

The Relationship of Meaning in Life and Quality of Life: Basis for a Leadership Development Program among Parent-Carers of Children with Special Needs

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Gunning Fog Index: 12.30 • Originality 99% • Grammar Check: 99%
Flesch Reading Ease: 46.09 • Plagiarism: 1%

ABSTRACT

The goal of the present descriptive-correlational study is to examine the relationship between the quality of life (QOL) and meaning in life (MIL) of Children with Special Needs (CSN) parent-carers utilizing the simple random sampling method. It included 186 respondents from a suburban private Christian school in Muntinlupa, Metro Manila. The Meaning in Life (MIL) questionnaire and Quality of Life Enjoyment and Satisfaction Short Form (Q-LES-Q-SF) questionnaire were used. The MIL dimensions revealed that, on average, the CSN parent-carers' Presence of MIL is partly high while the Search for MIL is neither high nor low, which reveals that they have a valued meaning and purpose, yet they are still openly exploring them. The QOL of CSN parent-carers is overall good, with family relationships receiving the highest score and work with the lowest, revealing that there is a marked satisfaction in family relationships while discontent and unfulfillment with work. There is a significant relationship in terms of age, sex, and living status profile variables with MIL, except for education and monthly family income. A strong significant relationship is demonstrated between MIL and QOL of CSN parent-carers. Overall, MILs partly high for Presence, neither high nor low for

Search, and QOL's good result imply that CSN parent-carers have a relatively positive understanding of both MIL and QOL in their life and their determination to keep on pursuing this meaning, purpose, enjoyment, and satisfaction in life. The significant relationship and prevailing themes form the basis for LEAD (Leading, Equipping, and Developing), a parent leadership program where one identified recommendation is the review, enhancement, and endorsement for implementation to ascertain understanding, appreciation, and development of QOL and MIL in CSN parent-carers' life.

KEYWORDS

Meaning in life, quality of life, parent-carers, children with special needs, parent leadership program, descriptive-correlational, Philippines

INTRODUCTION

Over one billion people, or 15% of the world's population, were reported by the World Health Organization to be living with some form of disability, and between 200 to 240 million have significant difficulties in functioning. At least a quarter comprising over a billion individuals can participate fully and equally in every sphere of life, and creating an enabling environment for them to be able to live with dignity continues to be a far-off scenario. The estimated number of children 0-18 years old ranges between 93 and 150 million who fall under this category and would need a definitive amount of time and financial resources to be cared for. With this data, the statement remains unwavering that there is much to be done for the welfare of CSN and the parents and families who care for them.

Not uncommon is the School Leader's dilemma and backlash of having to turn away Children with Special Needs from enrollment primarily due to resources, staffing, and lack of training issues. The sad reality of connecting with parent-carers (usually mothers, house helpers, and at times, fathers) who are usually ill-prepared, ill-equipped, or "just clueless" in advocating even for their own child has persistently been prevalent. Many parent meetings end up in profound helplessness due to the grim prospect of non-stop care and support for a child with special needs. Stressors and obstacles associated with parent-caring coincide with the paucity of existing research in the lens of the increased risk of stress, anxiety, and depression (Burke & Hodapp, 2016). Expectedly, disabilities bring you to reflect on your life's meaning and question the quality or station in life you are at. Different authors have described how varying disabilities can affect a child's quality of life, requiring special attention to their unique needs. It is imperative to note that although disability surely affects individuals with special needs, attention should also be given to its effects on the people around them, particularly their parents. The problems they face and the issues they address are different from parents with neurotypical children.

Philippine Republic Act 7277 Magna Carta for Disabled Persons defines Children with Special Needs as someone who experience difficulty in their ability to live a normal life and frequently require special care and assistance. This places a great deal of burden on the family, most especially their parents. The daunting task of caring for a CSN requires special parenting skills that can be detrimental to the physical health of their parents. Mohan and Kulkarni's (2018) study findings show that parent carers' health worsens due to being time-poor, absence of control, and decreased psychosocial energy brought about by their roles. Consequently, there is a tendency for mothers to perceive themselves as stigmatized by their child's condition, with stronger affinities to mothers than fathers (Weitlauf et al., 2014) also linked to marital distress and eventual separation and divorce (Malhotra et al., 2012).

Evaluating one's meaning in life and quality of life will make sense of purpose, priorities, and impetus in life crucial to the overall health, wellness, and wholeness of an individual (Steger & Dik, 2009). Several international research journals confirm the presence of meaning in life and the quality of life associated with the well-being of many individuals. The major additive contribution of the present study is to create a parental leadership and skills training program that will highlight meaning and quality of life as further defined to be having greater life satisfaction, more happiness, and less depression (Funke, 2019).

While there were studies conducted previously on this particular concept, the researcher observed that these studies did not dwell on parent-carers exclusively - either single parents or the standalone role of mothers in caring for CSN. Also, previous studies either focused on meaning in life or quality of life and not both for CSN parent-carers. Thus, in this study, the connection or association of meaning in life and quality of life would be examined to see if this provides an encompassing parent leadership program for CSN parent-carers.

Being a School Principal, now Counselor, and Special Education Coordinator, the researcher has seen the overall impact of working with CSN as pivotal when parent-carers are involved, engaged, and well-informed. With collaborative knowledge, the researcher would like to contribute to the creation of a parent leadership development program interwoven into the Filipino culture and fully aligned to the meaning in life and quality of life themes that would be identified. Pragmatic as it is for this research to be used not only in educating, guiding, and supporting CSN parent-carers but to create and improve current and future policies, protocols, programs, and processes in various agencies and institutions.

FRAMEWORK

Diversity, equity, and inclusivity in education have been the hallmark of current educational research in the 21st century. The inclusion of persons with disabilities and promotion of "lifelong opportunities for all," stated as the fourth goal of the United

Nations Sustainable Development Goals (UN-SDG), which is to improve the quality of education across levels, remains to be the focus in the international education arena. In the same vein, UNESCO reiterated that “inclusion is an ongoing pursuit to promote diversity, to learn to live with difference and to learn to learn from difference.” The global roadmap focuses specifically on education for children with disabilities and draws on national and international policy documents and legislative frameworks. It critically analyzes existing disability-related policies, practices, and educational tools in many countries and will examine how ideas of inclusive education can be mainstreamed into national education systems.

Quite relevant in this study is Rollo May’s existential work centering on the capacity for growth and achievement in human beings (De Castro, 2011). The concept explored and believed that facing feelings of anxiety and fear was a necessary experience if personal growth and meaning were to be achieved in life. Moreover, he focused on the concept of freedom as the pinnacle of human existence. Freedom, in May’s theory, represents the power to choose and direct one’s life. Adding to the idea, May also investigated the concepts of love and will as crucial in negotiating life’s challenges (Friedman & Schustack, 2012). Both anxiety and guilt are prevalent in a parent carer’s life and take a toll on the day’s search for meaning and quality. Another of May’s perspectives is intentionality – which is the structure that ushers meaning to experience and allows people to make decisions about the future. Last but not least, care, love, and build the triad of driving force for any individual, and this study will propel any parent-carer to value and celebrate life as much as one’s own. In all these, these three will define action.

Along the same line, Abraham Maslow’s self-actualization theory was framed in its most essential humanistic advocacy to move from the base of the pyramid to the apex or the transcendental level, which is self-actualization. The first level of needs includes the basic needs of survival, such as goods, water, elimination, sex, and sleep. The second level includes safety needs which are needs desired to fulfill a human’s psychological need to feel safe, such as social structure, order, security, and predictability. A third level includes the need for humans to have a high level of self-esteem to have a sense of belonging and safety in the world. This is what quality of life is all about – the understanding of significance, substance, and purpose.

Reputed as a consistent theory of quality of life, Maslow based his theory for development towards happiness and true being on the concept of human needs. He described his approach as an existentialist psychology of self-actualization based on personal growth. To take more responsibility for one’s own life, one must take more of the good qualities that must be used and the feeling of freedom, power, happiness, and health.

In the Philippines, parent-caring fell on the shoulders of the parents, particularly the mothers and hired help. The burden of raising a child with special needs puts in question the meaning of life and quality of life that seem to have been evasive when even the basic physiological needs are inaccessible. Hence, the creation of a parental

leadership program will help create a leadership development, skills training, and systems intervention program for parent-carers of CSN.

OBJECTIVE OF THE STUDY

This study determined the relationship between meaning in life and quality of life among Parent-Carers of Children with Special Needs (CSN) as a basis for the Parental Leadership Program.

METHODOLOGY

Research Design

This study made use of the descriptive-correlational method. The descriptive method was used particularly in investigating the CSN parent-carers' demographic profile, their meaning in life (MIL) scores in two dimensions presence of meaning and search of meaning, and CSN parent-carers' quality of life enjoyment satisfaction (QOL) scores. Meanwhile, the correlational part examined the three hypotheses of the study. Employing a descriptive correlational design effectively describes two or more variables and shows their associations but not necessarily presenting their cause and effect (Sousa et al., 2007).

Locale of the Study

The study was conducted at GCF South Metro Christian School. This school is a private co-educational Christian school with a growing number of students coming from different religious backgrounds. For almost 15 years now, the school has been in its seventh year of the Special Education Inclusion Program, providing educational and therapeutic services to children with different disabilities. Additionally, this school partner (private tutorial centers and private related service providers like occupational therapists, speech therapists, physical therapists, and behavior therapists) provides academic, behavioral, and therapeutic services for Children with Special Needs.

Research Respondents

The respondents of the study were 186 parent-carers of children with special needs broken as follows: 144 mothers and 42 fathers. Simple random sampling was used in the study. Slovin's formula was utilized to calculate the valid sample size necessary to achieve a certain confidence interval when sampling a population. Random sampling ensures that results obtained from your sample should approximate what would have been obtained if the entire population had been measured (Kirk, 2011).

Research Instrument

Three instruments were used in the study. They had been sourced from standard questionnaires from previous studies:

First is the questionnaire eliciting the profile variables of the CSN parent-carers - age, sex, living status, monthly average income, and educational attainment.

Second is the meaning in life (MIL) 10-item questionnaire, which also measures the presence of and the search for meaning in life (Steger, 2009). Meaning in life questionnaire (MLQ) is an important resource for determining the parent carers understanding of personal values, inclination, and disposition. The Presence of Meaning subscale measures how fully respondents feel their lives are of meaning. The Search for Meaning subscale measures how engaged and motivated respondents are in efforts to find meaning or deepen their understanding of meaning in their lives (Steger et al., 2008). The presence of the meaning subscale measures the subjective sense that one's life is meaningful, whereas the search for meaning measures the drive and orientation toward finding meaning in one's life. Participants responded to each item on a 7-point Likert scale from 1 ('absolutely untrue') to 7 ('absolutely true'), with item 9 reverse scored. An overall Life Meaning score can be obtained by summing responses to all 10 items (resulting in a maximum score of 70). A score can also be calculated for the Presence subscale by summing responses to items 1, 4, 5, 6, and 9 (with a maximum score of 35).

Items on the Presence subscale are concerned with the degree to which participants feel they already have some source of meaning in their lives. For example, item 1 states, 'I understand my life's meaning.' Similarly, scores for the Search subscale can be calculated by summing participant responses to items 2, 3, 7, 8, and 10 (also resulting in a maximum score of 35). Search items examine the extent to which an individual is searching for meaning in their lives. For example, item 3 states, 'I am always looking to find my life's purpose.' Higher scores indicate higher levels of the presence or search for meaning. Steger (2010) provides information on scoring and interpreting the MIL questionnaire. Individuals can theoretically highly endorse items on both subscales at the same time. That is, individuals can report currently experiencing meaning in their lives and, at the same time, report that they are searching for additional meaning. Alternatively, individuals may endorse items more highly on the Presence subscale as compared with the Search subscale, suggesting that while they feel a sense of life meaning, they feel less of a desire to search for more meaning. An opposite combination of responses (more highly endorsed Search than Presence items) suggests that an individual may still be searching for meaning while having limited meaning in their life at the present time. A fourth theoretical combination may be low-scoring responses on all items, suggesting the respondent feels he/she lacks meaning and at the same time, is not searching for it.

The third instrument is the abbreviated version of the Quality-of-Life Enjoyment and Satisfaction Questionnaire Short Form (Q-LES-Q-SF) which is the quality of life (QOL) 16-item questionnaire. This short form version (Q-LES-Q-SF) includes general

activities subscales plus two questions about medication and overall life satisfaction. In detail, the following QOL areas were investigated: physical health, mood, work, household activities, social relationships, family relationships, leisure time activities, ability to function in daily life, sexual drive, interest and/or performance, and economic status, living/housing situation, ability to get around physically without feeling dizzy or falling, your vision in terms of ability to do work or hobbies, overall sense of well-being, medication and overall life satisfaction and contentment (Stevanovic, 2011).

Data Gathering Procedure

Initially, the school principal was contacted to obtain her consent with the use of the GCF South Metro Christian School's Special Education Department with its identified CSN and communication with parent-carers, who were mainly the study participants. Some parent-carers who availed of private tuition but nevertheless were currently given service by the school and its partner therapy centers were invited to participate in this study too. In gathering the data for the study, an ethical standard of research was considered. Essentially, the respondents were oriented as to the purpose of the study. The researcher emphasized that they need to be honest in answering the questions because the data taken from them shall be held with utmost confidentiality and anonymity. The researcher also observed research ethics and procedures by asking the respondents to give their e-signature in demonstration of their Free and Prior Informed Consent Form. The study consisted of three phases. Phase one involved a simple random sampling method where 186 CSN parent-carers of GCF South Metro Christian School (GCFSMCS) Alabang were given the MIL and Q-LES-Q-SF questionnaires. Phase two involved data gathering, and the data were encoded in MS Excel 2020. The scores on the 10-item (Meaning in Life) MIL and 16-item Q-LES-Q-SF questionnaires were summed up in each domain using the prescribed scoring guideline given by the World Health Organization. Descriptive statistics and Pearson's r correlation coefficient with the utility of SPSS were used to identify the relationship between MIL and Q-LES-Q-SF original version questionnaires. Finally, Phase three involved parental leadership development program creation based on the result of the tests provided. Alongside this, during the administration of the MIL and Q-LES-Q-SF tests, CSN parent-carers were interviewed - they were not required, but parent-carers who responded were knowledgeable and articulate about their perceived meaning and quality of life. From the interviews, themes were formed and analyzed.

Statistical Treatment

To enable the researcher to tally, tabulate, compute, analyze, and interpret the data gathered, the following statistical treatments were used:

Descriptive statistics (frequency count, rank, percentage, and mean) were utilized in analyzing the CSN parent-carers profile variables in terms of age, sex, living status, family monthly income, and educational attainment. Meanwhile, the Pearson r Correlation

Coefficient formula was used in determining a significant relationship between CSN parent-carers' profile variables and meaning in life (MIL), both in terms of the presence of meaning and search for meaning. The same statistical tool was used to measure the relationship between CSN parent-carers' profile variables and quality of life enjoyment and satisfaction and the relationship between parent carers' MIL (presence and search for meaning in life) and quality of life enjoyment and satisfaction (QOL). All analyses were tested at a 0.05 level of significance using IBM SPSS.

RESULTS AND DISCUSSION

Table 1. Frequency and Percentage Distribution of CSN Parent-Carers' Profile Variables

PROFILE	ATTRIBUTE	Frequency (n=186)	Percentage 100%
SEX	Male (Fathers)	42	22.58
	Female (Mothers)	144	77.42
AGE (in years)	26 -33	44	23.66
	34 - 41	48	25.81
	42 - 49	29	15.59
	50 - 57	30	16.13
	58 - 65	35	18.82
\bar{x} Age = 43.76-44			
LIVING STATUS	Living alone	29	15.59%
	Living with a spouse	157	84.41%
MONTHLY INCOME (Php)	P40,000 - 60,000	56	30.11
	P60,001 - 80,000	47	25.27
	P80,001 - 100,000	48	25.81
	P100,001 - 120,000	21	11.29
	>P120,001	14	8.06
\bar{x} = 80,000			
EDUCATIONAL ATTAINMENT	High School Graduate	14	7.53
	College Graduate	124	66.67
	Master's Graduate	48	25.81

Table 1 shows that the majority of the respondents are mothers (144 or 77.42%) who fall under the 34 - 41 years old range (48 or 25.81%), predominantly living with a spouse (157 or 84.41%), belonging to the middle-income strata with Php 40,000 - 60, 000 (56 or 30.11%) monthly income and completed a bachelor's degree (124 or 66.67%). It is deemed appropriate the inclusion of parent carers' demographic profiles that would impact their personal involvement in raising their own CSN. The age, sex, living status, economic status, and educational attainment expectedly, within bounds, translate to their MIL and QOL response and contribute to the high predictability of results.

The sex of the CSN parent-carers reinforce the cultural tendency in the Philippines for mothers and, broadly females, as solely responsible for caring and nurturing. The middle-aged adult range (34 to 41 years old) appeared to be ideal as this is conclusive of vigor, maturity, and preparedness to raise a family. In many developmental research efforts, middle age (30-50 years old) proves to demonstrate resilience in the most challenging of situations (Lindo et al., 2016). The living status of parent-carers, particularly the ones living with a spouse, obviously has access to shared responsibility while single parent-carer or the ones living alone (29 or 15.59%) would more often than not serve as the main and only source of child care, support, and guidance. It is given that CSN parent-carers living with a spouse (157 or 84.41%) are readily seen as most likely to thrive, with better MIL and QOL scores due to the presence of the “other” component, which bears half of the care duty and responsibility. Another very strong culturally bound concept is education (124 or 66.67%). As expected, having completed a degree seems to predict financial stability. This CSN parent-carers’ profile ensures options that are considered reliable, particularly the entailing financial burdens in providing their child with the best intervention they need. As all respondents are Filipinos, they understand their security in the future is chiefly dependent on college completion. Finally, in this study, the family of the parent-carers is mostly within the middle-income range of P40,00 to P60,000 (56 or 30.11%) (Family Income and Expenditure Survey, 2012), which affords them a fulfilling basic academic behavioral and therapeutic services for their child.

Table 2. Meaning in Life (MIL) Scores (Presence and Search) of CSN Parent-Carers

PARAMETERS	MEAN	SD	DESCRIPTIONO
1. I understand my life’s meaning.	4.44	1.40	Somewhat True (Partly High)
2. I look for something that makes my life meaningful.	4.08	1.26	Can’t Say True or False (Neither High nor Low)
3. I always look to find my life’s purpose.	4.45	1.49	Somewhat True (Partly High)
4. My life has a clear sense of purpose.	3.56	0.96	Somewhat Untrue (Partly Low)
5. I have a good sense of what makes my life meaningful.	4.33	1.23	Can’t Say True or False (Neither High nor Low)
6. I have discovered a satisfying life purpose	4.47	1.38	Somewhat True (Partly High)
7. I always search for something that makes my life significant.	4.18	1.34	Can’t Say True or False (Can’t Say High or Low)
8. I seek a purpose or mission for my life.	4.23	1.22	Can’t Say True or False (Neither High nor Low)

PARAMETERS	MEAN	SD	DESCRIPTIONO
9.* My life has no clear purpose	5.28	1.06	Somewhat True (Partly High)
10. I am searching for meaning in my life.	3.71	1.28	Can't Say True or False (Neither High nor Low)
Presence of Meaning	4.42	1.21	Somewhat True (Partly High)
Search for Meaning	4.40	1.20	Can't Say True or False (Neither High or Low)

Table 2 illustrates the average of the CSN parent-carers’ Presence of Meaning in Life is partly high ($\bar{x} = 4.44$) while the Search for Meaning in Life is neither high nor low ($\bar{x} = 4.40$). Although with a marginal difference, this indicates that the CSN parent-carers feel their life has a valued meaning and purpose, yet they are still openly exploring that meaning or purpose. They are likely satisfied with their life, generally optimistic, experience feelings of love frequently, and rarely feel depressed or anxious. In individual reports with high levels of presence of meaning in life, it is logical to conclude that they would not be searching for meaning in life. The mean score stating that the search for meaning in life is neither high nor low only goes to show that, on average, CSN parent-carers cannot tell where they are at exactly - dispositionally and situationally. Perkins et al. (2010) argue that individuals who have found meaning continue to pursue the issue, suggesting that the search for meaning in life is ever-present. For some individuals, it appears that they never cease searching for meaning in life, and, according to this study, these individuals can also be happy. Rather than the searching process causing distress, for these CSN parent-carers, it appeared to be a joyous and delightful experience. Steger et al. (2008) offer an affirmative answer to this question by stating that individuals with low scores in both presence and search for meaning in life are better compared to those who are not actively searching for meaning in life short term wise. Also, interestingly, individuals who have a high presence of meaning in life may be more attuned to the deepening of their understanding of life and that the process of searching is not seen in a negative manner.

The MIL statement with the highest score for Presence of Meaning in Life is statement number 9 ($\bar{x} = 5.28$), “My life has no clear purpose.” while Search for Meaning in Life is statement number 3 ($\bar{x} = 4.45$), “I always look to find my life’s purpose.” This implies, notably, in terms of the Presence of MIL, CSN parent-carers find that their life has no clear purpose at all. The clarity in purpose means knowing exactly what it is that one wants. There is no degree of ambiguity or vagueness but a complete, spelled-out, detailed goal in one’s purpose. This hints at the idea that many CSN parent-carers face the difficulty of existential understanding why they are in this world and accepting their calling. Meanwhile, in Search for MIL - as Frankl (2006) mentioned,

“The central feature of human life is the pursuit of meaning and that people make their own meaning by seeking and creating their own understanding of the broader purposes in life.” This can further be explained by finding a sense of meaning that makes one examines the life and how this feels at the present moment (Sutin et al., 2020). Also, this describes activity, interaction, engagement, and commitment to all that the world offers, including hardships and opportunities.

The MIL statement that obtained the lowest score for Presence of Meaning in Life is statement **number 4** ($\bar{x} = 3.56$); *My life has a clear sense of purpose*. while in Search for Meaning in Life is statement **number 10** ($\bar{x} = 3.71$); *I am searching for meaning in my life*. This connotes that most of the CSN parent-carers find their purpose to be unclear and does not elicit enough reason to do the things that matter most to them. Meaning in life may be present but when purpose is indefinite, one would always feel like groping in the dark, unaccomplished or even stagnant. Rising issues in caring like physical and emotional health due to family and work demands bring about the lack of certainty in purpose. Having said that, this finding explains the low score in terms of Search for Meaning which apparently affirms the CSN parent-carers’ quest for meaning in life - persevering to find reason in one’s existence. By increasing Presence of meaning in life, well-being levels may be augmented which then might positively influence the individual’s judgments of their lives leading to new attitudes and approaches to continuing the search for meaning. Alternatively, people may benefit from recognizing their individual levels of how important meaning in life is for them and to what degree they may search for meaning (Frankl, 2006). With the acceptance of individual degrees of presence and search for meaning in life, well-being levels may be cushioned from any negative impacts which occur from having low levels of presence and search for meaning in life.

Table 3. Quality of Life (QOL) Scores of CSN Parent-Carers

PARAMETERS	MEAN	SD	DESCRIPTION
Taking everything into consideration the past week, how satisfied have you been with your...	2.50	1.01	Poor
1....physical health?			
2....mood?	2.53	1.11	Poor
3....work?	2.27	1.03	Poor
4....household activities?	3.31	1.00	Fair
5....social relationships?	2.59	1.02	Poor

PARAMETERS	MEAN	SD	DESCRIPTION
6....family relationships?	3.96	1.25	Good
7....leisure time activities?	3.49	1.08	Good
8....ability to function in daily life?	3.30	1.08	Fair
9....sexual drive/performance?	2.58	1.02	Poor
10....economic status?	3.42	1.15	Good
11....living/housing situation?	3.55	1.04	Good
12....ability to get around physically without feeling dizzy, unsteady?	3.48	1.13	Good
13....your vision in terms of the ability to do work/hobbies?	3.53	1.10	Good
14....overall sense of well-being?	3.54	1.14	Good
15....medication?	3.49	1.07	Good
16....how would you rate your overall life situation and contentment during the past week?	3.64	1.04	Good
Weighted Mean	3.42	1.10	Good

Table 3 reveals that the QOL of CSN parent-carers is overall **good** ($\bar{x} = 3.42$). This implies that there is a marked satisfaction within the areas of family relationships, leisure time activities, economic status, living/housing situation, the ability to get around physically without feeling dizzy/unsteady, one’s vision in terms of the ability to do work/hobbies, overall sense of well-being, medication and overall life situation and contentment during the past week. This finding affirms the study done by Mugno, et. al. (2007) amongst CSN who even with very challenging circumstances, parent-carers are determined to make life worth living through improving family and social relationships.

The QOL statement with the highest mean is *Family Relationships* ($\bar{x}=3.96$; Good). Other QOL areas that scored *good* include leisure time activities, economic status, living house condition, mobility or the ability to move around, vision, overall sense of well-being, medication, and overall life situation and contentment. This finding is very much evident to the cultural upbringing of many Filipino parent-carers who place their family front and center in their life. QOL is enhanced by the positive relationship that

exists among family members and consequently many other life's areas as well. Grit and resilience are anchored completely to the psychological and emotional bearings a family support system can afford. As fairly viewed, family provides a good stead, comfort, and guidance in both times of joy and distress. Moreover, the saying, "a burden shared is a burden halved." rings exactly true to this dynamics. Family is where everything is shared together - wins/losses, success/failures, birth/death, and delight/grief. This finding is corroborated through the study by Marsamadi and Abdi (2017) stating that in many cultures, the availability of help through the family system augments the many needs for survival.

The QOL statement with the lowest mean is *Work* ($\bar{x}=2.27$; Poor) alongside other areas such as physical health, mood, social relationships, and sexual drive or performance which all scored *poor* similarly. Such a finding amplifies the fact that a CSN parent-carers' responsibility to earn and provide for a child with special needs aggravates the overall burden of caring. This also conveys the reality that for those who cannot afford basic educational and therapeutic services more so private tuition would have to resort to working outside for a decent income. Adding to this is the all-time high demands of any outside paid employment which means less time and attention for the CSN. This further compounds the issue of having to hire or avail third-party services in order to provide care for CSN which in turn adds to the financial burden of the family. Safety issue is presented alongside hiring someone to care for CSN at home when parents must work. Such a finding affirms the decision of many families for one parent to be a full-time homemaker to ensure quality care provision, security, productivity and economic stability (Shek, 2021). In this regard, QOL is greatly affected by worries on safety, security, fatigue, emotional-physical stress and overall burnout (Turnage, 2019).

When discussing the broader meaning of "quality of life", there is a caution against equating quality of life with the value of life. When accepting QOL as equal to the value of life, it may result in eliminating the unprotected and helpless, allowing only the strong to live. This idea contradicts the philosophy of caring particularly for the vulnerable CSN as this is considered one of the most stressful situations for parents. No parent would dare consider giving up on their calling to care for their very own. Many themes emerged from the additional interview with CSN parent-carers' QOL. They found it relevant to share freely as to shed light on the parent-carers' experiences, namely, objective challenges in terms of financial challenges, employment issues and demands of care; subjective challenges in the form of stigma, isolation and pity. On the other hand, although less popular are the positive experiences notable to mention such as the child's progress, respect and happiness; material and financial needs; and improved coping mechanisms which include better life beliefs, family support and positive attitudes towards one's plight.

Table 4. Relationship Between CSN Parent-Carers’ Profile Variables and Meaning in Life (MIL) Dimensions of Presence and Search

PROFILE VARIABLES	p and r-values on the Meaning in Life Dimensions	
	PRESENCE	SEARCH
Age	p = 0.00** r = 0.224	p = 0.774 r = 0.021
Sex	p = 0.729 r = -0.026	p = 0.002** r = -0.228
Monthly Family Income	p = 0.628 r = 0.036	p = 0.940 r = 0.006
Living Status	p = 0.730 r = -0.020	p = 0.001** r = -0.221
Educational Attainment	p = 0.242 r = 0.086	p = 0.757 r = 0.023

Legend: ^{ns} correlation is not significant at 0.05 level (2-tailed) 95% probability
 ** correlation is highly significant at 0.01 level (2-tailed)

Table 4 shows that there is a significant positive relationship between *age* and *Presence of Meaning in Life* ($p = 0.00, p < 0.01$). This implies that the older the CSN parent-carers, the more apparent presence of meaning in life is demonstrated in their life’s domains. Notable is the fact that with older age, there are more opportunities to reflect and learn from past failures and mistakes which firms up the presence of MIL. Adding to this is the understanding that with maturity, people tend to think more about their finite existence, thus, upholding the values and morés of a “life well-lived.” This is affirmed in the study done by Yu and Chang (2021) highlighting maturity and relationships that give meaning to our existential moorings.

Interestingly, the *sex* of the parent-carers and the *Search for Meaning in Life* have highly significant negative correlation ($p = -0.002, p < 0.01$) which implies that female respondents are more likely searching for the meaning in life. This conveys the idea that mothers oftentimes spend their life seeking out what is best for their child with special needs - from looking for teachers and therapists, figuring out which academic or behavior program to follow up to the long-term possibility of home or facility care for when the time comes that she could not physically attend to her own child. Apparently, in the present modern cultures, mothers lose their identity as an individual and become someone’s mother or someone’s wife (The New York Times, 2020).

Noteworthy is the *living status* of CSN parent-carers and the Search for Meaning in Life having high significant positive correlation ($p = 0.001, p < 0.01$) which asserts that CSN parent-carers who live with a spouse are mostly inclined to search for MIL. This may be attributable to more concerns and issues to consider when one lives or “shares

life” with another person. Normally, living with a spouse is synonymous to having a partner who can help or to belong to someone who can help ease up the burden of caring. However, one has to consider the welfare, interest, priority and goals of the other spouse as crucial to coming up with even a simple choice. This consideration of the other spouse brings forth more issues and can pose more of a disadvantage. Also, sometimes, meaning, purpose and motivation are lost along the way particularly for those who have lived together for many years. Consequently, when this happens more problems arise in caring for the CSN.

Other variables like educational attainment and monthly family income did not result in a significant correlation on the presence of meaning and search for meaning in life. This implies the reality that education and money cannot be equated to our understanding of purpose and significance but may shape our future understanding of life as a whole. In sum, as there is a strong association between MIL dimensions of search for and presence of MIL and age, sex and living status, there is a significant relationship between parent-carers’ profile variables and MIL as a whole.

Table 5. Relationship Between CSN Parent-Carers’ Profile Variables and Quality of Life’s Enjoyment and Satisfaction (QOL)

Profile Variable	QUALITY OF LIFE ENJOYMENT AND SATISFACTION	
	r	p-value
Age	-0.073	0.323
Sex	-0.091	0.217
Monthly Family Income	-0.057	0.436
Living Status	-0.089	0.215
Educational Attainment	-0.040	0.592

Table 5 illustrates the relationship of CSN parent-carers’ profile variables and Quality of Life (QOL). While the correlation was not significant relative to the standard alpha level of 0.05, there might be a plausible reason for this. The data below underscore the relationship between CSN parent-carers’ profile in terms of sex, age, living status, monthly family income and educational attainment and QOL. Following the trend will give a crucial notion that sex corresponds to a particular caring stereotype; mothers as females are predominantly carers while being primarily homemakers. Age variable matters in CSN parent-caring, however, CSN parent-carers’ vitality, vigor, drive, and motivation, do not predict their preparedness to provide care. Living with a spouse would always be advantageous in an ideal parenting set-up where both husband and wife work together to fulfill their roles - provider and sustainer of all the important family activities crucial to the growth of CSN. Although becoming very common nowadays,

raising a child as a single parent presents innumerable challenges but not impossible. Many studies have proven that single parents are equally prepared and able to provide the primary needs of their CSN which in turn leads to living a life with high QOL. Along this line, family income as a profile variable may ensure stability in parent-caring and can significantly increase QOL. However, many well-being studies connected to QOL attest to the fact that money cannot completely solve the many concerns of CSN parent-caring. QOL tapers down for many various reasons like health, relationships, social support (Bernard, et. al, 2015). Another profile variable is educational attainment which accounts for the fact that completing a degree ascertains employability leading to economic stability and predictably increased QOL. However, with further analysis, the non-significant correlation may be attributable to many factors. Some response narratives from CSN respondents include a number of factors that might have led to the absence of correlation. These parent-carers simply need the resources to deal with objective challenges which in a developing context are not easily attainable. This analysis contradicts the previous research done by Campos, et. al (2014) stating that the factors associated with low QOL were increasing age, sex (being female), living alone, low education and unstable economic status.

Table 6. Relationship of CSN Parent-Carers’ Presence of and Search for Meaning in Life (MIL) and Quality of life’s Enjoyment and Satisfaction (QOL)

Quality of Life Enjoyment and Satisfaction	p-Values on the Association of Meaning in Life (MIL) and Quality of Life (QOL)	
	PRESENCE	SEARCH
	p = 0.000 r = 0.712	p = 0.000 r = 0.753

Legend: ** correlation is **highly significant** at 0.01 level (2-tailed)

Table 6 reveals that the Meaning in Life dimensions of Presence and Search (MIL) are positively correlated to the Quality of Life (QOL) of CSN parent-carers. Results in this study show that there is significant positive relationship between the CSN parent-carers’ *Presence of Meaning* (p = 0.000, p < 0.01) and *Search for Meaning* (p = 0.000, p < 0.01) in Life and *Quality of Life, Enjoyment and Satisfaction*. Overall, this means that as Meaning in Life increases the Quality of life increases correspondingly. This can be explained by the previous statement that clarity in purpose and constancy in finding one’s life can be an indicator of a good quality of life as this shows reinforced effort to keep searching for meaning as this has led to QOL. Also, both MIL and QOL revolve around growth in family relationships which may lead to more leisure activities involvement, improved economic status, better living or house conditions, mobility, vision, overall sense of well-being, medication, and overall life situation and contentment. This can further be accounted to the availability of appropriate support

for families and the advocacy for them, communication and relationships with services and professionals, the availability of information and attitudes towards disability and overall community support. Surely, CSN parent- carers will find the emotional support from family beneficial, and will definitely enhance their capacity to manage their own well-being, as well as their primary caregiving roles. It is interesting to note that in Bernard, et. al. (2017) study emphasizing the importance of MIL as a contributor to QOL, meaning in life is attributed to family, social relations, spirituality and religion, social commitment, and growth and less likely to cite finances, have no one “to talk to” and a gap in their social networks.

Interestingly, from the CSN parent-carers interview, it was reported that the QOL is related to autonomy and the ability to work. The dimensions of QOL included: resuming work and functional ability, body image, having leisure and interpersonal relationships. Their descriptions revealed their feelings and attitudes about resuming their previous activities and social lives, particularly concerning the work. The WHO defines QOL as “the individual perception of the position in life in the context of culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns all of which revolve around the context of work. This study can also further claim that if parent-carers have improved QOL, mental health and wellbeing, it is also possible that the benefits will be transferred to that of their children (Keen, et. al., 2010). One aspect that can be impacted by caring for CSN can be the engagement in and occupational performance of paid employment (Puff & Renk, 2014). Paid employment can offer many benefits to carers such as financial security, social interaction, structure and meaning to daily routine, sense of identity and respite from carer duties (Thomas, et al., 2016). Parent-carers have indicated that maintaining their worker role can balance out their caring role and positively impact wellbeing. Parent-carers who are in paid employment also have the opportunity to maintain their social networks and would be less vulnerable to social isolation. Also, this would enable them to retain their adult identity by socializing with other adults (Weiss, et. al., 2013). Therefore, even though there are difficulties in combining work and care, the positive impacts of paid employment appear beneficial to many parent-carers with the right support in place which in turn increases meaning in life and quality of life. Therefore, MIL also enhance the QOL by motivating CSN parent-carers involvement in activities that promote social integration and the quality of social relationship.

Consistent with past research (Bernard et. al., 2017), the MIL was positively associated with aspects of life satisfaction, happiness, and positive affects that are synonymous to QOL and negatively associated with depression and negative affects. Furthermore, MIL was positively associated with well-being and subsequently, QOL—greater life contentment, more happiness, enjoyment, and satisfaction— among those who already had substantial meaning in their life (Yu & Chang, 2021). The search for meaning is not only morally worthy but as it succeeds, eventually satisfying and contributes wholly to quality of life.

A Proposed LEAD Program: Leadership, Education and Development Program for Parent -Carers of Children with Special Needs

Introduction

The Proposed Parent Leadership Program for Parent-Carers of Children with Special Needs (CSN) entitled **LEAD** -(**leading, equipping and developing**) a leadership development, skills training and intervention systems program came about to purposefully lay down the foundation for parent empowerment and practicable support systems for this specific population. Not only the Children with Special Needs (CSN) are affected largely by the overburdening issues that wrought parent-carers but likewise impact the life of all the individuals who in one way or another interact with them. Over the long course of time, relationships deteriorate and lead to disintegration of family units and contribute ultimately to community issues and the macro-society at large.

LEAD, while a proposition, is distinctly translated as response or answer to a particular question and is thus contextually defined as response to a need. CSN parent-carers presumably have pertinent needs that must be addressed with a definitive sense of expediency and authentic care. The burdens that these parent-carers experience cannot be undermined by the emotional apathy as usually afflicted by the unknowing, biased and prejudiced society.

The glaring reports from the respondents enumerated the following points: desire to possess a life outside caring and keeping certain control over one's life, balance between caring and parenting, building physical and emotional well-being, stable financial resources, disconnect and partnership issues with academic, therapeutic and medical services, unsubstantial social interaction, doubting self-worth, ideations of isolation and thoughts of sexual/physical inadequacy. As expected, these reports formed the basis for the proposition of LEAD - Parent Leadership, Skills Training and Systems Intervention Program.

Having considered all the aforementioned scenarios, the researcher saw the exigent need for interventions to be put in place that will produce improved MIL and QOL of CSN parent-carers. The methods, approaches and strategies under this proposition are designed to perfectly match targeted needs of those carers specifically providing wrap-around services to CSN.

The purpose of this parent leadership program essentially taps four areas: leadership, education, counseling and therapy. In all of the iterations, leadership and skills training, project-based learning, guidance process and therapeutic service provision will be comprehensive, developmental and sequential. Another very important purpose of this proposition is to pinpoint evidence-based practices, theories and concepts that are conclusively expedient and effective. Finally, this LEAD program purports to lay down the groundwork and outline a process for tailoring a comprehensive parent leadership

program model that would meet the needs of the increasing number of CSN parent-carers.

The LEAD Parent-Carers Intervention Program Objectives

The guide is intended for all parent-carers, school leaders, counselors and educators seeking to validate or improve the effectiveness and efficiency of parent organization, special education and school counseling programs specifically to the roles and responsibility parameters set for CSN parent-carers.

Parent-Carers: to help them understand, contribute and support a quality parent leadership, special education and school counseling program in order to effectively guide, support, and nurture their children's development.

Principals/Head of Schools/Directors: to help them collaborate with parent-carer-leaders to design a quality parent leadership program and to create pedagogical leadership direction for the delivery of various services.

Counselors: to help them establish, implement, and manage programs that will benefit all of their students including parents and the special education population

Teachers: to help them understand the goals of parent leadership, special education and school counseling program so that school and parent partnership can work to the maximum benefit of students.

Special Needs Educators: to maintain their collaboration with parent-carer-leaders and school counselors as they go through the process of creating individualized education plans that are holistically empowering and intentional in goals and objectives accomplishment.

Therapists (Speech and Language, Physical and Occupational): to create a seamless integration of all therapeutic services and improve program service delivery through the themes of diversity, inclusion, equity, and equity.

Legal Bases

Approximately 60% of the recorded Filipino children with disabilities were out of school in 2019 according to the Department of Social Welfare. Moreover, the inability to access education services and learning resources was one of the major concerns cited in the 2020 survey of the Council for the Welfare of Children Sub-Committee on Children with Disabilities. With the enactment of Republic Act 11650, there will be parent programs in the Philippines like LEAD that will ensure alignment with the recommendations of the UN Convention on the Rights of Persons with Disabilities (UNCPRD) and the United Nations Convention on the Rights of the Child (UNCRC) - CSN would further learn meaningfully and reach their maximum potential. Moreover, with this law, provisional policies that institute educational programs, services, and protocols pushing the agenda for CSN in support of inclusive education will be made accessible. Inclusive education allows for the provision of fundamental needs of children

with special needs (CSN) including and not limited to their care. This law states that all public schools nationwide are required to identify learners with special needs and provide these learners with free basic and quality education through learning centers. Given the allowance for resource centers, a parent leadership program will be deemed necessary and relevant to initiate or even sustain the work of caring for CSN. Along this line, the Department of Education (DepEd) through its subordinate rule-making power issued DepEd Order No. 54 s of 2009 as amended by DepEd Order No. 83, s of 2010, or the “Revised Guidelines Governing Parents-Teachers Associations (PTAs) at the school level. Parents-Teachers Association (PTA) is a mechanism for effecting the role of parents as an indispensable element of the educational community. Rather than being totally independent of or removed from schools, a parent-teacher association will be deemed instrumental to the growth of education through partnership and network. Being an indispensable arm, the official status will pave the way for transparency in the creation of programs and the relevance of practice in the process of implementation, enhancement, and evaluation pertinent to the needs of families raising CSN With PTA, practices, protocols and programs are easily initiated not just for the welfare of the students and teachers but primarily the parent-carers who would largely benefit from this partnership.

PROGRAM OBJECTIVES

This proposed LEAD (Leading, Equipping and Developing) Program for Parent-Carers aims to:

1. To promote increased knowledge and understanding of CSN parent-carers leading to empathy-rich efforts and practicable activities worthy of implementation.
2. To participate in planning, implementing, and evaluating a comprehensive leadership developmental and interventional program to serve CSN parent-carers and to address the special needs of both neurotypical and neurodivergent students.
3. To provide CSN parent-carers with information about available services taking into account the best methods, strategies and approaches inclusive of health professionals and what to expect.
4. To deliver leadership development, skills training and systems intervention activities serving as a resource to school parents, school leaders and teachers imparting experience based on family relationship, dynamics and projections.
5. To promote first-hand experiential skills that can support parent-carers to frame problems into perspective and accommodate them in a timely and effective manner.

6. To increase skills development that can ensure sustainable efforts for parent-carers to put problems into perspective and deal with them in a judicious, practicable and effective manner.
7. To enlist supporters, advocates and institute leaders to communicate collaboration as an effective instrument for sustainability programs and efforts.

CONCLUSION

The MIL dimensions revealed that, on average, the CSN parent-carers' Presence of MIL is partly high while the Search for MIL is neither high nor low, which reveals that they have a valued meaning and purpose, yet they are still openly exploring them. The QOL of CSN parent-carers is overall good, with *family relationships* receiving the highest score and *work* with the lowest, revealing that there is a marked satisfaction in the area of family relationships while discontent and a sense of unfulfillment with work. There is a significant relationship in terms of age, sex, and living status profile variables with MIL, except for education and monthly family income. A strong significant relationship is demonstrated between MIL and QOL of CSN parent-carers. Overall, MIL's *partly high* for Presence and *neither high nor low* for a Search result, while QOL's *good* imply that CSN parent-carers have a relatively positive understanding of both MIL and QOL in their life. The prevailing challenging and popular themes like "*My life has no clear purpose,*" "*I always look to find my life's purpose,*" and attitude towards *work* will be considerably impactful in the creation and structuring of a LEAD parent leadership, skills training, and system Intervention program for parent-carers of CSN.

RECOMMENDATIONS

In view of the foregoing findings and conclusions, the following recommendations are hereby presented:

1. For the LEAD program to be reviewed, enhanced and endorsed for implementation by the following entities: families, schools, therapy centers, community centers, and government agencies.
2. To increase intentional participation of more fathers, both married and single, college graduate parents in the caring-nurturing of CSN parent-carers for sustained training, coaching, and overall instruction and program enrichment.
3. Create programs for the understanding of meaning in life both the presence of and search for both the CSN and the parent-carers through the inclusion, integration and amplification of socio-emotional/mental health programs in the curriculum for both academics and content.
4. For quality of life to increase in the areas of family relationship and work by marshaling resources that will amply provide for support, guidance, creativity, leisure, self-agency and life-work harmony.

5. Provide more financial resources to school leaders and administrators to open inclusive environments both structurally and instructionally. These resources will ascertain consistency in program implementation by having consistent educators, staff, and many service providers.
6. For School Counselors and SPED educators to contribute to the process of disability identification, service delivery, assessment and evaluation for sustainable work and optimal service provision. This will also pave the way to the creation of meaningful projects and activities for overall health and improvement.
7. The rise in the number of research capacities through collaborative work of previous and present researchers that will pave the way to the understanding of collaboration and partnership in solving familiar, communal and social problems.
8. For the local and national agencies and departments to address the various supports needed by both parents and educators that will help legislate, validate, assimilate global issues relevant to the understanding of the entire advocacy program of CSN and more advanced health, educational, therapeutic and behavior service provisions.

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