

## The Experience of Hope for Mothers with Speech-Language Delay Children

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### Abstract

Hope is an essential attribute for parents to build a positive perspective on children with developmental problems. Due to the importance of hope, this study explored the experience of hope for mother with speech-language delay children. Eight semi-structured interviews were conducted with six mothers and analysed the data using the constant comparative method as proposed by grounded theory. The results showed that mothers do experience changes in their hope about their child. Mother's hope is moving between unrealistic to realistic hope, which is influenced by various protective and risk factors. Unrealistic hope is the wrong hope that is not suitable for the child condition (wishful thinking), resulting in incorrect parenting processes. It also becomes a burden for the mother to make it happen. Realistic hope is the correct hope suitable for the child condition, resulting in correct parenting process and not be a burden for the mother to make it happen.

**Keywords:** *mother's hope, unrealistic hope, realistic hope, speech delay children*

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### Introduction

Speech and language skills are developmental tasks that must be mastered by children to articulate what they want and need, provide critical tools for learning, engage in social relationships, behaviour and emotion regulation from infancy onward (Kaiser & Roberts, 2011; Cohen, 2010). Speech refers to the mechanics of oral communication by articulating

verbal expression. Language encompasses the understanding, process, and production of communication (Shetty, 2012).

Children use their eyes, facial expression and gestures to communicate and build social interaction with the people around them before they can speak. The speech-language abilities of children continue to evolve with age. It is a dynamic process, resulting from the complex interaction between innate biological abilities and environmental stimuli (Schirmer, Fontoura, & Nunes, 2004; Shetty, 2012).

At five years of age, children are expected to gain much information about the world around them. They should be able to communicate their feelings, needs, and expectations. Their speaking and language skills should enable them to participate in social interactions and shape their views on the reality with that of the surrounding society (Chess & Rosenberg, 1974).

However, not all children can achieve normal speech and language development. Shetty (2012) illustrated that several children around the age of five shows lack of vocabulary, compared to the average children their age, coupled with poor pronunciation, behaviour problems, and psychosocial adjustment disorder. These are indication of speech and language delay. Generally, speech-language delay is a term used to refer to a child with speech and language development that are significantly below the average child at his or her age (Leung & Kao, 1999; Macias & Wegner, 2005; Shetty, 2012).

Nowadays, the number of child developmental disorders continues to increase, with speech-language delay being one of the most common of them. Current estimated prevalence of speech-language delay in preschool children ranges from seven to ten percent, with a significantly higher proportion of boys being affected (Macias & Wegner, 2005). In Indonesia, speech-language delay in children is quite high. Survey conducted by UKK *Tumbuh Kembang Pediatri Sosial* IDAI at seven educational hospitals (Surabaya, Jakarta, Bandung, Palembang, Denpasar, Padang and Makassar) found that the incidence of speech-language disorders in children ranged from eight to 33 percent, with an average of approximately 21 percent (Saputra, 2013).

A delay in speech development could be a symptom of many disorders, including mental retardation, hearing loss, expressive language disorder, psychosocial deprivation, autism, elective mutism, receptive aphasia and cerebral palsy (Shetty, 2012; Whitehurst & Fischel, 1994). It is categorized as a secondary language development delay. This category poses a

more complex problem because it encounters other problems stemming from the developmental obstacles experienced (Whitehurst & Fischel, 1994).

Speech-language delay acquisition is an early indicator of developmental deficits that could affect the academic performance of school children, ranging from their personal, social, academic, and future vocational life (Kaiser & Roberts, 2011; Leung & Kao, 1999). Delayed language development have been shown to affect children's language, social, emotional, and academic performance later in their life, signifying the importance of research on early childhood language disorder (Tsybina & Eriks-Brophy, 2007).

Parents have a crucial role in managing children with developmental disorders. In this case, they are in charge of caring for their children. Through parenting, parents can monitor their child's growth, turning them into the most accurate early detector of developmental disorders in children. Good cooperation between parents and professionals will also ensure early detection and management of developmental disorder runs optimally (Glascoe & Marks, 2011). Early detection and treatment can reduce the emotional, social, and cognitive problems experienced by children with speech-language delay (Leung & Kao, 1999).

The question is, can parents of speech-language delay children perform good parenting assignments? Data have proven that this is not always the case. Parenting a child with speech-language delay is challenging. This is because children with speech-language delay, particularly those caused by developmental disorders, often ignite family problems that can hinder parents in carrying out their parenting assignments.

The diagnosis of child development disorder often comes as an unexpected news for parents. It is an extremely hard experience to deal with, causing parents to feel shocked, in denial, angry, scared, and anxious about the uncertain future of their children (Huang, Kellet, & Jhon, 2010; Marvin & Pianta, 1996; Fernández-Alcántara, 2014; Riley & Rubarth, 2015; Schuengel, dkk, 2008; Lightsey & Sweeney, 2008).

Mothers are often affected more strongly. A number of studies have found that mothers of children with developmental disorders experience deeper emotional reactions and finds it very difficult to accept their child's diagnosis (Marvin & Pianta, 1996; Huang, Kellet, & John, 2010; Kearney, Britner, Farrel, & Robinson, 2011; Barak-Levy & Atzaba-Poria, 2013; Ceylan & Aral, 2007; Rudolph, Rosanowski, Eysholdt, & Kummer, 2003; Sen & Yurtsever, 2007). This

is because mothers tend to use emotional coping style in the face of stressors (Barak-Levy & Atzaba-Poria, 2013).

Mother of children with developmental disabilities have high level of stress (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Hastings, et al., 2005; Weiss, 2002), anxiety and depression (Bumin, Günal, & Tükel, 2008; Rudolph, et. Al, 2003). Increased level of depression and anxiety affect mother's quality of life (Bumin, Günal, & Tükel, 2008). In turn, this condition caused a sense of hopelessness for them (Ceylan & Aral, 2007).

However, hope is important for parents with a disabled child (Ogston et al, 2011). Hope has been found to be a strong predictor for parent's acceptance of their child's disability (Jovunen & Leskinen in Kausar, Javne, & Sobsey, 2003). Hope is identified as life instinct, implies process, adventure, moving forward, a confidence search (Menninger, 1959). Hope and positive transformation are meaningfully interconnected in the lives of parent of children with developmental disabilities. Thus, further research exploring the positive attributes of hope may be highly valuable for these families (Kausar, Javne, & Sobsey, 2003). Hope is a critical factor in dealing with life challenges. It acts as a source of psychological strength and resilience that facilitates the coping process to achieve well-being (Elliot, et. Al, 1991; Velle, Heubner, & Suldo, 2006; Ong, Edwards, & Bergeman, 2006; Faso, Neal-Beevers, & Carlson, 2013).

Previous published studies on hope in family caregivers, family member, and parents have mostly been exploratory in nature. They have described the hope of family members of people with brain injury (Kuipers, et al, 2014), family caregivers of someone with chronic illness (Duggleby, et al, 2010), parents of a child with Duchenne muscular dystrophy (Samson, et al, 2009), family members of traumatic coma patients (Verhaeghe, et al, 2007), Parents of adolescents with Cancer (Kylmä, Juvakka, 2007), informal caregivers of palliative patients (Holtlander, et al, 2005), and family caregiver of terminally ill people (Herth, 1990). The context that the previous studies used were mainly families of a chronically and physically ill patients.

Bouma & Schweitzer (1990) found that there are different patterns of stress between mothers of children with chronic physical illness and chronic psychological disorders. Chronic physical illness patients may disturb family life for a relatively short period. The

mothers of children with chronic physical illness are more concerned about the physical limitation of the child, life span care, and the terminal nature of the illness. Meanwhile, children with chronic psychological disorders can disrupt family life for a relatively long period. The mothers of children with chronic psychological disorders are more concerned about dependency and management demands, physical limitation, and the nature of psychological disorder characterized by developmental disorder of their child. Chronic psychological disorders in children was found to contribute more significantly to family stress than chronic physical illness.

Based on the findings of Bouma & Schweitzer (1990), it was concluded that previous studies on hope cannot be used as a reference to explain the experience of hope in mothers of children with developmental problems, due to differing context. Nevertheless, exploration on the hope of mother with developmental problems is scant. The purpose of this study is to explore and understand the mothers' experience of hope with speech-language delay children. Further, it also aims to explore the dynamic of hope in mother with speech delay children, and its relation with parenting process.

## **Method**

The method used was Strauss & Corbin's grounded theory. It is a qualitative research, using a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon. The research findings constitute a theoretical formulation of the reality under investigation (Strauss & Corbin, 1990).

Inclusion criteria for the participants were: a) mother with speech delay children, b) can tell the experience of hope as a mother of a speech-language delay child, c) willing to be a research participant and fill out informed consent. Researchers looked for prospective participants for the study by seeking information on a number of hospitals, therapy sites and schools that provide services to children with developmental delays.

As many as 20 people volunteered as participants, however only six met the inclusion criteria. The data were collected by the researcher through face to face interviews. An interview guide was prepared as a framework to collect data as seen below:

I. Tell me about the situation when you first received the diagnosis that your child is experiencing developmental speech delay

2. Tell me about your hopes for your child
3. Tell me about your process of changing hope

Interview data were transcribed and analysed using a constant comparative method of coding and categorization. Coding represents the operations by which data are broken down, conceptualized, and put back together in new ways. Analysis in grounded theory is composed of three major types of coding. There are: (a) open coding, (b) axial coding, and (3) selective coding (Strauss & Corbin, 1990).

Open coding is the analytic process by which concepts are identified and developed in term of their properties and dimensions. Open coding process include: asking questions about data and making comparisons for similarities and differences between each incident, event, and other instances of phenomena. Similar events and incidents are labelled and grouped to form categories (Strauss & Corbin, 1990).

Axial coding is a set procedure whereby data are put back together in new ways by making connection between categories after open coding. The final coding in grounded theory study is selective coding. It is the process of selecting core category (the central phenomenon whereby all the other categories are integrated), systematically relating it to other category, validating those relationships, and filling in categories that need further refinement and development (Strauss & Corbin, 1990). Table I provides an example of the coding process.

To increase credibility and trustworthiness, two external reviewer (the second and third author) who are familiar with grounded theory method and literatures on developmental psychology reviewed the accuracy of data collection, analysis and interpretation.

Furthermore, this study also conducted member checking to ensure credibility and trustworthiness. After that, researcher cross-checked the result of this study with the participants. All participants agreed to the results of study, none suggested revision or proposed new data.

## **Result**

The definition of hope was inductively derived from the participant's experience. Hope is defined as power, an energy that facilitates mothers to formulate goals and exert effort to

achieve the goals associated with the child's future. Hope is very important to the participant. One participant stated, *“Having hope motivated me to keep searching for ways to help my child better”*. Nevertheless, all the participants mentioned that hope is a dynamic process, always changing depending on the progress of the child's development. It is also an ongoing condition. If the child has progress, his or her mother will feel hopefulness. In contrast, if the child shows no progress, the mother will also worry.

### *Unrealistic Hope*

Every mother hopes to have her child grow optimally, normally and ideally according to their development. This was expressed by several participants in various ways below.

*“when my daughter was young, I had so much hope for her, I hoped to have a normal child like any other parent”*.

*“An ideal child to me is to have this child be like her sister who have normal development”*

The diagnosis that a child has speech-language delay because of a psychological disorder, raises many negative reactions such as shock, anxiousness, and sadness because it is very unexpected. One participant described, *“It was like experiencing rain in broad daylight”*.

Having an ideal child sometimes becomes an unrealistic hope for mothers of children with speech-language delays. During this time, mothers will strive to manifest the ideal child. Everything will be done. As described by participants:

*“I will do whatever it takes so that this child can have a normal development”*

*“I have done various treatment, such as medical treatment with a physician, treatment alternatives - even going as far as traditional healers (dukun)- with the hope that my child can be improved”*

Unrealistic Hopes lead to strong urge to undertake all kinds of ways to reach the goals, including through illogical ways. It is sometimes not relevant to the children's conditions and needs.

Table I  
 Example of Coding Process

Transcripts	Indicator	Categories	Concepts
“An ideal child to me is to have this child be like her sister who have normal development”			
“I have done various treatment, such as medical treatment with a physician, treatment alternatives - even going as far as traditional healers (dukun)- with the hope that my child can be improved”	Striving to realize the ideal child	Unrealistic hope	
I tried to be patient, wait for the results, but there is no change in my daughter. Repeated failures, my daughter is still like it			
Until finally I feel depressed. I have made many sacrifices...time, effort, cost. I left my job, but there is no change in my child	Dealing failures	Realize	Dynamics of changing hope
Feeling tired, repeatedly failed, and did not know what to do anymore			
Finally, I know that this child is like this, cannot be a normal child	Evaluating goal, reviewing hopes		
Now, I have to understand the problem my daughter, so I try to fit her needs. I seek how to make my child can talk, can understand, that's all	Adjust hopes with the child's condition	Realistic hope	

### Realize

Mothers often fail to achieve the ideal child. Initially, she tried to be patient and waited for the change in her child. However, once effort has repeatedly failed, mothers tend to feel depressed. This is because they feel that, despite many sacrifices, their child still has not shown improvement. One participant said,

*“Repeatedly failed, I tried to be patient, wait and wait, but my daughter is still like this. Until finally I feel depressed. I have made many sacrifices...time, effort, cost. I left my job, but there is still no change in my child”*

After repeated failures, mothers finally stopped trying. They became tired and clueless as to what to do next. Finally, they will come to the realization that their child cannot be as



normal as children in general. This condition causes them to change their hope and define new goals. One participant stated,

*“Finally, I know that this child is like this, he/ she cannot be a normal child”*

### *Realistic Hope*

Mother's hope can change into realistic hopes when mothers can introspect her failure in achieving the irrational goals. Realistic hope is the hope that adjusted to the child's condition. Our findings identified that realistic hope would be formed when mothers realize that their child has developmental delays and cannot be forced to become normal as the average children their age.

After this hope has been achieved, mothers will define new goals. As one participant said:

*“Now, I'm not expecting anything heroic, what is important to me is how this boy could say a word”*

Realistic hope facilitates individuals to formulate specific goals according to the needs so that the efforts in realizing the goals are also appropriate. As described by a participant:

*“Now, I have to understand my daughter's problems, I try to fit her needs. I seek how to improve her speaking skills, to understand, being communicative, that's all...”*

### *Dynamic change of hope*

The central category found in this study is dynamics change of hope experienced by mothers with speech-delay children. It was found that there is a dynamic change of hope from irrational to rational. In other words, mothers always have hope but it is not always appropriate because it is not adjusted to the child's condition and needs. Inappropriate hope cause incorrect purpose, inappropriate efforts appropriate, and failures.

Failure does not diminish mothers' hope. However, it does cause mothers to experience negative reactions such as feeling sad, worried and depressed. When she feels tired and does not know what to do anymore, mothers will realize that the child cannot develop normally.

In this condition, mothers will change their hopes and formulate new goals. The results of this study indicate that when mothers have inappropriate hopes, parenting process and efforts to handle speech delay in children also becomes inappropriate. It inhibits children from developing optimally.

## **Discussion**

This study identified hope for mother with speech-language delay children as a power and energy that facilitates mothers in formulating goals and exerts effort to achieve the goals associated with the child's future. The meaning of mother's hope gives a positive impact for mother's condition and parenting for the child. This finding has also been described in previous study. Among others, hope was described as life instinct (Menninger, 1959), life force (Default & Martocchio, 1985), the basic source (Kylmä, Vehviläinen-Julkunen, Lähdevirta, 2003), and inner strength, building self-confidence to make sense of their completely changed situations. They were learning to stay positive and move ahead with their lives (Holtslander, et al, 2005). Therefore, it can be concluded that, hope aids people in dealing with difficult situations.

As noted in a number of literatures, hope in this study is also a dynamic process. Hope was found to evolve stepwise up and down (Verhaeghe, et. al, 2007); altering balance between interconnected hope, despair, and hopelessness (Kylmä, 2006); between eroding hope and hanging on to hope (Holtslander, et. al, 2005). Additional finding in this study, the dynamic of hope not only evolve stepwise up and down from hope to hopelessness, but also from unrealistic to realistic hope.

Our findings show that mothers' hope for their child's future can sometimes be inappropriate due to them denying the condition of their child. Most mothers still struggle to get her ideal child. As a result, mothers maintain her hope to reach the ideal child and build unrealistic hopes. Unrealistic hopes lead to strong urge to undertake all kinds of ways to reach the goals, even through irrational ways are irrelevant to the children's needs. Barak-Levy & Atzaba-Poria (2013); Schuengel, et.al, (2008) mentioned that the majority of mothers were unresolved with their child's diagnosis. Unrealistic hopes can be destructive because being unable to adjust hope could cause hopelessness to the said person (Links & Kramer, 1994; Insani, 1963).

Introspection in this study has been identified as a stimulator to help realize that the child cannot develop normally. Introspection helps mothers in understanding their child's condition, realizing that their hopes are inappropriate, learning to adapt with the child's condition, and proceeding to adjust their hopes. In this condition, the mother will change her hopes to realistic hopes. Zembat & Yildiz (2010) in their study found a linear relationship between acceptance and hopelessness levels in mothers of children with disability. It was found that mothers were more hopeless in case of rejection, whereas hopelessness level decreased in case of acceptance.

Realistic hopes facilitate individuals to formulate specific goals according to the child's needs, so that the efforts in realizing the goals are also appropriate. Realistic hopes provide considerable support, facilitating the ability to make appropriate decisions about future plans, treatment, and issues of personal importance (Links & Kramer, 1994).

## **Conclusion**

Mothers of children with speech-language delay have serious concern about their children's future. She cannot accept the child's condition and often struggles to create her ideal child, building unrealistic hope. Unrealistic hope has a negative impact on the mother, particularly on her parenting behaviour.

Introspection was identified as an important factor that help mothers in understanding their child's condition by realizing that her hopes are not appropriate, learning to adapt with the child's condition, and adjusting her hopes more realistically. Realistic hopes facilitate mothers to make appropriate decisions about future plans and best treatment for her children.

The results of this study cannot explain the variation in the dynamics of mothers' hope based on the type and level of child's developmental disorders, causing the child to experience delays in speech-language development. Therefore, future researchs are advised to consider the type and extent of developmental disorders experienced by children in exploring the concept of hope in the context of children with special needs.

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