect the self of the parents, especially mothers, are points of great concern because the best predictor of children's academic success is the self-esteem of the mother (Schlessinger, 1992 in Luterman, 2006).

The challenge of having CHL starts way before the diagnosis; that is during the pre diagnosis period, when the parents suspect that "something is wrong" with their child. This uncertainty period can range from several months to several years, during which the parents have to continue caring for their child in spite of not being able to put a name or find a reason to the stressing and uncertain situation (Spencer, 2000).

In Malaysia, there were 32,850 people registered as having HL (harapanpekakmalaysia, 2008; 2011). Similar to other disabilities, a child or person diagnosed with a HL by a medical officer is considered “Orang Kurang Upaya” (OKU- a Disable Person). An OKU gets an identity card which “identifies” the person as a person with a disability. The type of disability is also stated in the card and the card is colour coded according to the type of disability.

For an *OKU* to receive the benefits from the government of Malaysia (Malaysian Budget, 2007; Ministry of Finance, 2007; JKM, 2010; 2011) he or she has to be registered with the Jabatan Kebajikan Masyarakat (JKM). However, it is estimated that only 10% registered (Konsumerkini, 2010). This is why one of the contents of Memorandum OKUBANGKIT (2012) is to demand the registration of every child who has a disability to be the automatic (or as a duty of the government to register for them). Therefore, it can be said that majority of the OKU in Malaysia do not receive the benefits which are meant for them. Furthermore, the procedure for an OKU to receive the benefits can be long and difficult; at least for the OKU, as majority are not highly educated.

The contents of the 2007 OKU Act (JKM, 2010) are noble and the initiative is laudable, but the implementation of the act is still questionable. Even for a bright deaf student at a local university in Malaysia, there are at least five challenges that has to be faced (Amir Hamidi, 2000). The “equal opportunities” and “full participation within the society” for OKU as stated in the 2007 OKU Act fail to prevent discrimination of students with HL, or OKU in general (Shahrul Arba’iah, Norzaini and Manisah, 2008; SUHAKAM, 2006; Memorandum OKU Bangkit, 2012).

In a similar light, although the Special Education Regulations 2013 (Federal Government Gazette, 2013) is a positive move towards better education environment for OKU in Malaysia, educational future for CHL in Malaysia remains bleak and uncertain for several reasons. For a start, the Special Education Regulations 2013 does not seem to address CHL as a heterogenous population (Meadow-Orlans, Mertens and Sass-Lehrer, 2003) and the other is the absence of any mention of parents’ active role although it is an established fact that no programmes will be successful without parents’ or families’ participation.

In addition, in spite of continuously renewed regulations every now and then, the Malaysian social and education context still portrays that HL is “just” a loss of hearing; as is there is no big deal about it. This scenario is manifested via various websites related to special education in which certain disabilities seem to be given priority. One the “highlighted” and “big-coverage” disability is the lost of sight, and an example of such websites is i-Sayang (Pusat Maklumat Setempat Khas, 2016)

Empathy toward parents of CHL and parents of other disabilities seems to be lacking too, because, after diagnosis at the hospital, parents of CHL (or other disabilities) have to register their children to two other different departments; Namely the Welfare Department and the Local Education Authority. Registration may fail if parents do not bring the right documents. This situation is in contrast to other countries such as United Kingdom when parents of CHL (or other disabilities for the matter) do not have additional stress of registering to the various departments once a child is diagnoses with a disability. Parents only need to focus on their well being and the well being of their special children; registration matters are taken care of. If the CHL is below school-going age, a peripathetic teacher is assigned to the CHL, and visits the CHL and the family every week (my personal experience).

At the time of writing, there are three different school settings for CHL in Malaysia (MFD, 2011), namely (1) the Fully Residential Special School setting, (2) the Day Special School is setting, and (3) the Special Day Classes or Units in Ordinary/Regular School setting. In total, there are 25 primary schools and two secondary schools for CHL (MFD, 2011; MOE, 2012). Besides these special schools, there are 23 primary schools and 15 secondary schools which have special units for CHL (Apcdproject.org, 2008; MFD, 2011).

However, each school setting has its own problems. For example, it is often that the units in the regular school are not being managed by teachers trained in special education. Even for the Special Education School (SES) such as the one in the study, the majority of teachers were not trained in special education or hearing loss (interviews with Teachers 1-3). Furthermore, to save money, SES also hosted children with learning disabilities. Besides, the performance and achievement of the CHL in Special Day schools such as SES are also unknown.

In the higher education, Saleena's efforts was to secure scholarships for students with HL from Malaysia to study at Gallaudet was exemplary (Saleena, 2004), but only a handful of them were able to make it to Gallaudet or to the local universities in Malaysia for the matter.

To find a university which is user-friendly to students with HL is also a challenging task. At the time of writing, there seems to be only three universities which manage to attract and accommodate students with HL, namely LimKokWing University of Creative Technology (LUCT) in Cyberjaya, Universiti Sains Malaysia (USM) in Penang and Universiti Teknologi Malaysia (UTM) in Skudai. Even so, the courses available to students with HL are limited. This can be due to several factors such the readiness of the lecturers to teach students with HL and the "friendliness" of the faculty's culture to have students with HL.

Data on the wellbeing of PHL in Malaysia is unknown. For example, for the 32, 000 PHL registered with the JKM (harapanpeka.com, 2008; 2011) little is known about their income, life satisfaction or quality of life. From my personal knowledge, majority of PHL in Malaysia can be considered poor. Adding my own anecdotal evidence, there are married PHL who at times, have to eat their meals at their parents or siblings' houses due to money shortage.

There are many other issues related to CHL and PHL in Malaysia. Poor literacy is a common one. For example, the highest achievement for *Ujian Penilaian Sekolah Rendah* (UPSR) for the year 2011 for SES was a C and the majority of the students failed in the others (*Buku Mesyuarat Agung kali ke 25*, 2013). There was an improvement for UPSR 2012, but small (5.56% obtained a B in mathematics)[*Buku Mesyuarat Agung kali ke 25*, 2013].

The magnitude of the problems and the complexities of interplay of various elements in Malaysia can be overwhelming. I choose to start "somewhere" and that is, the parents of CHL. The most comprehensive study about parents of CHL in Malaysia was nearly 20 years ago (Siti Zamratol Maisarah et al., 1999) and thus I believe a study of helping parents of CHL is wanting and timely.

1.3 Statement of Problem

The family is an important asset in the building of a nation (Zuriah, 2000) and by fulfilling several vital functions, the family ensures continuity and survival of the society (Strong, DeVault and Cohen, 2008; Berns, 2007). Within the family, the parents' role is the most crucial and critical as every aspect of children functioning is affected by parenting practices (Hoghughi and Long, 2004). However, for parents of CHL, parenting is extra challenging because they have to face the ordinary challenges of parenting and the additional challenge of parenting a child with a disability that is HL. In addition, as the majority of parents of CHL are hearing, they are unprepared to handle the various issues and challenges related to parenting CHL (Marschark, 2007).

The myriad of additional challenges for parents of CHL starts before the diagnosis of the HL, followed by the period of shock and various other feelings that come along with the diagnosis. In addition to caring for the special child, the parents of CHL have to cope with their own emotional turmoil and simultaneously have to cope with other people's stigmatization towards HL.

There are also a lot of feelings of uncertainties along the way. On top of that, parents of CHL face other additional demands such financial demand and learning new communication skills. These challenges and demands on the parents will definitely affect their parental performances. To add to their already stressful situation, many parents of CHL are being treated by medical professionals who lack the use of emphatic skills in communication.

Psychologists, sociologist, social psychologist and child health experts have been interested in families and disability, but more from the perspective of the welfare of the children rather than their parents (Thurman, 1985).

Likewise, little is known about serious, large-scale and concerted efforts to help parents of CHL in Malaysia. What would happen then to the CHL in Malaysia? Are they going to grow up into PHL with low self-concepts, feeling isolated, lonely and maybe having mental problems? What about their academic achievements? Are

they going to live day-by-day with meagre income due to their low academic achievements? Without serious and systematic help for the parents of CHL, more likely than not, the CHL in Malaysia will grow into PHL with various psychosocial problems; faring badly in life. Hence, a helping framework or parents of CHL in a special education school Malaysia is most befitting to serve as a starting point to help the parents of CHL.

1.4 Research Objectives

There were two objectives of this study:

- 1.4.1 To investigate the experience of Muslim parents of CHL who were in a special education school (SES) in Malaysia.
- 1.4.2 To develop a framework for helping Muslim parents of CHL who were in a special education school (SES) in Malaysia.

1.5 Research Questions

Consequently, to achieve the objectives of the study, the research questions were as follows:

- 1.5.1 What was the experience of Muslim parents of CHL who were in a special education school (SES) in Malaysia?
- 1.5.2 What would be a viable framework for helping Muslim parents of CHL who were in a special education school (SES) in Malaysia?

1.6 Rationales for the study

Although some writers do not include “rationale for the study”, I am including it because I believe this sub-topic further illuminates the study; because “rationale” clarifies “why I did what I did”. I put forth two rationales for the study. The first one pivotson the objectives of the study and the second one on the choice of respondents.

The first rationale is that helping the parents of CHL is one of the wisest and most significant ways to help CHL in Malaysia as there is ample empirical evidence that have identified parents' involvement as the critical ingredient of effective intervention (Mahoney and Bridgette, 2007).

The second rationale is that I have to be realistic in my efforts to make changes. It would be a daunting task to make changes in systems that have been running for a long while. I am referring to the educational, social, medical and welfare system in Malaysia. There was also the political system of Malaysia as well as the Malaysian culture which influenced the parents of CHL, the school and wider family members and all the people who were in the system mentioned. However, an effort aimed at the most strategic point in a system would result in fruitful consequences and thus, I believe a good and sure start is to "invest" my time, efforts and resources are into parents of CHL.

As for the choice of respondents, it made a lot of sense that the person who experienced a phenomenon was the expert about the phenomenon. Decades of research in the helping profession points out that data from parties other than those experiencing the phenomenon would be prone to be at variance with data from the persons experiencing the phenomenon. As Straker and Becker (1997) remind, experience is a function of occupying a particular position.

Furthermore the choice of SES as the place of study was also apt because parents who had children at a primary school had a fresh reasonable amount of experience of having CHL. This is important because one of my approaches in my data collection was phenomenology, which in essence is making sense of the participants' experience. As to experience, van Manen (1990, page 36) states, that "live experience has a temporal structure and thus can never be grasped in its immediate manifestation but only reflectively as past presence."

Parents of CHL have first-hand experience of parenting their children. Besides in constant contact with their CHL, parents of CHL have unique spousal experience in parenting their CHL, experience with their wider family members, experience with the

school, medical or helping professionals, JKM, other parents, as well as other members of the community. By putting together all these experiences, meanings were captured and a helping framework for the parents of CHL at SES was thus developed.

1.7 Significance of the Study

This study would be significant to at least 11 groups of people, namely parents of CHL at SES, parents of CHL in Malaysia, wider family members of the parents, siblings of CHL, the professionals in the medical system, *JKM*, teachers of CHL, other members of the community, policy makers, researchers and of course helpers. The first group, which is the parents of CHL, is to whom this study is dedicated to, while the others are people who would have impact on the parents either directly or indirectly. Below, are details as to how this study would be significant to each group of people.

1.7.1 Parents of CHL in SES

It is crucial to develop a helping framework for parents with CHL who were in SES because SES is one of the few special education primary schools for the deaf in Malaysia. With 33, 000 Malaysians registered as have HL and related issues (JKM, 2010; 2011) a significant number of parents were sending their CHL to SES. This number would be increasing as the occurrence of HL is a common phenomenon in Malaysia and worldwide.

1.7.2 Parents of CHL in Malaysia

As the education system in Malaysia is centralised, the other parents with CHL in other special education schools in Malaysia would also benefit from this study. The parents would be able to take a few essential points from this study for their own consumption.

1.7.3 The wider family members

People dearest to the parents and the CHL are the family members in the wider family circle. The helping framework will become a guide for the wider family members so that they can help the parents of CHL better.

1.7.4 Siblings of CHL

Siblings of CHL are of great help to the parents of CHL, before and after diagnoses. Therefore this study would be significant to them too.

1.7.5 Professionals in the medical system

As other people's experience is one of the valuable forms of learning, professionals such as medical officers, audiologists and counsellors will also benefit from this study. By knowing what is important to parents of CHL, professionals can deliver their service better and with more empathy.

1.7.6 *Jabatan Kebajikan Masyarakat (JKM)*

JKM is the second place that parents of CHL go to after being diagnosed by the medical officers in the medical system. *JKM* will benefit by understanding parents of CHL better and can become part of the solution to the parents' challenges.

1.7.7 Teachers of CHL

Teachers, whether at special SES or at other schools where CHL are being integrated, or tutors specially hired by the parents to help the CHL, will benefit from this study. This study informs teachers of CHL about the challenges being parents of CHL, and thus teachers will have greater understanding of parents of CHL's situation. Greater understanding between parents of CHL and teachers of CHL will enhance parent-teacher collaboration.

1.7.8 Other members of the community

Other members of the community can be anybody as we are connected to each other, either directly or indirectly.

For a start, other “ordinary” parents have many common grounds with parents of CHL on the basis of being parents. Even being empathy and not saying “Oh, it is just a loss of hearing” is good enough.

Another important member of the community are the baby sitters and child-minders, and they have crucial roles in children development. This is especially true when the parents, especially the mothers have long working hours. Baby sitters are then become “second mothers to the CHL”.

Another important member of the community is the Muslim clerics, or *imams* or *ustaz/ustazah*. This is especially true because in the Muslim community, parents go to or listen to clerics’ advice. When the clerics have some knowledge about HL and understands the challenge of having to parent CHL, clerics can tailor their advice appropriately and specific to the needs of parents of CHL. One important characteristic of the advices are that they are practical and bring results relevant to the parents of CHL. For example, at times parents of CHL need the *zakat* money from the *Baitul mal* to help them to buy hearing aids for their CHL. Imams and *ustaz/ustazah* can become advocates to ensure speedy obtainment of the money.

1.7.9 Policy makers

This study will also be useful for policy makers in Malaysia, especially policies related to the welfare system, medical system and education. Policy makers have the power to make changes which will affect families of CHL. This study will provide information that can help policy makers shape policies that are sensitive to the needs of CHL and their parents.

1.7.10 Researchers

It is my great hope that more researchers will venture into research specifically related to parents of CHL in Malaysia. My greater hope is that this study could serve as a resource to trigger further discoveries in studies helping parents of CHL or CHL in general.

1.7.11 Helpers

Similarly, helpers whether formal, non-formal or informal, will benefit from this study. It would be useful when they encounter similar situations that called for their help. Coupled with good intentions to help parents of CHL, helpers could better equip themselves with insights from this study. It is noteworthy to mention that the helpers can be from any of the group of people mentioned above.

1.8 Scope of the Study

This was a qualitative study with the aim of developing a helping framework for parents of CHL who were in a special school in Malaysia. The main methods of data collection were interviews and observation. Documents were also examined when available. Besides the researcher as the main instrument, other instruments used were interview questions, a questionnaire, a research journal and memo.

The methodology utilised for this study synchronises with the theoretical frameworks of the study, namely Bronfenbrenner bioecological perspective and Islamic perspective. Parents' experience was investigated in relation to parenting CHL from the very beginning, until the CHL were at school.

The parents were Muslim hearing parents. As for the CHL, nine of them had HL only and two had HL with additional disabilities. Out of the nine CHL with HL only, one was using cochlear implants. The number of participants for the study was determined by the point when saturation was achieved.

Data were collected using pragmatic and flexible approach of Phenomenology, and analysed using Grounded Theory according to towards Strauss and Corbin (1990, 1998) and Corbin and Strauss (2008).

In addition, this study met the criteria of rigour (Liamputtong and Ezzy, 2005; Patton, 1990; Denzin, 1978; Conrad and Serlin, 2006) and trustworthiness (Lincoln and Guba, 1985), which were the equivalence of validity and reliability in quantitative studies (Seale, 1999).

1.9 Limitations of study

All studies have their limitations and mine is of no exception. As I was the main instrument of the study, the major limitations were related to me.

The first limitation was due to the fact that I was not a clean piece of slate; I brought along my world view into the study (Babbie, 2014). It may be possible that I fell into a situation whereby “I heard what I wanted to hear” (Johnson, 2001) or “saw what I wanted to see”. To overcome this situation, I increased my awareness so that I was constantly self-reminded who I was in relation to the study. In addition, I made good use two of the most useful elements from the counselor training. One was refraining from being judgemental and the other was listening. Thus, with awareness heightened, judgementalness on hold and listening skill was at its best, I was able to overcome the main limitation of the study.

The other limitation of the study was the truthfulness of the participants during the interviews. They may be faking good by narrating the good and fun side of things; thus giving a favourable impression to me (Rubin and Babbie, 2008). It could also be likely that narrations were modified to make them seemed more interesting (Alvesson, 2011). Or, the participants may have had told me what they thought I wanted to hear (Minichiello and Kottler 2010). To overcome this limitation, I interviewed nearly all parents two to three times. In fact, I met three of the parents four times.

The experiences explored were only related to the parents' selves and the parties in the parents' microsystem, namely, the wider family members, the siblings of CHL, the medical system, *JKM*, the school (SES), the other parents of CHL and the other members of the community.

As a whole, seven strategies were employed to ensure rigour or trustworthiness of this study (please see 3.12); simultaneously addressing the limitations.

1.10 Conceptual and Operational Definitions of Terms

This section defines the key terms in relation to the study.

1.10.1 Framework

A framework “is a system of rules, ideas or beliefs that is used to plan or decide something” (Cambridge Advanced Learner’s Dictionary, 2008; page 567) . Similarly, The Oxford Advanced Learner’s Dictionary (2007, page 616) defines “framework” as “a set of beliefs, ideas or rules that is used as the basis for making judgements, decisions, etc.”

A framework can also be considered as an outline that organizes the most important topics of a field (Mayer, 1998) and contains key elements to the subject matter (Holcomb-McCoy, 2007). Long (1996) includes a system outcome and process goals in a framework; Outcome is the “what to accomplish” while process is the “how to accomplish”

In this study, the framework contains ideas and key elements to help parents of CHL at SES taking into account the context of the study.

1.10.2 Helping

Helping can be defined as assisting others to understand, overcome or deal with internal or external problems, providing direct and indirect human services to a broad multitude of clients in various settings (Okun and Kantrowitz, 2008).

In a similar tone, Heron (2001) defines helping as supporting and enabling the well-being of another person. Maclean and Gould (1988) add that an effective helping has to be purposeful and an informed activity; combining caring, openness, trust, acceptance and support for change (Hubble, Duncan, and Miller, 2010).

Helping can also be understood by looking at the definition of a helper Kottler (1990). Okun and Kantrowitz (2008) explain that helpers may be professional helpers or generalist human services workers. According to Kottler (1990), generalist service workers are of two kinds: (i) people who work in other kinds of organization, such as teachers and human resource workers and managers who may work together with or independent of the professional helpers, (ii) informal helpers such as friends and neighbours who find themselves in the helping roles.

Mikulas (2002) uses the term “helper” in a general sense to refer to a person who provides informed and practical advice. However, Egan (2010) differentiates helpers into three categories, namely, (i) the formal helpers who work in a variety of helping professions such as counsellors, psychiatrists, psychologists, social workers and religious officers; (ii) non-formal helpers but working in their own specialised fields such as nurses and management consultants, and are expected to help people in a variety of ways, (iii) informal helpers, that is anybody who help other people to face life challenges.

In this study, helping means the purposeful assistance and informed activity rendered to the parents of the CHL to assist them in understanding, overcoming or dealing with internal or external problems related to the parenting of CHL. Helping is done through the provision of direct and indirect generic human services, accompanied by positive characteristics such as caring, openness, trust, acceptance and support for change. Helping can be given by any category of helpers as stated by Egan (2010),

using all types of helping skills possible and guided by two perspectives; namely Islamic and Bioecological perspectives.

1.10.3 Children with Hearing Loss (CHL)

The CHL in this study, were the children with HL who were at SES. The HL varied from mild to profound. One CHL had HL as well as a slow learner, while another had HL as part of Goldenhar Syndrome. Only one CHL had cochlea implant. These CHL had hearing parents.

1.10.4 Parents of CHL

Parents are adults who provide physical protection, emotional nurturing and socialization to children (Berns, 2007). The meaning of parents can also be understood from the verb “parenting”, in which Hoghughi and Long (2004) define “parenting” as “the purposive activities aimed at ensuring the survival and development of children” (page 5). In this study, the parents were the biological fathers and mothers of the CHL. They were all Muslims and hearing.

1.10.5 The medical system

The medical system is the system that deals with medical issues. In this study, people from the medical system who were involved with the parents of CHL were the medical officers at private and government hospitals, as well as the audiologists.

1.10.6 *Jabatan Kebajikan Masyarakat*

Jabatan Kebajikan Masyarakat (JKM) is the Welfare Department in the Malaysian current system. In this study, JKM is the department at which records the registration of OKU and allowances.

1.10.7 The school (SES)

In this study, “the school” refers to the Special Education School (SES) to which the CHL went. Inclusive of this “school” were the teachers in this school and an adjunct *Sekolah Agama* which ran between 2-5 pm daily. The SES also had a hostel which accommodated primary and secondary CHL.

1.10.8 The wider family members

These are people who were near and dear to the parents of CHL, either by blood, or by function. Examples are grandparents of the CHL, cousins, uncles, aunties and close friends. In this study, the wider family members were anybody in the wider circle of the nuclear family.

1.10.9 Other parents of CHL

In this study “other parents of CHL” meant the other parents who sent their CHL to SES, as well as those who did not.

1.10.10 Other members of the community

Other members of the community can be anybody other than those that fall under the terms stated above. Examples are baby sitters, colleagues at work and the Muslim clerics, or imams or ustaz/ustazah. The operational definition of “other members of the community” is the same.

1.10.11 Experience

“Experience” carries the implication of a direct personal participation or observation, or it may mean a particular incident, feelings and the like, that a person has undergone (The New Collins Dictionary and Thesaurus, 1987). Similarly, the dictionary online (Dictionary.com, 2012) defines “experience” as the observing, encountering, or undergoing of things generally as they occur in the course of time.

Bronfenbrenner (2001) posits that “experience” as an important element in the definition of the ecological model and refers to the realm of subjective feelings including anticipations, hopes, doubts and beliefs as being felt within the interconnected relationships. Interconnected relationships are relationships between the systems, namely the microsystems, the mesosystems, the exosystems and the macrosystems (Bronfenbrenner, 2005). Similarly, Strong, Vault and Cohen (2008) remind us that every experience is unique and the meanings attached to the experience are subjective and are affected by emotions felt within the relationship.

In this study, “experience” means personal participation or observation, which includes all feelings, perceptions, anticipations, hopes, doubts, beliefs, ideas and the like, of the participants of the study. The meanings attached to the experiences were subjective and were affected by emotions felt within the realm and context of the interconnected relationships involved in the study.

1.10.12 Family

The definition of a “family” is diverse (Cherlin, 2008), due to the unprecedented changes in “family” life, together with the choices and constraints of the new millennium (Benokraitis, 2005). There are currently various “family” living arrangements (Ingolsby and Smith, 2006) that reflect current “family” diversities.

It is sufficient to state that “family” in this study is an integrated and comprehensive definition, based on definitions given by Allen, Demo and Fine (2000), Benokraitis (2005), Olson, and deFrain (2006). Thus, in this study, “family” means “two or more people related and committed to each other by marriage, birth or adoption, or choice”. This definition includes “family” members defined by socio-economic ties and enduring responsibilities, especially in terms of dependence for support and nurturance, and who may share intimacy, decision-making responsibilities and values.

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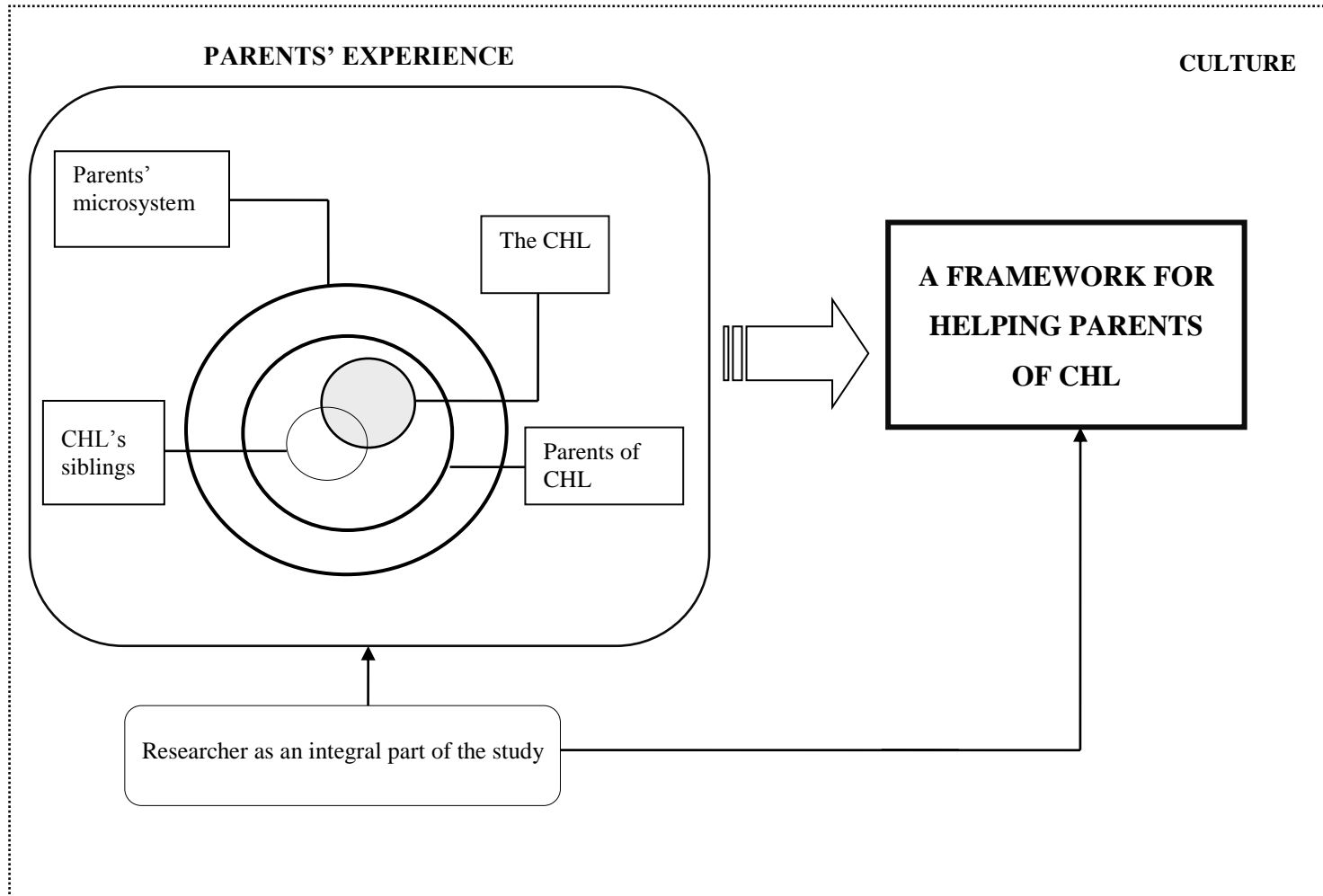


Figure 1.1 The Conceptual framework of study, adapted from Berns (2007).

Figure 1.1 in the previous page shows the conceptual framework of the study. On the left is the parents' experience, which embodies the first objective of the study, while the second objective, that is a framework for helping the parents, is on the right. The framework was developed from the parents' experience.

The parents' experience is a complex one because it was not only about themselves and the CHL, but all in the parents' microsystem, namely the wider family members, the medical system, *JKM*, the school (SES), the other parents of CHL and the other members of the community.

The CHL and the siblings of the CHL were also part of parents' microsystem, but they were special because of the special relationships between them.

The study was being guided by Islamic and Bronfenbrenner's Bioecological perspectives and I, as a researcher was part of the study. I was the most important instrument of the study and I brought along with me my world view and my life experience.

As culture's effect is ubiquitous and permeating in nature, thus culture had effect on the parents' experience. However, as the scope of the study was only for the parents' microsystem, the parents' culture was not explored in detail.

1.11 Summary

In this section, I refresh the readers by recapturing the essentials of the chapter. I began this chapter by highlighting the importance of the family and the crucial role the family plays in ensuring the survival of human beings. Parents are the key players and the family (Nik Azis, 2002). However, the joy parenting comes as a package, together with responsibilities as well as stress.

For parents of children with disabilities such as HL, the responsibilities and stress are manifold, affecting the parents' entire life style (Hall and Hill, 1996),

including parental self-esteem, wellness and sense of competence (Bauer and Shea, 2003) as well as security (Gestwicki, 2007). With the adequate and appropriate help, parents of CHL in Malaysia can give their very best to their children, so as to avoid, as much as possible the problems that are usually associated with CHL and PHL, such as self-concept and identity issues, feeling isolated and neglected, having low academic achievement and low income. This is the essence of this chapter. Bearing in mind the context of the study, which was Muslim parents of CHL in a special education school in Malaysia, as well as the theoretical framework of study, I specify two research questions and two objectives of the study. These research questions and objectives kept me on track throughout the study.

The “conceptual and operational definition of terms” gives clarity to the variables involved in the study while the rationales of the study explained “why I did what I did”. The scope of the study specifies the areas that I was studying. I elaborate this section to include the type of study, the respondents, and my framework. A brief explanation on how my data was analysed is also part of this section. As my framework is systemic, I indicate too, to what extent I will investigate each system. I also state the limitations of the study and I showed how these limitations were addressed by the research design. Last, but not least, the conceptual framework summarizes the whole study, putting the variables and key words together in a diagram; “A picture is worth a thousand words”.

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