# Examination of Chronic Sorrow Among Parents of Children with Disabilities: Cross Sectional Study

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## *Abstract*

**Background:** Parents of disabled children face many challenges when providing care, along with persistent worry and fear about the child health outcome, along with the impact of the child's disability on their lives. Parents of disabled children experience stressful situation and face many emotions one of which is chronic sorrow. Therefore, the Theory of chronic sorrow was introduced to examine and measure feelings of chronic sorrow among parents. Little attention has been made to examine Arab parents with disabled child and the utilization of chronic sorrow theory in this population.

**Objective:** The study aims to examine the application of chronic sorrow theory on parents of disabled children in Saudi Arabia.

**Methods:** A cross-sectional design was utilized to obtain data from 89 participants who are parents of disabled child. A questionnaire was disturbed via online to measure chronic sorrow.

**Results:** The study examined and applied the concepts within the theory of chronic sorrow. The concepts of loss experience yielded a moderately high score (mean 3.3, SD 1.10), of all the variables measuring loss experience, parents scored high in feeling sad when thinking about their child disability (mean 3.9, SD 1.24). Parents have also reported moderately high score (mean 3.3, SD 1.06) in the concept of disparity, specifically when their child doesn’t meet developmental milestone as their peer (mean 3.8, SD 1.30). Feelings of chronic sorrow also displayed moderately high score (mean 3, SD 0.87), with the periodic nature of chronic sorrow as the highest score within the concept of chronic sorrow (mean 3.6, SD 1.16). In addition, internal and external management methods parents believed are effective were examined. Internal management of chronic sorrow are believed to be of high importance by the parents (mean 4.6, SD 0.33), specifically the belief of fatalism (mean 4.8, SD 0.50). Parents also viewed external management of chronic sorrow as important in navigating their emotion (mean 4.5, SD 0.42), specifically reported social support from family and the community (mean 4.7, SD 0.55). The study has identified strong positive relationship between sorrow and loss experience ($r=0.765$; $P < 0.001$), and with disparity ($r=0.765$; $P < 0.001$). Lastly, the study have found no relationship between chronic sorrow and time passed since parents received diagnosis of their child disability ($r=-0.009$; $P= 0.936$).

**Conclusions:** The results of this study have utilized the theory of chronic sorrow among parents of disabled children, feeling of loss, disparity and chronic sorrow were reported. Therefore, screening, and parental emotional care are needed for this population. Importance of chronic sorrow management and creation of intervention to enhance parental mental health and well-being are important to be addressed and utilized by the health care workers. Parental acceptance of their child disability doesn’t entail absence of chronic sorrow as its normal grieving process but anticipating the triggers of chronic sorrow and utilizing management method, both internal and external are essential to promote parental mental health and overall child health outcome.

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The study examined the concepts within the theory of chronic sorrow. The concepts of loss experience yielded a moderately high score (mean 3.3, SD 1.10), of all the variables measuring loss experience parents scored high in feeling sad when thinking about their child disability (mean 3.9, SD 1.24). Parents have also reported moderately high score (mean 3.3, SD 1.06) in the concept of disparity, specifically when their child doesn't meet developmental milestone as their peer (mean 3.8, SD 1.30). Feelings of chronic sorrow also displayed moderately high score (mean 3, SD 0.87), with the periodic nature of chronic sorrow as the highest score within the concept of chronic sorrow (mean 3.6, SD 1.16). In addition, internal and external management methods parents believe are effective were examined. Internal management oof chronic sorrow are believed to be of high importance by the parents (mean 4.6, SD 0.33), specifically the belief of fatalism (mean 4.8, SD 0.50). Parents also viewed external management of chronic sorrow as important in navigating their emotion (mean 4.5, SD 0.42), specifically reported social support from family and the community (mean 4.7, SD 0.55). The study has identified strong positive relationship between sorrow and loss experience ($r$=0.765; $P < 0.001$), and with disparity ($r$=0.765; $P < 0.001$). Laslty, the study have found no relationship between chronic sorrow and time passed since parents recived diagnosis of their child disbaility ($r$=-0.009; $P$= 0.936).

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parental emotional care need to be delivered to this populaiton. Importance of chronic sorrow management and create intervention to enhance parental mental health and well-being are importnant to be addressed and utilized by the health care workers. Parental acceptance of their child disability doesn’t entail absence of chronic sorrow as its normal grieving process but anticipating the triggers of chronic sorrow and utilizing management method, both internal and external are essential to promote parental mental health and overall child health outcome.

# Introduction

In 2017 the Saudi General Authority of Statistics issued a detailed report of people with disabilities who reside in Saudi Arabia, the results were as follows: a total of 1,445,723 with varying degrees of disability that range from mild, moderate to severe, 52.2% were males and 47.7% were females [1]. Illustrating that people with disabilities are a main part of the Saudi community, and more attention should be directed to them and their families.

Parents of disabled children confront numerous difficulties in their daily life when caring for disabled child, along with feelings of worry and stress about their child's long-term survival and well-being [2]. The difficulties they face may include their ability to deal with day-to-day challenges, transformation of their social interaction with relatives and friends, and modification of their daily activity [2]. Parents of a disabled child worry about their child's acceptance in society, the opportunities, and resources that might not be available to them when caring for their child. And as the child grows and his condition persists, parents are concerned about where and with whom their child will live when they are adults [3]. In addition, parents of disabled children experience emotions that are overwhelming and don’t follow a predictable sequence. Their emotion can range from sadness, anger, frustration and is periodic in nature [4]. Multiple studies aimed to measure chronic sorrow, among parents of children with different health conditions have been explored. These include but not limited to, chronic illness and disabilities [5,6], autism [7,8], cancer [9], sickle cell disease [10], neuro developmental disorders [11], type 1 diabetes [12], and down syndrome [13].

As a results, the concept of chronic sorrow emerged to explore the phenomena these parents are living on a daily basis. Roos [14] defined Chronic sorrow as “a set of pervasive, profound, continuing, and recurring grief responses resulting from a significant loss or absence of crucial aspect of oneself (self –loss) or another living person (other – loss) to whom there is a deep attachment. The way in which the loss is perceived determines the existence of chronic sorrow. The essence of chronic sorrow is a painful discrepancy between what is perceived as reality and what continues to be dreamed of. The loss is ongoing since the source of the loss continues to be present. The loss is a living loss”

**The Theoretical Framework of Chronic Sorrow:**

Chronis Sorrow was initially proposed by psychiatrist Olshansky [15]. In his work with mentally challenged children, their parents, and family members. Olshansky observed that parents of disabled children display a widespread psychological response to the experience of having a disabled kid [15]. The parents of the disabled child suffered from long-lasting, chronic sorrow since the loss they experience lacked a clear end. It was also uncertain how long the loss would persist [16]. Parents who care for children with disabilities have described having profound emotional experiences. These emotions may be felt occasionally, but they may not always be present. These intense emotions may include shock, disbelief, feelings of isolation, rage, irritation, and a profound sense of sadness and loss. As a result, it is hypothesized that parents of children with disabilities are more likely to report experiencing persistent sadness [17].

Eakes, Burke, & Hainsworth [18] defined the variables of the chronic sorrow theory as the following:

- “Chronic sorrow: ongoing disparity resulting from loss characterized by pervasiveness and permanence. Symptoms of grief recur periodically, and these symptoms are potentially progressive”
- Loss: occurs because of the discrepancy between the “ideal” or “imagined” situation versus the lived experience and occurs in the early stages of the child diagnosis.
- Disparity: disparity follow the loss experience and can be classified as a trigger for chronic sorrow. Loss experience occurs in the early stages of the child diagnosis, whereas disparity remerges as time passes, when the child doesn’t meet his or her developmental milestone like

his or her peers, such as school graduation, and birthday parties.

- Management Methods: are strategies utilized by parents or individuals, or experience sorrow to minimize its impact. These methods can be internal (personal and individualized methods) or external (support from health care workers or institutions)

Studies that addressed chronic sorrow among parents of disabled child are very scarce, especially in Arabic. The Kendall chronic sorrow Scale was found to be useful in measuring the chronic sorrow of mothers of disabled child [19]. Fernandes, et al [20] analyzed the theory of chronic sorrow, found that the theory is well defined, and its concepts captured the phenomena understudy, and its high reliability in measuring its concepts. Lastly, the theory can be utilized by nurses caring for parents of children with disabilities, identify and use the needed comfort tools along with coping strategies.

This descriptive study aims to explore chronic sorrow among parents of children with different types of disability in the Kingdom of Saudi Arabia. With the objective to answer the following questions: with the use of chronic sorrow as theoretical framework, what are parental experiences of chronic sorrow towards caring for a child with a disability? Is there a relationship between the concepts of the chronic sorrow theory, specifically between loss and disparity with chronic sorrow? Lastly, is there a relationship between time passing since child diagnosed with disability and parental feeling of chronic sorrow?.

## Methods

### Design

A quantitative descriptive cross-sectional study design will be used to conduct this study to explore chronic sorrow among parents of children with disabilities. Along with identifying the strength of the relationship between the triggers (loss experience and disparity) with chronic sorrow. Lastly, investigate the impact of time since child been diagnosed with disability on parental feelings of chronic sorrow.

### Instrument

Data will be collected for this study through an online questionnaire. The questionnaire and consent form will be sent to the participants after obtaining the IRB approval from King Abdullah International Medical Center.

The questionnaire will be distributed via electronic version. The questionnaire consists of parental demographic data (8 items), loss experience (5 items), disparity (3 items), Chronic sorrow (9 items), management of chronic sorrow (9 items). Measurment of chronic sorrow was originally created by Kendall chronic sorrow instrument [21], then the Arabic version of the same instrument was created by Baker, Shanad, & Abdulhafiz [22] who confirmed an internal consistency of correlation coefficient of the scale are greater than 0.7, with high degree of validity in the Loach method for all the statement with a score of 0.62. Along with confirmed reliability of Cronbach alpha of 0.8. All the above parameters have met the psychmoteric properties of a valid and reliable instrument [22]. As result, the Arabic version of the instrument was utilized for the conduction of this study due to the proximity of the populations in both studies, both of which speak Arabic, share cultural characteristics and religious background.

For the measurement of chronic sorrow every item in the scale has a total of five responses (5-point Likert scale), ranging from strongly disagree (score of 1 point), disagree (2 points), neutral (3 points), agree (4 points), and strongly agree (5 points). scoring criteria will be as follows: 1–2 indicated low score of chronic sorrow, 2–3 indicated moderately low score, 3–4 indicated moderately high score, and 4–5 indicated high score of chronic sorrow.

**Sample, Setting, and Data Collection**

Recruitment of study participants will be non-probability convenient sampling. The tool will target parents with disabled child currently residing in Saudi Arabia. The participants who will be eligible to participate in this study should fulfill the following criteria: Mother, father or primary caregiver of child with disability, the disabled child have a confirmed medical diagnosis, parent can speak and read Arabic, and parent age is above 18 years old.

For this descriptive study, the significant level of alpha was set at 0.05, and power of 0.8. To calculate sample size and estimate power analysis. The sample size is estimated by G*Power software. This study will be the first to examine the use of chronic sorrow as theoretical framework among Saudi parents who have a child with disability. As a result, no effect size was found to be used in conducting power analysis. Cohen [23] stated that in cases like our study where effect size was not reported in the literature, estimation of effect size will be based on logic and judgment. Therefore, a medium effect size of 0.30, power of 0.80, and alpha significance level of 0.05 to guide our statistical analysis with a sample size of 64.

Potential participants will be recruited via invitation through WhatsApp application, Facebook, and X social platform. Upon filling out the questionnaire, the researcher will identify parents who meet the inclusions criteria and enroll them in the study. If the participant agrees to fill out the questionnaire after reading the consent, they will be directed to the questionnaire page.

**Data Analysis**

Once data collection has ended, it will be entered into an Excel database by the researchers for analysis. Statistical Package for Social Sciences (SPSS) will be used to analyze the data. Different types of analysis are proposed for this study. Descriptive statistics will be calculated on all variables of interest, including means, standard deviations, frequencies, and percentages, to describe study variables. Pearson’s correlation coefficients will be employed to examine the relationships among continuous variables. Statistical significance is based on the standard alpha level of .05.

For statistical analysis, we will import the gathered data into the most recent release of IBM's Statistical Package for Social Sciences (SPSS) on a password-protected computer.

Frequesncies and percetages will be used for analysing descriptive data for evalauting the variables of chronic sorrow. Pearson correlations, will be used for analysing numerical data between the relationhip of the triggers and the concept of chronic sorrow.

### Ethical Consideration

This study received ethics approval from the IRB of the King Abdullah International Medical Research Center (SP23J/144/09)

Various measures will be undertaken to maintain the privacy and confidentiality of participants. Although there is minimal risk, all measures to protect participants information will be taken. Participants' responses to each survey item will not be shared with other participants or individuals not associated with the research project. By accessing and completing the survey, participants gave their consent to take part in the study. Participation in the study is voluntary, and participants can withdraw from the study at any time.

## Results

### Participants Characteristics

As table 1 shows, a total of 89 participants completed the survey. Of these participants (76.7%) were the mothers of the disabled child, most of the participants (46.7%) were between the age of 40 and 49. Many of the participants were caring for a child with permanent disability (78.9%), the educational level of the participants is predominantly with a university level (60%). The participants reported time since child diagnosed with a disability is less than 1 year (90%) and most of the reported disability were children with Down syndrome (34.715)

Table 1. The sample demographic characteristics (N=89)

| Demographic variable | Participants, n (%) |
|---|---|
| **Persons completing the survey** | |
| Mother | 69 (76.7) |
| Father | 5 (5.6) |
| Nonparent | 15 (16.7) |
| **Age** | |
| 20-29 | 5 (5.6) |

| | |
|---|---|
| 30-39 | 20 (22.2) |
| 40-49 | 42 (46.7) |
| 50-59 | 16 (17.8) |
| 60-65 | 4 (4.4) |
| **The child with permanent or temporary disability** | |
| Temporary disability | 10 (11.1) |
| Permanent disability | 71 (78.9) |
| **Educational level** | |
| Primary school | 4 (4.4) |
| Intermediate school | 5 (5.6) |
| High school | 26 (28.9) |
| University | 54 (60) |
| **Time since child diagnosed with disability** | |
| Less than 1 year | 45 (90) |
| 2 - 3 years | 11 (12.4) |
| 4 - 9 years | 25 (27.8) |
| More than 10 years | 8 (8.9) |
| **Nature of the child's disability** | |
| Down syndrome | 39 (34.71) |
| Autism and ADHD | 15 (13.35) |
| Mental retardation | 8 (7.12) |
| Physical disability | 21 (18.69) |

### Descriptive statistics of the theory of chronic sorrow

The below data illustrates the descriptive statistics of the participants towards the concepts of the chronic sorrow theory which is used to measure the following aspects: the triggers of loss experience and disparity, chronic sorrow, internal management and external management

### Descriptive statistics for loss experience

As shown in table 2, the reported score of the loss experience parents of child with disability face was a mean of 3.3 (SD 1.10). Of all the variables measuring loss experience, feeling sad when thinking about the child’s disability was the highest at 3.9 (SD 1.24), and the sense of overwhelming sorrow scored the least variable within the loss experience with a mean of 2.8 (1.40). The results shows that parents with disabled children report moderately high loss experience.

Table 2, Descriptive statistics of loss experience (N= 89)

| **Loss Experience** | **Score, mean (SD)** |
|---|---|
| Feels like the disability happened to me | 3.5 (1.18) |
| Sorrow feelings when I think about my child disability | 3.9 (1.24) |
| Sorrow feeling remain as the day of the diagnosis | 3.3 (1.43) |
| Urges to cry when I remember the disability | 3.3 (1.42) |
| Overwhelming sorrow | 2.8 (1.40) |
| Total score of loss experience | 3.3 (1.10) |

**Descriptive statistics for disparity**

As shown in table 3, the total score of the concept of disparity reported by parents of disabled child is a mean of 3.3 (SD 1.06).  the highest score of the disparity variables was the feeling of sorrow and sadness parents faces when their child can meet developmental milestone for their age such as birthdays with a mean score of 3.8 (SD1.30). On the other hand, the lowest score reported was the feeling of sorrow when thinking about my child without the disability with a mean of 2.7 (SD 1.28). According to this study the feeling of disparity parents of child with disability is moderately high which is aligned with experiences of loss.

Table 3, Descriptive statistics of disparity (N=89)

| **Disparity** | **Score, mean (SD)** |
|---|---|
| Sorrow emerges when I remember my child disability | 3.3 (1.29) |
| I feel sorrow upon things that don’t matter for parents with healthy children (such as birthdays and entering school) | 3.8 (1.30) |
| I feel sorrow when I picture my life without the disability of my child | 2.7 (1.28) |
| Total score of disparity | 3.3 (1.06) |

### Descriptive statistics for chronic sorrow

As shown in Table 4, The total score of the chronic sorrow reported by parents of disabled child were reported with a mean of 3 (SD 0.87). Of the variables measuring chronic sorrow the variable of sorrow and its nature of coming and going as its periodic nature had the highest score with a mean of 3.6 (SD 1.16) along with reported energy to handle sorrow with a mean score of 3.6 (SD 1.11). On the other hand, the least reported variable within the chronic sorrow concept is parents reporting that their life is not what they imagined due to their child disability with a mean of 2.6 (SD 1.33), followed by feeling that parental desires and goals don't match what life has given them with a mean score of 2.7 (SD 1.32). Upon measuring the concepts of chronic sorrow, parents have reported moderately high levels of chronic sorrow indicating that these feelings of sorrow is manageable and can be reduced or its cyclic nature can be spaced out.

Table 4. Descriptive statistics of chronic sorrow (N=89)

| **Chronic sorrow** | **Score, mean (SD)** |
|---|---|
| Sorrow regarding my child disability comes and go | 3.6 (1.16) |
| I feel like my child disability makes me give away some aspects of my life | 3.4 (1.40) |
| I feel like I don't have control over life | 2.9 (1.36) |
| I feel like my life is not like I have imagined due to my child disability | 2.6 (1.33) |
| The feelings of sorrow can transform into feeling of loneliness | 2.8 (1.38) |
| I feel like I have energy to handle life stressors | 3.6 (1.11) |
| Sudden changes of my child disability have lead to exhaustion | 3.0 (1.26) |
| I think what I desire don't align with what life have given me | 2.7 (1.32) |
| I feel older due to the disability of my child | 2.9 (1.34) |
| Total score of chronic sorrow | 3.0 (0.87) |

### Descriptive statistics of Internal management of chronic sorrow

As shown in table 5, the descriptive statistics illustrated by parents of disabled children view the effectiveness of internally managing their child disability and means to overcome chronic sorrow, the total score of internal management shows a mean of 4.6 (SD 0.33) which is high score highlighting the important role of internal management of chronic sorrow. Of the variable measuring internal management of chronic sorrow, accepting my child disability as its destined by God or as its also known in the Islamic religion as fatalism demonstrate a high score with a mean of 4.8 (SD 0.50), followed by availability of resources parents need in managing their child disability with a mean score of 4.7 (SD 0.47). Followed by feeling better when parents are more aware and making independent decision about the child disability with a mean of 4.4 (SD 0.62). The results of the study showed that internal management of child disability are crucial is reducing chronic sorrow and empowering parent of disabled child to minimize the episodes of chronic sorrow and therefore, provide the best care their child need.

Table 5, Descriptive statistics of internal management of parents with disabled child

| **Internal management of chronic sorrow** | **Score, mean (SD)** |
|---|---|
| I feel better when I’m more aware of my child disability | 4.4 (0.62) |
| Making independent decision about my child disability is empowering for me | 4.4 (0.62) |
| Accepting my child disability as it is destined by God, make me feel better | 4.8 (0.50) |
| Availability of resources (Ex: financial and therapeutic) for my disabled child induce a sense of relief | 4.7 (0.47) |
| Total score of internal management | 4.6 (0.33) |

### Descriptive statistics of external management of chronic sorrow

As table 6 shows parental management of chronic sorrow with the utilization of external management display a great importance with a mean of 4.5 (SD 0.42). Of all the variables measuring external management of chronic sorrow, feeling better when social support is provided, it displayed the highest score with a mean of 4.7 (SD 0.55). Followed by feeling better when community is kinder and more considerate with a mean score of 4.5 (SD 0.56). The result of the study showed that external management along with internal management of chronic sorrow are important tools parents need to utilize and navigate to manage periodic and unpredictive nature of chronic sorrow.

Table 6, External management of chronic sorrow by parents of disabled child

| **External management of chronic sorrow** | **Score, mean (SD)** |
|---|---|
| I feel better when doctors and nurses provide more information about my child condition | 4.4 (0.64) |
| I feel better when support is provided by family and the community | 4.7 (0.55) |
| I feel better when I'm allowed to express my emotions freely and without judgment | 4.3 (0.71) |
| I feel better when I believe that we as a family have created a coping strategy that is specific for us | 4.4 (0.62) |
| I feel better when more people of the community are considerate and kind to me and my disabled child | 4.5 (0.56) |
| Total score of external management of chronic sorrow | 4.5 (0.42) |

### Association between chronic sorrow and parental loss experience and disparity

Table 7 shows a Pearson correlation between chronic sorrow and the sense of loss experience and disparity. The study results shows a strong correlation between chronic sorrow and the concepts of disparity and loss.

Table 7. Pearson correlation between chronic sorrow and loss experience along with disparity

| Variable | **Chronic sorrow** | **Loss experience** | **Disparity** |
|---|---|---|---|
| **Chronic sorrow** | r = 1<br>P - | r = 0.765<br>P < 0.001 | r = 0.765<br>P< 0.001 |

| | | | |
|---|---|---|---|
| | Value | | |
| **Loss experience** | r = 0.765<br>P < 0.001 | r = 1<br>P - Value | r = 0.791<br>P < 0.001 |
| **Disparity** | r = 0.765<br>P< 0.001 | r = 0.791<br>P< 0.001 | r 1<br>P - Value |

According to table 7, chronic sorrow is strongly and positively correlated with loss experience (r=0.765; *P*= <0.001). In addition, the same strong correlation emerged between chronic sorrow and disparity (r= 0.765; *P*=<0.001). Lastly, another positive strong correlation emerged between the concept of loss experience and disparity (r=0.791; *P*=<0.001).

### Association between chronic sorrow and time since diagnosis of the child disability

Table 8 illustrated the results of person correlation between chronic sorrow and the amount of time passed since parents received their child diagnosis of disability. The results of the study showed that correlation is negative yet very weak between the study variable (r= -0.009; P<0.936), indicating that as time passes associated feeling of chronic sorrow among parents who received their child diagnosis of disability doesn't subside, highlighting the importance of multiple intervention to manage and coexist with chronic sorrow.

Table 8. Person correlation between the concept of chronic sorrow and the time since diagnosis

| Variable | Chronic sorrow | Time since child diagnosis |
|---|---|---|
| Chronic sorrow | r 1<br>P - Value | r = -0.009<br>P = 0.936 |

| | | |
|---|---|---|
| Time since child diagnosis | r = -0.009<br>P = 0.936 | r 1<br>P - Value |

## Discussion:

### Principle findings

Literature examining chronic sorrow among parents with child of disability was scarce in the international and Saudi literature alike. Therefore, this study was designed to examine the application of the theory of chronic sorrow by Olshansky [15] among Saudi parents with disabled child. The study examined the major variables in the theory including loss experience, disparity, chronic sorrow, internal and external management. Also, the researchers attempted to examine the relationship between these variables, and whether time since diagnosis of child disability has a role in decreasing the sense of chronic sorrow. The results of the study showed that parents report moderately high level of loss experience, disparity and chronic sorrow. On the other hand, management method either internally and externally play a crucial role among these parents in adapting and managing their children disability. In addition, the reported concepts of loss experience and disparity had a moderately strong relationship with the feelings of chronic sorrow parents of disabled child are undergoing. Lastly, time passing since child diagnoses did not have inverse relationship with the feeling of chronic sorrow, indictive that time passing doesn’t play a role in the feeling of chronic sorrow.

Parents of children with disabilities have experience loss, which is different for every parent and their ability to navigate emotions. Loss experience can be interpreted as the loss of the ideal child [24]. The results of the study have illustrated a moderately high level of loss experience, and its consequences can trigger the feeling of chronic sorrow. Loss experience among parents of disabled child have been reported in the previous literature like the results of our study despite cultural and religious differences between the populations. A study by Phillips [25] have examined loss among parents of disabled child and viewed loss as a consequence that they are not familiar with, along with its ability to impact family's wellbeing. Another study by Fernández-Ávalos., et al [20] and Fernández-Alcántara., et al, [24] examined loss and grief among the same population and the concept of the theory of chronic sorrow emerged as well. Such as the loss of the ideal child, traumatic experience, and shock. Loss experience among parents is a crucial step, parents undergo to explore their chronic sorrow and eventually lead to acceptance and hope towards the future of their child.

Disparity is one of the major concepts of chronic sorrow theory, it follows the feelings of loss experience and it is triggered by certain developmental milestones that parents of disabled children view in healthy children [10]. Multiple studies illustrated the presence of disparity among parents and the results were congruent with the result of this study. A study by Nikfarid., et al [26] examined chronic sorrow among parents of children who were diagnosed with cancer, and another study by Olwit et al [10] investigated chronic sorrow of parents with children diagnosed with sickle cell diseases. Both of these studies parents expressed the presence of disparity  its role in triggering chronic sorrow and it's on-going nature. Lastly, a study by Masterson [27] explored parental chronic sorrow, along with disparity when the disabled child becomes an adult with cerebral palsy, the study showed that mothers still experience disparity and it triggered loss of hope as the child ages without meeting his milestones.

Chronic sorrow among parents with disabled child is different from the normal grieving process or sadness because it's characterized by its cyclic nature, and it can be triggered by feeling of loss and disparity [15]. Studies examining chronic sorrow among parents with disabled children is similar and consistent with the result of this study. Chronic sorrow theory demonstrates the realistic feelings and emotion parents with a disabled child encounter, and these feelings doesn't manifest the same way as grief or a single loss because it can appear after acceptance of the disability [28, 29]. A study by

Olwit et al [10] and Hobdell [30] found that chronic sorrow among parents need to be assessed by health care workers as it has the potentiality of affecting parental management of child disability and reduce its impact on parental health. Consequences of chronic sorrow on parents can appear as reduced social interaction, psychological distress, anger and even guilt [31- 33].

Internal management of chronic sorrow that is effective and utilized by parents play a crucial role in minimizing the recurrence of chronic sorrow episodes specifically if it employed correctly [18]. This study illustrates that fatalism and accepting God’s destiny towards the child disability is the most effective internal management of chronic sorrow, multiple studies regardless of different religion or spirituality have displayed similar results. Studies by Pandya [34], Pillay, et al [35] and Gull, & Husain [36] found that parents with disabled child found that religion and accepting God’s destiny is an effective coping mechanism that led to parental resiliency, acceptance and management of daily challenges. The participants are predominantly from the Islamic religion, and the concept of fatalism as a mean to internally manage chronic sorrow were reported the most among this population. Fatalism in the Islamic religion, known as the believe that the future of man is already determined by god and it can’t be swayed nor changed whether the destiny is good health or bad, and man should accept god’s destiny and surrender to his will. A study by Khan., et al [37] and Othman., et al [38] studied Muslim parents of disabled child and their results are congruent with this study, in which parents found comfort, hope and resiliency when integrating religion and spirituality when caring for their children.

External management of chronic sorrow aim to capture the most efficient method parents use. The results of the study have identified social support specifically from the family and community to be a key to externally manage chronic sorrow. The result of the study corresponds with Ha., et al [39] and Felizardo., et al [40] who investigated the role of social support from family and the community which yielded similar results to this study. Mantri-Langeveldt., et al [41] have conducted a scoping review to illustrate the important role of family support on the parent care giver to a disabled child, reaffirming the importance of social support measurement by health care professionals.

The study has identified strong positive relationship between chronic sorrow and loss, the loss expressed by parents of disabled children are known as ambiguous loss as its not officially nor clearly visible as the child is alive but lack normal development. In addition, loss associated with chronic sorrow in this population don’t have closure and the loss of ideal child can’t be mourn because it didn’t exist [42]. Brown [43] conducted a study to capture the importance of sorrow and grieving in the healing process for mothers of children with intellectual disabilities, the results are similar to this study in which mother have experience loss specifically after diagnosis, and the loss not only for the child but her role as a mother without caregiving. Goodwin et al., [44] described parental experience of disabled child and the results have identified the themes of sorrow and loss to be associated, along with other emerging concepts such as stigma and guilt.

The results of this study have identified another strong and positive relationship between chronic sorrow and disparity. Disparity unlike loss remerges as time passes and the parents can view the inability of their child to meet developmental milestones like their peers and as a result triggers feelings of chronic sorrow [18]. Coughlin & Sethares [6] conducted a literature review examining parental chronic sorrow among parent with disabled child, the results of the review have yielded multiple findings, one of which is the strong relationship of chronic sorrow and disparity. The review has identified events parents undergo that triggers chronic sorrow to resurge and its role in reminding parents the disparity and the gap between the “idealized and hoped for child” and “the ill or disabled child” [6]. Multiple studies have found the same phenomena remerges of disparity and its role in triggering chronic sorrow across parents caring for different types of disability or diseases process that require caregiving, such as autism spectrum disorder [45], sickle cell diseases [10], and cerebral palsy [46].

The study has examined the relationship between time passing since the parents received their child diagnosis of disability, and its impact on chronic sorrow. The results of the study have shown that there is no relationship between time passing and chronic sorrow, indicating that time don’t play a role in reducing nor increasing feeling of chronic sorrow. The result of the study corresponds with literature, a study by Fernández-Ávalos., et al [20] have found that loss and sorrow persist over time and therefore emotional intervention are crucial to the parent of disabled child. Fernández-Ávalos., et al [47] rationalizes this phenomenon by explaining that parents are faced with daily challenges and worries when caring for their child. As a result, it influences their perception of managing chronic sorrow and their quality of life as well. Therefore, early intervention and realistic expectation of the child development and diseases prognosis are crucial to be delivered and educated along with emotional care for parents. These interventions will play a role in managing chronic sorrow over time, and eventually lead to acceptance, resilience and enhanced mental health [48, 49]

## Limitation

The study collected data from parents who are primarily in Jeddah, Saudi Arabia. Therefore, the results of the study might not be generalizable to other countries or cultures. Another limitation was the type of disability the children were diagnosed with, as most of the data were collected from parents with down syndrome (34.7%) which limit the generalizability of another type of disability that can be more severe or require less caregiving.

Another limitation was the study’s cross-sectional design. Cross-sectional study designs create ambiguity about the direction of the causal relationship between study variables of chronic sorrow theory. Lastly, to overcome time and financial constrains the researchers were faced with, data were collected via self-reporting method. Therefore, the condition in which parents filled the survey were not controlled nor objectively measured.

## Conclusion and recommendation

The aim of this study is to examine parents with disabled child experiences with chronic sorrow in Saudi Arabia, with the use of the chronic sorrow theory. The result of the study has illustrated moderately high levels of loss experience, disparity and feelings of chronic sorrow. Therefore, the results of this study highlight the importance of chronic sorrow management and create intervention to enhance parental mental health and well-being. In addition, internal management of chronic sorrow play a crucial role, specifically fatalism and spiritual care among Arab Muslim parents of disabled child. In regard to external management, parents reported that family and community support are pivotal for management of chronic sorrow, highlighting the social responsibility of all members of the community contribution to provide support for the parents and the child. The study has also identified strong positive relationship between the concepts of the chronic sorrow theory, specifically between the identified triggers of loss and disparity with chronic sorrow. Lastly, the study results have found no relationship between feelings of chronic sorrow and time passing since parents received their child diagnosis with disability. Given the result of the study, parents of disabled child need to be periodically screened for chronic sorrow and management of these feeling need to be addressed. Parental acceptance of their child disability doesn’t entail absence of chronic sorrow as its normal grieving process but anticipating the triggers of chronic sorrow and utilizing management method, both internal and external are essential to promote parental mental health and child health outcome.

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