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Navigating the terrain of caregiving of children with intellectual and developmental disabilities: importance of benefit finding and optimism

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Empirical studies have indicated that benefit finding and optimism greatly help caregivers of children with intellectual or developmental disabilities. Specifically, it has been suggested that these two constructs serve as critical coping strategies for those engaged in the caregiving process. Here, a qualitative study was undertaken to explore the impacts of benefit finding and optimism on caregivers of children with intellectual and developmental disabilities in Malaysia. Twenty (20) caregivers of children with intellectual and developmental disabilities were interviewed concerning their perception and use of benefit finding and optimism. Results identified these strategies as supporting and guiding caregiving responsibilities and skills, improving personal growth, relationships and spirituality, as well as increasing positive perceptions. Therefore, policymakers and stakeholders in Malaysia should implement targeted interventions to facilitate and support caregivers in applying benefit-finding and optimism in their caregiving, thereby assisting them to better cope with the physical and mental demands of caring for children with intellectual and developmental disabilities.

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Introduction

The family is an integral part of society (Azman et al., 2020) and, as a significant social institution, dictates the fundamental beliefs and values that affect children's upbringing and the formation of their moral compass. This influential role also applies to children with intellectual and developmental disabilities, who struggle with a range of mobility, communication and social issues and constraints in their daily lives. These challenges make them highly dependent on their caregivers (Amin et al., 2016; Williams et al., 2021), leading caregivers to become overly protective of their children (Islam, 2015).

It has been well documented that caregivers face issues and challenges—primarily in the areas of social, logistical and technical support—in managing children with intellectual and developmental disabilities. Not only is there little help from the state in this regard, but the caregivers are ill-equipped, lacking the proper tools to effectively carry out their essential role (Singh et al., 2020). Most of the social support and services provided by the state and NGOs for persons with disabilities are only available in urban areas (Amin et al., 2016). Consequently, caregivers in rural and sub-rural areas must overcome multiple challenges to access these facilities and services and to obtain the information they need to equip themselves with the necessary skills and resources for their caregiving responsibilities.

The current study examined how caregivers of children with developmental and intellectual disabilities are able to cope and carry out their duties as a result of benefit finding and optimism, specifically in the Malaysian context (Slattery et al., 2017). A previous study of the caregivers of children with autism in Malaysia linked aspects of caregiving with caregiving burden, such as a lack of quality time with other family members, additional concerns about their children's education and future employment, and financial difficulties in accessing quality services for their child (Sitimin et al., 2017). Further studies demonstrated that these negative attitudes and stresses directly undermine caregivers' psychological well-being and quality of life (Isa et al., 2016).

Disability in Malaysia

In Malaysia, stigma and religious perspectives inform the people's understanding and acceptance of disability (Sheri, 2015; Ling, 2007). For example, a study of children with Down syndrome in Sarawak reported that Malay Muslim families viewed children with Down syndrome as a predestined gift from God who would assist them in raising the child (Chan, 2012). However, in other cultures, the issue of disability is shrouded in negativity and pessimism. The Iban community in East Malaysia, for instance, believes disability is a result of the child's mother having broken certain religious taboos (Mamba, 2010). Therefore, elements of religion and spirituality are embedded in the understanding of disability in Malaysia.

In most traditional societies in Asia, shamans or traditional healers are much sought after, as the families believe these individuals can treat their child (Botros et al., 2006; Lauber and Rössler, 2007; Ali et al., 2020; Singh et al., 2020). Studies have shown, however, that in Malaysia, the Malay and Chinese communities do not subscribe heavily to the supernatural or superstitious element as being the cause of disability. Instead, the majority of them believe that the cause is emotional, social or psychological (Edman and Koon, 2000).

Benefit finding and optimism

According to Slattery et al. (2017), benefit findings can be contextually defined as a possible means to lessen the negative repercussions of caregiving on parents of children with disabilities. However, further studies are needed to generalise the likelihood of caregivers engaging in benefit findings. Additional studies are also needed on the topic of optimism, which has been considered a fundamental personological characteristic for the perception of benefits, particularly when facing troubled or challenging circumstances. Despite this understanding, more needs to be discovered about the mechanics of the psychological aspects of optimism in benefit-finding relationships. A recent study on caregivers living with children with intellectual and developmental disabilities only supports optimism as indirectly influencing benefit finding through positive reappraisal and social support (Slattery et al., 2017).

Empirical studies have found that most caregivers of children with disabilities rely on benefit finding and optimism to help them cope with caregiving challenges (Blacher and Baker, 2007). This approach has proven successful by focusing on positive contributions, gratifications and positive aspects of caregiving (Hastings et al., 2005; Valentine et al., 1998; Kenny and McGilloway, 2007). Studies also supported the idea that using a benefit-finding and optimistic approach in caregiving for people with intellectual and developmental disabilities has contributed to caregivers' personal growth (Slattery et al., 2017). Thus, benefit finding and optimism can be categorised as solution-focused coping strategies, as they assist in alleviating the stress and pressures that caregivers face. Accordingly, benefit finding is an important asset for caregivers in overcoming the stress and pressure of caregiving.

In addressing the research question on how caregivers utilise benefit finding and optimism in caregiving for children with disabilities, studies have reflected that caregivers rely on these two constructs as coping approaches. Seeking to ensure consistency and continuity of care for their children with disabilities, caregivers utilised benefit finding and optimism as sources of encouragement in providing this care (Blacher and Baker, 2007). Specifically, caregivers focused on positive contributions (Hastings et al., 2005), magnifying gratifications (Valentine et al., 1998) and the positive aspects of caregiving (Kenny and McGilloway, 2007) to help them cope with caregiving challenges.

Methods

In-depth interviews of caregivers enabled the researcher to obtain detailed information about the caregivers' experience in managing children with intellectual and developmental disabilities (Liamputtong, 2013). This qualitative method provided a holistic approach that was considered appropriate for extracting perspectives on emotional and personal subjective issues (Alan and Robert, 1999; Ali et al., 2020; Azman et al., 2019; Parker et al., 2015). Exploring caregivers' experiences can be a sensitive endeavour, as personal histories, perspectives, experiences, opinions and feelings are discussed, highlighting the appropriateness of employing open-ended and semi-structured questions in the study.

Study informants. A total of 20 family caregivers who were parents of children with intellectual and developmental disabilities and who accessed services offered by Community-Based Rehabilitation (CBR) centres located at Universiti Sains Malaysia were selected to participate in this study. The caregivers in this study were connected to a local CBR centre that provides relevant services and psychosocial support.

Twenty participants were selected owing to data saturation. According to Padgett (2016), Liamputtong (2013), and Sulaiman et al. (2013), data collection stops when the data reaches the point of saturation or no new information can be obtained from informants. Robinson (2014) also suggested that qualitative sample selection should include only 3 to 16 samples to avoid data burden. Specifically, a convenience sampling technique was used to recruit the participants.

Informant selection procedure. The participants were caregivers of children with intellectual or developmental disabilities.

The following inclusion criteria were used to select the participants:

i. Primary and full-time caregiver of children with intellectual and developmental disabilities
ii. Member of the nuclear, extended or single-parent family, where:

  - Nuclear family includes the biological family of children with intellectual and developmental disabilities, such as parents and siblings;
  - Extended family includes an extension of the biological family, such as grandparents, cousins, uncles and aunts; and
  - Single parent includes the father or the mother of a child who is solely responsible for the maintenance of the child, without any internal or external familial support

iii. Lived with and cared for children with intellectual and developmental disabilities for at least six months

Data collection. A semi-structured in-depth interview technique was adopted to collect data, and adherence to all appropriate guidelines was maintained (Barriball and While, 1994; Islam et al., 2019). The interviews were conducted between October 2021 and January 2022, and each interview lasted between 40 and 120 min. Due to COVID-19 restrictions, the interviews were conducted via phone and Google Meet application after obtaining full consent from the participants. All the dialogue and nuances of the conversations were recorded on an audio recorder with the informants' consent and were presented verbatim and translated into English. The interviews were conducted both in Malay and English. All 20 informants were provided with pseudonyms to protect their identity and ensure confidentiality.

Data analysis. The recorded interviews were meticulously transcribed at least twice for data accuracy and then carefully analysed. The transcribed data were coded, organised and grouped into different emerging themes and sub-themes in line with the study objectives. Selected verbatim quotes from the informants were presented to indicate themes and sub-themes.

Ethical considerations. Ethical approval was obtained from the Human Research Ethics Committee (JEPeM), Universiti Sains Malaysia (USM/JEPeM/19120969) before commencing research. The in-depth interview questionnaire and research proposals were first reviewed by the Human Research Ethics Committee (JEPeM), Universiti Sains Malaysia to ensure that the questions were relevant and appropriate to the research objectives. Confidentiality of informants was ensured, as was an attitude of being non-judgemental towards informants regarding the information they provided during their interview. The entirety of the study and its objectives were explained to the participants, and their questions were answered. An explanatory letter about the study was also provided to the participants, informing them that they could withdraw from the study at any time without penalty. The interviews were conducted in a familiar and comfortable language for the informants, who selected the time and setting of their interview.

Research limitations. First, the study lacked diversity in terms of the race and ethnicity of the respondents. Future research should include different ethnic groups to enhance the validity and generalisability of the present study. Second, the study did not consider the severity of the children's disabilities or the attitudinal issues that might contribute to parental stress. Third, the correlation between benefit finding and optimism with other potential family stressors—such as financial implications and marital satisfaction—were not considered in the study and may be tackled in future work. One final limitation: due to the COVID-19 pandemic, face-to-face interviews were a risk and, therefore, in-depth interviews were conducted via telephone and the Google Meet application, depending on the comfort of the informants. Due to this condition, additional time and engagement were needed to build enough rapport to obtain the informants' feedback. However, the researcher acknowledges that the level of trust and communication with the informants were affected due to this method.

Findings

Informant details. Twenty (20) Malaysian caregivers of children with intellectual and developmental disabilities participated in the study. Twelve (12) were mothers, and eight (8) were fathers; ages ranged from thirty-five (35) years to fifty-six (56) years. All informants had been caregivers for five (5) to sixteen (16) years.

Benefits of being caregivers of children with disabilities

Personal growth. Interviews were examined to determine how personal growth approaches benefited caregivers' cognitive functions and how these individuals perceived their own personal growth. Results suggested caregivers were aided by benefit finding and optimism.

One of the research participants, a male caregiver of a child with cerebral palsy and autism, stated:

> Slowly, we began to communicate with him to have him tell us the reasons behind his tantrums. Because he is a non-verbal child, sometimes it is hard to communicate. I used to assume that his tantrums were because of his disabilities, but at least now we know that there is a reason behind every tantrum. Because of that, we have both grown as individuals and understand each other better.

The above indicates that the caregiver and his son achieved personal growth from their eight years of interactions. Benefit finding helped the caregiver view the relationship more positively and prevented him from becoming anxious and exasperated. He had realised there was a reason for his son's tantrums, even though they could not communicate effectively. Their increased understanding of each other's situation further demonstrated their personal growth.

Another caregiver said that her knowledge and understanding of children with disabilities had grown after six years of caregiving for her child. She recounted:

> Before having him, I wasn't informed at all about disabilities, but I knew a bit about children with autism and Down syndrome. After having him, my knowledge and understanding of autism has grown, and autism is more common than in the old days.

She acknowledged that before having her child, her knowledge and comprehension of children with disabilities were limited. Her knowledge and general understanding of what her child was facing thus improved, assisting her in her caregiving process.

A male caregiver of an autistic child shared his experience:

> We can't be in denial, and we must accept everyone around us. For me, I was in denial for a long time. I couldn't accept him as a special needs child. But, after some time, I accepted that he has his own quirks and his thought process and problem-solving are different from others.

After 13 years of caregiving, he achieved personal growth when he learned to accept his circumstances, including embracing his child's strengths and weaknesses. His understanding improved as he stopped living in denial and became more accepting of his circumstances, reflecting his growth not just as a caregiver but as a person.

Improved relationships. Caregivers in the study collectively claimed that benefit finding improved their relationship with their children, which greatly helped the caregiving process.

A male caregiver remarked:

> You could say that our relationship with him got better. Before he was diagnosed, he was a very quiet person and very unsociable. He barely interacted in class according to the teacher. He did not open up about his struggles. Now, he shares all kinds of things with his mom and me: with his mom, he talks more about personal matters, and with me, he discusses games and school. It's very fulfilling to see our relationship with him improve drastically.

In short, the caregiver admitted his relationship with his child improved when his son became more expressive in sharing his feelings and emotions. Hence, it is clear from the above passage that the caregiver's relationship and communication with his special needs child improved after they (both father and mother) changed their approach.

A female caregiver recounted:

> For me and my son, our relationship improved when I became more transparent with him about my struggles dealing with his condition. I explained to him that he is different from his peers. If I'm angry or sad, I tell him, and he does the same. Eventually, a mutual respect developed between us, and we understood each other better.

It is evident from the above that the caregiver's decision to be transparent with her child led to an improvement in their relationship, which ultimately boosted the caregiving process. Her son became more expressive and open as well.

Another female caregiver with two children with disabilities explained that their conditions brought all of the family together to find ways to improve their lives. Understanding the situation, their cousins treated them well, which ensured very few awkward moments. She added that 'our relationship as a whole family improved as everyone understood each other'. The caregiver further expressed how collective caregiving bound the family together as they began to find solutions, including therapy for her differently abled children. Her relationship with her extended family improved when they accepted her children and treated them better, creating a closer bond within the family.

Dimensions of spirituality. This study found spirituality to be an important component of the caregiving process. The respondents believed that incorporating spirituality into the caregiving process increased their sense of purpose and duty.

A male caregiver said:

> Sometimes, it is hard, and I do get tired, but this is what God gave me; I have to face it. Maybe it is tough now, but perhaps it will help me in the hereafter.

He believed the obstacles and hurdles he faced were from God and that he would be rewarded in the afterlife for his sacrifices. Further, his sense of purpose for existence had been enhanced since his child was born. In sum, adopting this belief and approach helped him to endure the difficulties of the caregiving process.

This view is supported by another caregiver, who said:

> Right now, all praise to God, caregiving for him does not affect my work. Before, I was very busy, but now my workload is much more manageable. So, I couldn't help but feel that this is God's plan for me. Now, if he's having tantrums at school and I have to pick him up, it does not interfere with my work.

He was happy that he received a promotion after having his son. The new position was flexible, and its workload was manageable. This made him feel even more grateful to the higher power that has made his life easier. He also acknowledged that he had a better understanding of his sense of purpose in the world.

Another caregiver recounted:

> As a Muslim, I believe these children with disabilities are heaven's gift. They cannot deceive; when they cannot deceive, they cannot lie. They are basically so pure that they are free from committing sin. That's why those who care for them are promised heaven in the hereafter.

He added that in Islam, children with disabilities are guaranteed heaven. Thus, caregiving for them ensures happiness in the afterlife. Children with disabilities are held in high regard in Islam, and those who put their utmost care into caring for these children will be rewarded in the hereafter.

Positive perceptions. In this study, caregivers described how benefit finding and optimism assisted them in coping psychologically. One respondent explained how he kept his expectations concerning the survival of his child low, especially when the doctor said she could be disabled for life, even if she survives:

> I'm not that affected psychologically because when she was about to come into this world, the doctor said she wouldn't survive. She was drowning for 9 min, and her heart stopped. So, when she survived, I was very grateful.

He further admitted that he was not sad or devastated when he discovered his child would be disabled because his child's survival had already surpassed his expectations. This positive attitude assisted him in approaching the caregiving process. Additionally, he did not have any unrealistic expectations regarding his child's development.

Another caregiver echoed his sentiments:

> First, caregivers must be able to manage their own expectations—that a Down syndrome child will have limited ability, and sometimes, all they can do is support him or her emotionally and financially. We must acknowledge our weaknesses and sometimes rely on professionals.

He confessed that his role in caregiving was limited, and he did not have unrealistic expectations about his child and himself. He relied on professional support and expertise to guide his care of his child.

A female caregiver recounted:

> Actually, I was prepared way before she was diagnosed when I went on holiday with my family. When she refused to leave the pool after 4 h, I told my husband that we must manage our expectations of her and be prepared for any eventuality. We must accept; we don't want to be too down when the doctor diagnoses her. Plus, her autism is mild; there are other children with worse conditions than her.

She managed her expectations by having a positive outlook and being prepared for the worst. She downplayed the complexities of her child's autistic tendencies by telling herself that her child's condition was not as bad as that of other children with disabilities. By having a positive perception and outlook, she was ready to deal with her child's disabilities and hence did not see it as a burden.

Discussion

This study explored how a positive approach toward caregiving assisted caregivers of children with disabilities in managing their roles and expectations. It found that having a positive perception and outlook, which translates into benefit finding and optimism, was crucial for caregivers to navigate the treacherous waters of caregiving.

Most of the caregivers reported stress from managing their special role in the lives of their children with disabilities. Nevertheless, studies have shown that caregivers can demonstrate positive coping experiences and benefit from serving in this capacity (Hastings and Taunt, 2002). These positive adaptational outcomes can be described as optimism, benefit finding or positive reappraisal (Rini et al., 2004). These attributes have been linked to a higher quality of life for caregivers (Brand et al., 2014). Furthermore, focusing on these approaches helps them to tackle depression (Cheng et al., 2012; Halim et al., 2020) and promotes their well-being (Helgeson et al., 2006). Thus, these positive adaptational outcomes are important tools for caregivers of children with intellectual and developmental disabilities to use in coping with their challenging roles (Slattery et al., 2017).

Various studies support these findings (Slattery et al., 2017; Blacher and Baker, 2007; Kenny and McGilloway, 2007; Konrad, 2006; Hastings et al., 2005; Baker et al., 2005; Scorgie et al., 2001; Valentine et al., 1998). Post-traumatic growth is achievable when caregivers adopt the benefit-finding and optimism approach when caring for their children with disabilities (Konrad, 2006). The informants of the current study described their frustrations and difficulties in caregiving, but they also acknowledged that the process contributed to their personal growth. Informants also shared how enabling environments, such as appropriate working conditions and ample support, have helped them to alleviate some of their burden of care. In addition, studies have shown that caregivers of children with disabilities are more compassionate, patient and less self-entitled than caregivers of children without disabilities (Scorgie and Sobsey, 2000). Previous studies have shown that caregivers of children with intellectual and developmental disabilities have experienced enhanced personal growth from benefit-finding and optimism approaches (Slattery et al., 2017). Past studies have also acknowledged that female caregivers of children with disabilities were more directly impacted by the experience compared to male caregivers (Hastings et al., 2002).

Caregivers with a positive or benefit-finding mindset often experience enhanced relationships with other family members and individuals (Scorgie and Sobsey, 2000). In this study, informants felt that having special needs children brought their families closer and strengthened their bond and social support for the caregiver and their children.

According to a literature review by Beighton and Wills (2019), having children with disabilities leads to a better spiritual life. Caregivers are reported to have gained a better perspective on life, expanded social networks and an increased sense of purpose (Cheng et al., 2014; Scorgie and Sobsey, 2000). This finding is supported by the current study, where informants agreed that having children with disabilities increased their sense of purpose in life. Underpinning this is a belief in the religious dimension—namely, that these children are God-sent and that they, the caregivers, are called by God to be responsible for the children.

Studies have documented that having a positive outlook, such as optimism and benefit finding, is a key factor for successful caregiving. Caregivers explained how sharing their experience with others in a similar situation further boosted their positive outlook. A paradigm shift happened when they adopted a more positive approach to their caregiving process (Baker et al., 2005; Azman et al., 2021). However, further studies are needed to explore this intricacy.

In this study, the respondents explained that they managed their expectations to cope with the heavy and difficult responsibility of caregiving. They also adopted the gratitude approach and had realistic expectations of themselves and their children. This finding is consistent with that of earlier studies—namely, that a positive perception via benefit finding and optimism leads to better psychological and physical well-being and a better quality of life for caregivers (Brand et al., 2014; Helgeson et al., 2006; Baker et al., 2005).

Greater social support and services, as are already available in urban areas, must be given to caregivers from rural and low-income backgrounds. This will contribute to creating a system where caregivers from all walks of life are able to access support and services and where Malaysia can take further steps towards improving the social functioning of children with disabilities. In conjunction with Malaysia's Persons with Disabilities Act (2008), an efficient collaboration between agencies, such as the Department of Social Welfare of Malaysia and the Ministry of Health of Malaysia, can help caregivers better cope with their circumstances.

Crucially, the Malaysian government has a responsibility to enhance its social care support and assistance for caregivers of children with disabilities. As Malaysia has committed to ratifying the Convention on the Rights of Persons with Disabilities, it must prioritise and upgrade its services and training targeted towards caregivers. Improved and more accessible services and financial assistance are particularly important, especially for those from the low-income group (United Nations Convention on the Rights of Persons with Disabilities, 2006). Although benefit finding and optimism focus on individual caregivers and their children, additional efforts and support are needed to work towards removing societal barriers that prevent the access of children with disabilities to basic services, including education, health, transport, play and rehabilitation. It is also critical for caregivers to be recognised for their skills and insights on caregiving responsibilities for children with disabilities. Thus, it is imperative that caregivers be given an opportunity to be included in policy-making alongside government service providers to overcome the existing barriers within the sector. Ultimately, we do not want these children to be marginalised from society and seen as a burden, as they can potentially contribute to the nation's socio-economic development.

Conclusion

Benefit finding and optimism are fundamental elements in the caregiving process. This study's findings highlight the influence of these two factors on helping caregivers cope with the challenges of caring for their children with disabilities. Utilising optimism and benefit finding when caring for children with disabilities is therefore crucial, if not key, to sustaining the caregiving process and ensuring that caregivers and children with disabilities do not become depressed, overwhelmed or dejected in dealing with such a challenging issue. The key outcome is that by maximising their resources, caregivers developed greater insight into their role by attaching additional meaning and values to their caregiving responsibilities.

The findings of this study have practical implications. Policymakers and non-governmental agencies could play a more significant role in effectively supporting caregivers. Targeted interventions by stakeholders to support and facilitate caregivers in applying benefit finding and optimism in their caregiving can help them cope better with the physical and mental demands of being caregivers for children with intellectual and developmental disabilities. Additional advocacy efforts, especially for improved access to quality services for children with disabilities, are equally important in achieving this goal.

Data availability

The qualitative dataset can be viewed in the supplementary file.

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Author contributions

PSJS and AA: revised the main manuscript text and gave final approval for the version to be published, agreeing to be accountable for all aspects of the work, including investigating and resolving questions related to the accuracy or integrity of any part of the work. MIHMN: made substantial contributions to data collection, analysis, and critical revision for important intellectual content. SD and ACA: reviewed the manuscript for accuracy.

Competing interests

The authors declare no competing interests.

Ethical approval

Ethical approval was obtained from the Human Research Ethics Committee (JEPeM), Universiti Sains Malaysia (USM/JEPeM/19120969) before commencing research.

Informed consent

The authors confirm that informed consent was obtained from all participants.

Additional information

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