THE LIVED EXPERIENCE OF HEARING CHILDREN WITH DEAF PARENTS IN NEGROS ORIENTAL, PHILIPPINES

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Learning Objectives

1. The learner will be able to identify the six (6) major themes presented in the analyzed data gathered in this study.

2. The learner will express appreciation of the significance and relevance of this study in understanding the meaning of the lived experience of children of deaf adult(s).
“If you become a child of someone who is deaf, you must have patience and must understand your father. It won’t matter if he is deaf because he is still your father and you can never change this fact.”
INTRODUCTION

Over 5% of the world’s population, 360 million people, have disabling hearing loss.

✓ 328 million adults
✓ 32 million children

The majority of people with disabling hearing loss live in low- and middle-income countries.

(Source: World Health Organization Statistics Fact Sheet on Deafness and Hearing Loss)

World Stats: Disabling Hearing Loss

Number of people affected by hearing loss expected to increase from 900 million to 1.1 billion by 2015

Canada
3.15 million are hard of hearing

US
48 million with some degree of hearing loss

Central/East Europe & Central Asia
9%

Middle East & North Africa
9%

Sub-Saharan Africa
3%

South Asia
27%

East Asia
22%

Asia Pacific
10%

IMPACT
Most people with hearing loss live in low and middle income countries

Over 5% or 360 million people worldwide have ‘disabling’ hearing loss

91% or 328 million are adults

9% or 32 million are children

1/3 of people with hearing loss are 65+
The majority are school and working age

http://www.who.int/pbd/deafness/estimates/en/
http://www.who.int/mediacentre/factsheets/fs300/en/
http://www.hearingloss.org/content/basic-facts-about-hearing-loss
http://www.cad.ca/statistics_on_deaf_canadians.php
Philippines:

• "About 100,000 to 4.2 million people have hearing problems." (Turkington, Carol, et al., 2004)

• The 2000 Philippine census
  ✓ approximately 121,000 Deaf people living in the Philippines

• There were no studies on the deaf parents and their hearing children done in the Philippines. (Peace Corps Response, 2015)
  ✓ Jackie Beals and Angelie Infantado undertook the first Philippine study on deaf parents of hearing children. (Peace Corps Response, 2015)
• 90% of all deaf parents have hearing children (children who are able to hear) (Allsop & Kyle, 1997)

• Researchers are more focused on the experiences of the hearing parents of deaf children (Keri, 2003)

• “Very few studies have been conducted for children who are born hearing into deaf families.” (Buchino, 1993; Singleton & Tittle, 2000; Filer & Filer, 2000)

The gap addressed in this study:

**FOCUS on offspring /children rather than on parents**
INTRODUCTION

- **mother father deaf**
  - phrase used in the deaf community to label a hearing child of deaf parents (Clark, 2003)

- **deaf**
  - term used to refer to person whose hearing impairment prevents the “processing of linguistic information through audition” (Hockenberry & Wilson, 2007)

- **Children of Deaf Adults (CODAs)**
ISSUES OF HEARING CHILD of DEAF PARENT/S

• CODAs are faced with challenges:
  
  • Deaf parents develop frustration when emotions, needs, problems, and thoughts cannot be effectively communicated to their children (Schuster and Ashburn, 1980).
  
  • A child’s growth and development is mainly affected by parenting style that necessitates open communication (Hockenberry & Wilson, 2007).
  
  • Children with deaf parents have language difficulties due to the impaired communication between parent and child (Barker, et. al., 2009).
  
  • Few studies have been conducted for hearing children with deaf parents (Clark, 2003).
• What is the *lived experience* of hearing children with deaf parents in Negros Oriental, Philippines?
PURPOSE OF THE STUDY

• To understand the meaning or essence of the lived experience of individuals aging 18 years old and above with deaf parents residing in Negros Oriental, Philippines

http://www.fondazionecaltagirone.it/allegati/image/2012/07/9751.jpg
METHOD / METHODOLOGY
PHENOMENOLOGY

• illustrates the **essence** and **meaning** of the lived experience of a person

• seeks and attempts to explain concepts which are not well understood and rarely studied

http://www.intergate-immigration.com/blog/study-without-an-endorsement-on-these-visas/
Philosophical Underpinning:

• Husserlian Phenomenology
  o Epoche/Bracketing was used

Method of Analysis:

• Collaizi’s Method of Data Analysis
CONCEPTUAL MODEL

Husserlian Phenomenology

researchers

enter into their world

perceived object

sense perception

perceived

co-perceived

Phenomenological Reduction

bracketing

biases

impressions

presumptions

internal time essences

themes or pure essences

Collaizi’s Method of Data Analysis

Phenomenological Description
METHOD

• site
  o Dumaguete Effata Association of the Deaf, Inc.

• sampling method
  o purposive and snowball sampling
  o Total of 10 respondents
    (Saturation was reached with the 8th participant.)
ELIGIBILITY CRITERIA

• Male or female
• At least 18 years old
• Filipino
• With at least one biological deaf parent (s)
• Without any mental or sensory problem
• Able to articulate their experience
• Willing to participate in the study
DATA COLLECTION

• Use of *open-ended questions*

• Two were assigned to personally conduct the interviews.

• Duration of each interview was around 45 minutes to 1 hour.
ETHICAL CONSIDERATIONS

• A clearance from **Human Research Ethics Committee** of Silliman University College of Nursing, Dumaguete City, Negros Oriental, Philippines was obtained
Guide Questions

(1) What is it like to live as a child of a deaf parent(s)?

(2) What are your experiences as a child of a deaf parent(s)?

(3) Can you please tell me a story which best describes your life as a child of a deaf parent(s)?

(4) How did you first see yourself? As a child of a deaf parent(s)? Can you please describe to us this phenomenon elaborately?

(5) Can you please tell me in depth everything you remember about growing up and living with your deaf parent(s)? (e.g., experiences, lessons, significant life events)

(6) Is there anything else you would like to talk about being a child of a deaf parent(s)?
COLLAIZI’S METHOD OF DATA ANALYSIS

1. Read all the protocols or subject’s descriptions.

2. Return to each protocol and extract significant statements.

3. Try to spell out the meaning of each significant statement.

4. Organize formulated meanings into cluster of themes.
5. Integrate the results into an exhaustive description.

6. Formulate the exhaustive description of the investigated phenomenon.

7. Return to the subjects and verify about the findings.
RESULTS, CONCLUSION, AND RECOMMENDATION
RESULTS

• Based on the steps of Collaizi, there were:
  • One hundred forty-eight (148) Significant Statements
  • One hundred sixty-nine (169) formulated meanings
  • Twenty-six (26) Themes
  • Six (6) Theme Clusters
THEME CLUSTERS

1. Emotional Distinctions
2. Approaches in Communication
3. Developing Awareness
4. Forming Social Relations
5. Values and Beliefs
6. Coping with the Condition

https://hbr.org/2016/11/3-ways-to-better-understand-your-emotions
THEME CLUSTER 1: Emotional Distinctions

- This includes the themes:
  - Emotional Pain
  - Satisfaction
  - Embarrassment
  - Emotional Burden
  - Sympathy
  - Parental Dissatisfaction
  - Helplessness

https://de.wikihow.com/Die-eigenen-Gef%C3%BChle-kontrollieren
“It is painful when I cannot express my feelings.” – Maria

“She never left us and neglected us like other parents do. She really tried her best.” – Lucas

“We feel ashamed when others tell us that our father is deaf while theirs are not.” – Ava

“We pity her. It is inevitable that other people mock her being deaf.” – Henry
“...the fact that my mother has come to such state is a great pain in my life.” –Lily

“It is a burden for me to be the one who can only hear the problems.” - Emma

“My mother’s way of disciplining us is a problem. When I try to explain my side, she gets mad. She cannot understand because she cannot hear.” –Alex
• Individuals experience **different levels of pain** in different ways and varied reasons. Feelings disregarded might lead to some form of **depression** (Videbeck, 2008).

• A **feeling of embarrassment** leads to possible loss of self-esteem (Stuart & Laraia, 2005).

• Children of deaf view their parents as less competent making them “**parentified**” children (Singleton & Tittle, 2000).
THEME CLUSTER 2: Approaches in Communication

- This includes the themes:
  - Difficulties in the Medium of Communication
  - Communication Disparities
  - Innovative Ways of Communicating

https://mrslaurafaulkner.files.wordpress.com/2016/04/communication.jpg?w=670&h=355
“It’s hard to use sign language because there are some words that need further explanation.” – Emma

“We do not understand each other so I’ll just remain silent.” – Alex

“There are times when I have problems, I cannot say nor express it.” – Henry
“When she does not notice, we just throw something towards her direction so that she will notice. That is what we do especially when we have something urgent to tell her.” – Lucas

“I use paper and ballpen and write in large fonts to express my feelings to my father.” – Noah
• The **ability to hear**, see, feel and smell are important adjuncts to **communication** (Kozier, 2004).

• A **hearing child** will pick up sign and a spoken language just as the children of immigrants who typically learn the language of their parents (Levy, 2002).
• As the individual progresses through the various stages of life cycle, each developmental phase requires increasingly complex communication abilities and skills (Wong, 2007).

• They serve as interpreters for and assist their parents in communication (Hadjikakou, et. Al., 2009).
THEME CLUSTER 3: Developing Awareness

- This includes the themes:
  - Accepting the condition of the deaf parent/s as part of life
  - Appreciation of the experience
  - Realization of the condition of the deaf parent/s
  - Acknowledgement of difference between deaf parent/s with parents who do not have auditory and speech impairments
“I was 9 years old when I became aware of the condition of my father. I started interpreting for my father when I was thirteen.” –Noah

“I have accepted my mother for what she is.” –Emma

“It won’t matter if he is deaf because he is still your father and you can never change this fact.” –Noah
“I long to have a mother who has no disability. I constantly hope my mother’s hearing will change.” –Lily

“If I compare it to others, we are really different because our mother has a disability.” –Henry
• **Acceptance** is the avoidance of judgments of other people, regardless of their behavior (Videbeck, 2008).

• As they get older and know better, the children of deaf adults are not bothered by their parent’s deafness. They know it as a “fact of life” and just accept it (Preston, 1994).

• The conversations of the deaf tend to be more **superficial** as they are unable to further articulate and explain everything in detail through sign language (Preston, 1994).
THEME CLUSTER 4: Forming Social Relations

- This includes the themes:
  - Isolation from Family
  - Emotional Attachment
  - Social Alienation

“It was difficult for me to have a deaf mother while growing up because the understanding was only between the both of us, while others don’t understand us.” – John

“The fact that my mother cannot talk, we feel that we are left out.” – Emma

“We are like sisters and that is the unique thing about me and my mom.” – Sophia
• **Isolation** comes in forms such as feelings of being left out and having silent treatment from people (Williams, 2001).

• Not all members of the family can learn **sign language** at a great depth that this deters their relationship to the member with the disability (Southwick, 2000).

• Parents with disability are inappropriately **stigmatized** because of mistaken assumptions about their capabilities, but research shows that many of these parents have raised their respected families successfully (Preston, 2013).
THEME CLUSTER 5: Values and Beliefs

- This includes the themes:
  - Possibility of Inheriting the Condition
  - Spiritual Realization

“I fear that my child would have the same condition as her.”  
–Sophia

“We did not complain about our mother’s condition. That is what God gave us.”  
–John

“Granting my mother the miracle of being able to hear is my dream.”  
–Lily
• **Hearing impairment** is very common in human populations, but it is a very heterogeneous disorder, with a wide range of causes (Steel, 2012).

• Defining **spirituality** as a psychological wellbeing associates it directly with mental health, making interpretation of the relationship between spirituality and health (Koenig, 2007).
THEME CLUSTER 6: Coping with the Condition

- This includes the themes:
  - Altered Growth and Development
  - Gaining Autonomy
  - Surrogacy
  - Discipline
  - Adjustment Difficulties
  - Behavioral Problems
  - Constructive Adjustment
Audit Trails/Verbatims

“It was difficult for me to have a deaf mother while growing up...” – John

“...I served as her ears and as her guide.” – Emma

“The condition of my father affected my growth and development. I had vices because my father was not able to really care for me like a normal father would have. I discipline myself.” – Noah
“My mother is better than other mothers because despite her condition, she was still able to discipline us.” –John

“Despite my mother being a deaf mute, we should not be affected by negative remarks of other people and continue to strive hard.” –Lucas
• **Deaf culture** involves having its own customs, morals, history, arts, language, educational establishments, and groups (Fileccia, 2011).

• The Merriam-Webster (2013) dictionary defines **adjustment** as “a process of adjusting or to adapt or conform oneself (as to new conditions)”.

• **Constructive adjustment** was stated in Preston (1994) and Hadjikakou et. al. (2009) as most of the hearing children (who participated in the study) developed **good relationships and no problems in interacting to their parents.**

• Bucchino’s study (1993) discussed on **common themes of negativity** such as **disappointments, forced to grow-up early, and increased demands from their deaf parents and from the environment.**
Despite the presence of their parents' condition, they have "accepted them, no matter what they have become." The lived experience of hearing children with deaf parents cannot go without certain difficulties in the medium of communication.

As for their day to day lives, the effect of the condition of their parents in the usual conversations has a huge impact in how they see and define their lives as well as live their lives.
Emotional pain was a major element in the process of the creation of their lived experiences. Most of the participants expressed that they pity their parents whenever their parents get hurt by other people.

The lived experiences of children of deaf adults have been understood in this study in view of the fact that the participants have a degree of acceptance of their parents’ condition.
Despite the negative impacts the participants saw in having deaf parents, eight (8) of the participants stated that they are loved by their parents. They consider taking care of their parents as their life's undertaking.

The largest meaning that was found in the process of understanding the lived experience of deaf adults is the difficulties they had in finding a medium for communication which largely affected their bond with their parents and their emotional growth.
RIGOR (Lincoln & Guba, 1985)

- Credibility
- Dependability
- Confirmability
- Transferability
CONCLUSION

The shared experiences and testimonies of the hearing children of deaf parents are anticipated to be acknowledged and that information about their experiences will provide awareness to the society regarding what they have lived through.

This research will greatly help the community to better understand and deal with people who are in the same situation.
• To conduct more qualitative and quantitative research on CODAs


