

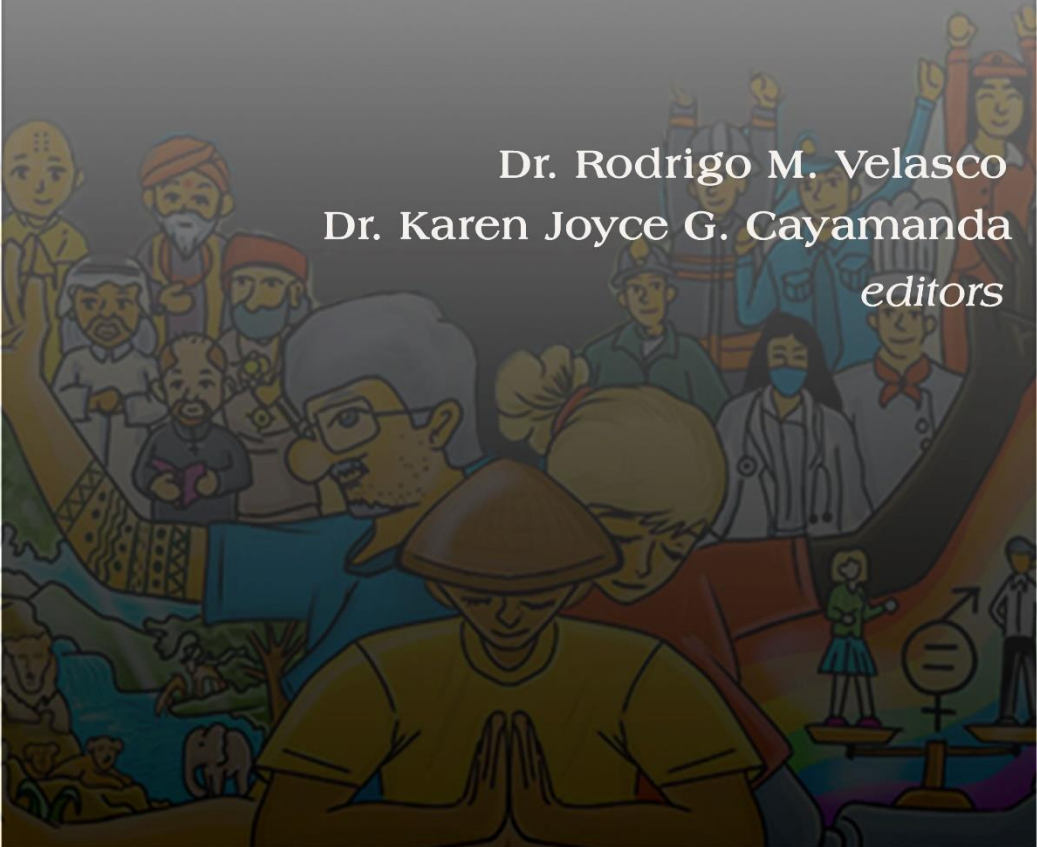
# The WORLD

## in Different PERSPECTIVES: Rebuilding Lessons after a Crisis

Dr. Rodrigo M. Velasco

Dr. Karen Joyce G. Cayamanda

*editors*



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# Preface

The world is in chaos. The emergence of COVID-19 pandemic created the havoc that all parts of the globe had to deal with. In addition, there are still other personal and social crises that everyone endures.

Rebuilding Lessons after a Crisis attempts to present the whys, whats and hows of humanity's risk perception across the world as we embark on this challenging journey and help define the most appropriate and most effective risk-related behaviors for survival.

The current pandemic has brought about the abrupt shift in all sectors of the society in different parts of the world. It has resulted to immediate adjustments and development of coping mechanisms to transcend beyond the challenges of this pandemic. Like any other crisis, the current situation taught us to reflect and manage its overwhelming effects.

This book compiles articles that reflect the different perspectives in varied concerns such as health, economy, education, and social transformations. Its impact to the physical, emotional, psychological and financial conditions of humanity across the world are also presented.

Part I as the opening chapter attempts to describe the situation in terms of how a crisis has been evaluated in different lenses as to the risk perception and the risk related behaviors as to how various sectors have adapted to the situation.

Part II describes the varied effects of the pandemic and the adjustments and coping responses manifested by the different sectors.

Part III offers the strategic actions and coping mechanisms that can help recover and sustain ways of life in these challenging times.

## About the editors

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# **Elderly Parent Caring for an Adult with Down syndrome**

*Thessalonica M. Sinohin*

## **Introduction**

Down Syndrome (DS), also called Trisomy 21, is generally caused by the presence of an extra chromosome 21 resulting in trisomy. Trisomy 21 is the most common kind of Down syndrome. A typical person has 46 chromosomes; a person with DS has 47. This genetic disorder is characterized by developmental delays and physical features typical of the disorder. These include weak information processing, social interaction, demonstrating language, receptive and motor skills (Gandy et al., 2020).

The presence of mental and physical disabilities within the family members can be complicated and difficult to handle. Parents of children with mental disability take on the role of primary caregiver in their child's care (Juandó-Prats et al., 2021). Dealing and taking care of children with chronic illness, mental retardation and handicapped may bring painful experiences to the parents, as well as to the other members of the family. According to the family systems perspective, attributes of each family member influence the relationship, roles and function of the family because all parts of the system are interconnected (White, Klein & Martin, 2015). If one member of the system isn't functioning well, the whole system will struggle.

Studies showed that raising a child with developmental disability, such as Down syndrome, have less negative effects and more positive effects to their parents as care givers. This is due to the acceptance and understanding of parents to their children's condition (Widyawati et al., 2021). However, an old aged person raising an adult with Down syndrome with occasional epileptic seizures is a whole different experience.

Thus, the purpose of this case study is to examine the unique relationship, challenges and demands of an elder parent caring for an adult with life-long mental illness. This study aimed to identify the difficulties experienced by an elder parent of an adult with down syndrome, understand the family's interaction pattern during the crisis, and examine the family's adaptability and coping strategies.

## **Literature Review**

### ***Theoretical Framework***

Family systems theory has been applied to understand family under study. According to Keller and Noone (2019), family systems theory is used to better understand family relationship processes among family members. The theory stated that families are interconnected member of a system and individuals within the family are involvedly related to each other and that the events in one area of the system affects all other sections of the system. The connectedness of the family is a key concept of the family systems theory which asserts that all outcomes are the results of numerous causes. The family dynamics which includes all types of communication within the family, family rules, family structure and roles play significant roles within the system (Murray, 2006). Also, this theory focuses on the concept of holism. It states that to understand an individual or a family, a person must look at the family as a whole (Bowen, 1978; Keller & Noone, 2019).

From the perspective of family systems theory, the relational life of families provides the basic environmental setting in which children are raised. The traits that each family member bring to family relationship, as well as their opinions, have an impact on the family system. The presence of a child with mental disability, such as Down syndrome, is likely to have a wide-range impact on the family system.

The presence of disability is a family issue that can cause stress to the family. The severity of the disability determines the

amount of stress of the family (Pang, 2010). However, a family under trial can cope and adapt to the present challenges through the unique interaction, unity and interconnectedness of its members (Keller & Noone, 2019). The family systems theory will provide a better perspective of the adaptability, coping strategy, struggles and strengths of the family under study.

### ***Family Dynamics and Stress***

A number of studies were conducted to see the dynamics going on in families of children with mental disabilities. It shows that children with intellectual disabilities have greater needs and have significantly negative impact and consequences to the family members (Lima-Rodríguez et al., 2017; Luijkx et al., 2017; Mulya et al., 2019). According to Hassall et al. (2005), parents and caregivers of children with disabilities experience greater stress than those without disabilities. The stress level (emotional, physical, mental and social) of parents and caregivers was commonly examined to understand the demand and the level of difficulty they experience. The level of difficulty is commonly associated to the severity of the disability and behavior problems (Boehm and Carter, 2019).

Few studies showed that mothers and fathers respond differently to the difficulties and struggles related with raising a child with Down syndrome. Although, the overall stress levels of both mothers and fathers of children with Down syndrome did not differ, the patten of stress were significantly different. It was reported that mothers got higher level of stress in terms of the parental roles while the fathers had higher stress level due to their feelings of attachment to the child (Krauss, 1993).

Siblings of mentally disabled children also experience stress in the family set-up. Adjustment in household activities are typical struggles. Also, siblings of children with mental disabilities turned out to have difficulties with their interpersonal relationships, managing leisure time, and school performance (Goudie et al. 2013).

Although there are several factors that can contribute to the level of stress of caregivers and family members, the child's behaviour problem often plays a major role in the stress (Luitwieler et al., 2021). Nevertheless, family being a system has its unique function of adaptability (Keller & Noone, 2019) which creates resiliency during time of stress. A positive coping strategy will likely decrease familial stress which have a positive effect on the child with mental illness (Sangawi et al., 2018).

### ***Children with Down syndrome***

A child with mental disability has different demands from an adult with the same disability. As the individual grows, the demands increase, both on the parents and the individual. The condition of the child as he or she grows leads to parental adaptation which has been studied extensively in relation to parental well-being. From adolescence to adulthood of a person with DS, parents experienced wide-range of challenges and stress as a result of their emotional response to the demands of their role (Cuskelly et al. 2009). In addition, parents of children with mental illness have common apprehensions regarding the future of their children. A study showed that adults with Down syndrome, aged 50 to 59, experienced more life events than other adults with mental illnesses. These life events includes changes in daily routines, adjustment on living condition, death of a parent and medical problems (Desriyani et al., 2019). Inevitably, these life events will be faced not only by the parents but by the whole family.

### **Methodology**

A qualitative, descriptive approach was adopted to explore the experiences and occurrences in the life of an elderly caring for an adult with mental disability. The study used a single-case design which focuses on a particular story or phenomena. Single-case design is a strong procedure helpful to understand underlying relations (Nock et al., 2007), specifically among family experiences. Different sources of data were used in the study

such as direct observation, in-depth interview and questionnaire. The data obtained were systematically collected, analyzed and presented in narrative form.

The participant is a family of two – a 79-year old father and his 44 year old youngest daughter with Down syndrome and epilepsy. The father works as a home-based hog raiser and is a retired plant nursery worker in Saudi Arabia. He worked abroad for 11 years and came back to the Philippines, for good, last 1997. His wife died due to complications of kidney failure. His other three daughters are living with their own families and his only son died in 1996. They lived in a small bungalow house in close proximity with their relatives in the town of Masaya, Bay, Laguna, Philippines. The father started living alone with her mentally disabled daughter after her wife died in year 2000.

The case study utilized three methods in gathering data – direct observation, non-structured interview and Parental Stress Scale Questionnaire (Berry & Jones, 1995). Direct observation was done during the interview and during the visits to the participant's residence. Observable data were taken using notes of what was seen, heard and sensed in the area. The observations focused on human actions and the physical environment of the participant. On the other hand, the interview was recorded and conducted at face-to-face. Open-ended questions were asked to reveal the reality of the participant's condition which provided significant insights for the case. Lastly, the Parental Stress Scale Questionnaire was used to measure the level of stress experienced by the parent at present. It is an 18 item self-report scale that shows the positive and negative aspects of parenthood (Berry & Jones, 1995). It used a 5-point scale to represent strongly disagree, disagree, undecided, agree and strongly agree to describe the kind of relationship the child have with the parent.

The data from observational notes were examined thoroughly, while the data of voice recording obtained from the interview were transcribed verbatim. The combination of observational



notes and transcribed recordings were linked together to get the whole picture of the story. Moreover, the data from Parental Stress Scale Questionnaire was computed based on the scoring procedure. The items 1, 2, 5, 6, 7, 8, 17, and 18, which showed the positive aspect of parenting, was reversely scored. The scores from all the items were then summed. The total score of the Parental Stress Scale signify the level of stress of the parent. The score of 18 indicates the lowest level of parental stress and the score of 90 indicates the highest level of parental stress (Berry & Jones, 1995).

## **Findings and Discussion**

### ***The Family Story and Interaction***

The family was consisted of a father, mother, four daughters and a son. The first and second child were girls, followed by a boy, then another two girls. The father worked as a plant nursery worker in Saudi Arabia for 11 years. He consistently comes home every 2 years and in 1997 he came home for good. His wife was a public school teacher at Masaya Elementary School. Their first four children displayed the typical characteristics of a normal child. However, when their last child came, it was quite different. The family never knew that their youngest child has special needs until they observed something unusual.

*(“Ang napansin naming sa kanya na kakaiba ay napakatahimik nya nung baby pa sya kesa nung baby pa yung iba naming anak. Di sya uniiyak masyado at wala din syang kiliti. Papalit-palit din kami ng gatas noon sa kanya pero parang wala syang magustuhan. Dahil napansin naming na kakaiba nga sya, nagpunta kami sa doctor nung mga tatlong taong gulang sya. Tinignan sya ng doctor at pinatest yung bata. Sinabi sa amin ng doctor na may Down Syndrome sya... Kwarenta na sya ngayon pero ang edad ng isip nya para lang walong taong gulang na bata.”)*

Raising their children was not a great challenge to the couple. Even with the condition of their youngest child, their growing

years were normal. Her siblings loved her and were protective of her, especially her only brother. They easily accepted her condition and one factor of that was because their daughter was not a difficult child. They did not experience tantrums or difficult behavior with her. According to Widyawati et al. (2021), acceptance of family members to the child's mental disability is vital to family resilience. Positive perception of parents leads to happiness and understanding in rearing their children which serves as a coping resource to them (Suzuki et al., 2015). As a result, the family cultivated good relationship with each other as well as with their youngest daughter.

*(“Eh sa isang pamilya naman hindi nawawala ang mga problema, pero hindi sya naging prolema sa amin. Hindi sya pinagmumulan ng away sa kanilang magkakapatid. Sa loob ng bahay namin, madalas tahimik lang sya. Gustong-gusto nga din sya ng mga tao duon sa amin. Palabati sya sa mga tao at mahilig sya makipaglaro sa mga bata kaya gusto din ng mga bata sa kanya.”)*

The family provided everything their child's special needs. They had her checked to the doctor on a regular basis when she was growing. She had her own nanny and was enrolled in a special school in San Pablo City. In these times the father wasn't involving much in her early years because of his work abroad. He only saw her every two years for a month. But when he decided to stay, he needed to learn how to relate to her daughter well. He also ventured to small businesses to have a continuous source of income for the increasing needs of her daughter. After their three other daughters got married and their only son died in an accident, he and his wife was the only one left to take care of their special daughter.

*(“Ang asawa ko talaga ang madalas kasama ng anak ko at sya din ang nag-aalaga sa kanya. Sya ang nagpapaligo, nagpapakain at nagpapatulog sa kanya. Tumutulong naman ako minsan pag wala akong trabaho. Kaya lang nung umabot sya ng mga 30 years old nag-umpisa syang mag-seizure... Pinatignan namin sya at ang sabi sa amin epileptic daw ang anak namin.”)*

During this time, the family experienced extreme difficulty. Their daughter was having seizures, his wife got critical because of kidney problem and his small business was not running good. His wife needed to undergo dialysis thrice a week and grew very weak. The father had not much time to make a living because his time was consumed in care giving of his wife and daughter. The hardship of taking care of his mentally disabled daughter and his sick wife was the beginning of crisis in their family. Crisis is defined as “the subjective reaction to a stressful life experience that compromises the individual’s stability and ability to cope or function,” (Roberts & Ottens, 2005).

### ***Challenges Faced by the Father as Caregiver***

In year 2000, the wife died and the father was left alone to take care of their daughter. Adjustment period was painful and frustrating at times. According to the father, many times he did not know what and how to give care for his daughter. From the task of giving her daughter a bath and helping her to sleep was a struggle since his wife was the primary caregiver back then.

*(“Kapag inaatake ang anak ko, hindi ko alam ang gagawin. Nagpapanic kasi ako at napapasigaw na lang. Ang asawa ko ang madalas nag-aalaga sa kanya, madalas akong wala dahil sa mga baboy naming. Natagalan talaga ako bago ko matutunan maging kalmado. Noon naawa ako sa sarili ko at anak ko kapag inaatake sya. Parang wala akong magawa eh. Pero natutunan ko rin naman kung paano ang gagawin kapag inaatake sya.. Para sa akin para ko ba syang partner sa buhay ko at syempre eh mahal ko ang anak ko.”)*

Parental adaptation was extensively studied in relation to parental well-being and stress. The emotional response of the parent to the demands of the parenting role predicts the level of adjustment the parent had with the child’s condition (Widyawati et al, 2021). In our case, the father realized that he needed to learn caregiving skills to support the needs of her daughter, such as giving first aid for seizure patients. His attitude toward her daughter’s condition was motivated by love. He humbly learned how to comfortably give bath to her daughter and assist her

during her monthly period. Other daily concerns, such as preparing coffee, washing the dishes, and sweeping the floor, were able to do by his daughter. Their partnership had given him confidence that her daughter can survive even at times he is not at home. This kind of perspective gives him hope for his child in the future.

**Table 1**

*Positive aspects experienced as a parent*

1	I am happy in my role as a parent	Strongly Agree
2	There is little or nothing I wouldn't do for my child(ren) if it was necessary.	Strongly Agree
5	I feel close to my child(ren).	Agree
6	I enjoy spending time with my child(ren).	Agree
7	My child(ren) is an important source of affection for me.	Strongly Agree
8	Having child(ren) gives me a more certain and optimistic view for the future.	Strongly Agree
17	I am satisfied as a parent.	Strongly Agree
18	I find my child(ren) enjoyable.	Strongly Agree

Table 1 shows the positive aspect experienced being a parent which he scored the highest. It supported his claims that he looked at his daughter as a partner and not a burden. He appreciates her, enjoys her company and he feels close to her. He is also hopeful for the future of his daughter. At present, it shows that the father is satisfied in his role as a parent.

Table 2 shows the negative aspect experienced by the father. It shows that the father did not look at her daughter as a source of stress and he did not regret having her in his life. He also expressed that the continuous demands in taking care of her

daughter made him feel that his efforts were sometimes not enough. And being the only care giver to his child, he felt overwhelmed with the responsibility accompanied by having a child with Down syndrome.

**Table 2**

*Negative aspect experienced as a parent*

3	Caring for my child/ren sometimes takes more time and energy that I have to give.	Agree
4	I sometimes worry whether I am doing enough for my child/ren	Agree
9	The major source of stress in my life is my child(ren).	Strongly Disagree
10	Having child(ren) leaves little time and flexibility in my life.	Agree
11	Having child(ren) has been a financial burden.	Disagree
12	It is difficult to balance different responsibilities because of my child(ren).	Disagree
13	The behaviour of my child(ren) is often embarrassing or stressful to me.	Disagree
14	. If I had it to do over again, I might decide not to have child(ren).	Strongly Disagree
15	I feel overwhelmed by the responsibility of being a parent.	Strongly Agree
16	Having child(ren) has meant having too few choices and too little control over my life.	Agree

According to the result of the Parental Stress Scale, the father got the total score of 39 points. The maximum score of 90 points signifies the highest level of parental stress, while the minimum score of 18 points signifies the lowest level of parental stress. The result showed that the father has low level of parental stress at present.

Lastly, as a solo parent, another challenge he's facing, is his own health. The related issues of growing older, such as declining health status and widowhood, make him vulnerable to stresses of caring to his daughter. Older parents have little energy both in making a living and tending to the needs of their mentally disabled child. As a result, the uncertainty of the child's future is often the dilemma of older parents.

*("Kapag umuwi ang mga anak ko tuwing pasko at bagong taon, ibinibilin ko sya sa kanila. Ako'y mahina na at marami na bang nararamdaman sa katawan kaya alam kong hindi ko sya maalagaan ng matagal. Lagi bang masakit ang mga kasukasuhan ko at minsan nga eh hindi ako makabanong sa katre. Marami nga akong nararamdaman eh hindi ko naman makuhang magpatingin dahil mas priority ko ang kakainin naming dalawa. Ipinapanalangin ko na lang na pakalooban pa ako ng lakas ng Diyos dahil kailangan pa ako ng anak ko.")*

### ***Adaptability and Coping Strategies***

The relationship among family members plays a fundamental role, not only to the emotional and social development of the child, but as well as the emotional well-being of the family members. In our case, the family's acceptance to the condition of the daughter served as a strength of the family. Aydin and Yamac (2014) defined acceptance as "the warmth, affection, care, comfort, concern, nurturance, support, or simply the love that the child can experience from their parents and other caregivers." Family system theory states that family resilience are often strengthen with the presence of mental illness in the family (Keller & Noone, 2019). It was felt by the daughter who in return showed the same kind of love to her family.

Another positive source of strength for him and for his whole family was their relentless faith to God. The father often stated in the interview that their strength comes from God alone. When tough time comes, together as a family, they acknowledge the fact that God is in control of everything. They live their lives one day at a time, knowing that the promises of God are true in their

lives. Their faith reflects the strength they have as a family, as well as an individual.

*(“Nung panahong naghihirap talaga kaming pamilya dahil sa sunod-sunod na pangyayari, dasal lang talaga ang ginagawa namin. Lagi naman naming kasama ang Panginoon at hindi Niya kami bibiguin. Siya din naman ang nagpapalakas sa aming lahat at hindi Siya nagkukulang hanggang ngayon na dalawa na lang kami. Minsan, kapag pinanghinaan ako ng loob nagdadasal na lang ako. Alam kong ang mga pagsubok sa amin ay nakakapagpalapit sa amin sa Kanya.”)*

Several studies have shown that having a sense of self-reflection as well as a good support system and confidence to deal with challenges have been associated with resilience (Rutter, 2013). Social groups and relationships, such as the church, are recognized to play a major role in promoting long-term resilience in people with mental disorder. The father stated that when his wife died, he never felt alone. His bible study group, the church and the support he got from his community made him realize that he was not alone in his journey. The people around him, aside from his relatives, showed their love not only to him, but to his daughter as well. The relationship in a support group is identified as a central influence of reliance and that resilience requires ongoing growth and development within the environment of the current challenges (Suzuki et al., 2015). Families’ positive adjustment to challenging life conditions are influenced by the support they received from their social groups.

## **Conclusion**

The case of the family gave a lot of valuable insights about the challenges and struggles they had as a family under trial. The family was able to find strength through their faith in God, within themselves and among the circle of support they had, to adapt and handle the stresses that accompanied the daughter’s disability. The story also gave us a picture of the hardships experienced by the father as the only caregiver of her mentally disabled daughter. Despite the hardships experienced by the

father, it was shown through the result of his Parental Stress Test that he is experiencing low level of stress. His coping mechanism and resilience came from his faith and perception in life, as well as the support he received from the people around him, made him positive and expectant of what the future may bring to him and his daughter.

Proper planning for future care must be taught to parents, as well as to other family members, of children with mental illness. It is suggested to have supporting services from the government that cater the needs of such families such as free legal consultation, family budgeting workshops and health insurance.

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