

A Description of the Psychological Well-Being of Parents Who Have Children with Special Needs at Slb Asuhan Kasih Kupang

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Abstract

This study aims to describe the picture of the psychological well-being of parents who have children with special needs and physical disabilities at the Asuhan Kasih Kupang special school. This study used 6 subjects with criteria determined by purposive sampling technique, namely parents who have children with special needs and physical disabilities. This study uses a qualitative method, with a data collection method, namely interviews. The data that has been obtained was analyzed using thematic analysis techniques and produced three main themes, namely, the process of acceptance, care, and social support. The psychological well-being of parents who have children with special needs and physical disabilities can be described through the ability of parents to accept the child's condition, parents try to develop effective parenting strategies according to their children's needs such as teaching children independent skills and providing positive affirmations to children, and social support from the environment such as emotional, practical and moral support. This study provides suggestions for parents to carry out various stress coping techniques such as carrying out spiritual activities to increase parents' feelings of gratitude, doing activities together with children, schools as a place for children to learn can continue to establish good communication so as to reduce parental anxiety.

Keywords: Psychological Well-being, Parents, Disabled.

Introduction

The presence of children in a family is considered a gift that brings happiness and hope for the future [1]. However, not all parents are blessed with healthy and normally developing children; some have children with special needs, including children with disabilities [2].

Children with special needs have different characteristics from children in general and are classified into several categories, including disabilities. Based on data from the Central Statistics Agency the number of children with special needs in Indonesia is quite significant, including in East Nusa Tenggara (NTT). In NTT, the number of children with special needs reaches 17% of the total population, with 3.5% of them being children with disabilities. This data shows that many families in NTT face similar challenges in raising children with special needs.

This study was conducted at the Asuhan Kasih Kupang Special School (SLB), which provides inclusive facilities for children with disabilities, such as wheelchair ramps and accompanying teachers. These facilities are very helpful in meeting the special needs of children, but parental anxiety remains. Although the facilities are quite good, parents still feel anxious about their children's conditions at school. One of the parents interviewed expressed his anxiety even though there were adequate facilities, and continued to accompany his child to school to reduce his anxiety. This shows that physical facilities alone are not enough to overcome parents' emotional concerns.

Physically disabled, or children with physical limitations, experience various difficulties in carrying out daily activities [3]. This condition causes psychological stress for parents, including feelings of panic, shock, and shame [4].

According to psychological well-being involves a balance between negative and positive impacts, as well as the ability to manage stress and accept various aspects of self-identity [5]. added that psychological well-being reflects individual satisfaction and happiness, involving acceptance, affection, and achievement. Social support provided by the family can be in the form of emotional support, information support, appreciation support, instrumental support. Conversely, lack of social support can hinder their well-being, increasing the risk of stress, anxiety, and depression [6].

This study aims to describe the psychological well-being of parents who have children with special needs and physical disabilities at SLB Asuhan Kasih Kupang. By understanding their psychological condition, it is hoped that effective ways can be found to support them in this important role [7].

Method

The type of research used in this study is a descriptive qualitative research type that aims to describe the picture of the psychological well-being of parents who have children with special needs and physical disabilities at SLB Asuhan Kasih Kupang. The data collection technique used semi-structured interviews with 5 parents who have children with special needs and physical disabilities as participants. The data analysis technique used thematic analysis which was arranged into several themes and sub-themes based on each participant's answer, then analyzed based on the theory of psychological well-being dimensions put forward by and supported by other studies. This research was conducted in Kupang City, East Nusa Tenggara. The participant selection technique in this study used purposive sampling, namely biological parents (mother and/or father) who have children with special needs and physical disabilities who attend elementary school at SLB Asuhan Kasih with a classification of moderate and mild special needs, biological parents who live under the same roof as their children, residing in Kupang City, willing to sign informed consent as research subjects [8].

Result

Acceptance process

This acceptance process also reflects the dimensions of self-acceptance and personal development based on the theory of psychological well-being dimension development according to which involves the ability of parents to see and accept all aspects of themselves and their children's physical limitations including good and bad qualities of life in the past and present, and parents also have good personal growth because of the self-acceptance they have, allowing parents to gradually have an increase in gratitude over time [9]. a. Tragic situation This tragic situation is also related to theory of developing dimensions of psychological well-being in the dimension of life goals, namely that someone who does not have a sense of meaning in life has a low score in the dimension of life goals in his theory of psychological well-being. This was expressed by the participants as follows:

- “Awalnya kayak tidak menerima, karena waktu keluar dalam kandungan tuh kan semuanya normal-normal saja dari bapak juga dia sulit menerima dan kecewa juga.” (MS)
- “Syok pastinya sedih juga dan sulit menerima awalnya, cuman kan itu pemberian Tuhan jadi harus banyak bersabar

dan bersyukur.” (A)

- “Kalau rasa sedih ya sedih tapi kenyataan yang ada yah harus kita terima, mungkin sudah takdir juga.” (YK)
- “Ya kalo awal-awalnya memang tidak terima, syok juga, kek sedih dia divonis juga dari dokter kalo dia mengalami kelumpuhan saraf otak.” (IR)
- “Jujur ya, saya sebagai seorang bapak ya saya sangat kecewa, saya sangat sakit pokoknya campur aduklah tidak menerima juga.” (MR)

Feelings of Gratitude

The feeling of gratitude experienced by parents is also connected to dimension of psychological well-being, namely self-acceptance, where the feeling of gratitude reflects the ability of parents to accept conditions and situations that cannot be changed, both those that have occurred in the past, but still feel valuable and meaningful in their lives. This was expressed by the participants as follows:

“Kita tidak bisa mengukur berapa lama waktu untuk terima, tapi kita jalani saja seiring berjalannya waktu dan syukuri saja pemberian Tuhan ini.” (MS) “jadi untuk repot yah pasti tapi kita harus selalu jalani dan syukuri.” (MS) “Tidak, karena saya percaya kalau ini titipan dan anugerah Tuhan jadi harus kami syukuri dan terima apa adanya.” (A) “Sekarang saya bersyukur punya dia, memang kerepotan, banyak hal yang dia tidak bisa tapi itulah titik Tuhan menguji kita dan yah saya bisa lewati sampai titik ini.” (IR) “Sekarang sudah bersyukur saja, jadi ya harapan saya sekarang itu minimal dia sudah bisa jalan lah biar kehidupannya tidak terlalu sulit lagi.” (MR)

“Ya lebih butuh usaha dan waktu ekstra untuk membesarkan dia sejauh ini dan kami bersyukur untuk itu.” (NK) “Terus terang saya sangat bersyukur dengan Tuhan, walaupun dia berkebutuhan khusus tapi saya sangat sayang dia dan saya juga setiap hari selalu berdoa dan berharap kepada Tuhan agar anak saya juga bisa jalan dan lebih baik lagi biar kalau kita sudah tidak ada lagi, dia sudah bisa mandiri.” (MR)

Parenting This parenting is in line with the dimensional theory proposed bynamely about independence and positive relationships with others. In this context, the dimension of independence refers to the ability of parents to feel competent and effective in caring for their children with special needs so that parents need to develop appropriate strategies and support to help their children develop independence [10-13].

Challenges for Parents of Children with Disabilities

The challenges of parents with special needs and physical disabilities are also connected to the theory owned by namely the dimensions of independence and personal growth. Independence involves the ability of parents to manage their own lives and make decisions more freely. This was expressed by the participants as follows:

“Mandi saja kita harus mandikan sampai usia SMP dan aktivitas kecil sehari-hari kayak pakai sepatu juga itu kita harus bantu.” (MS) “Kita dulu kesulitan dalam membawa anak saya berobat karena tidak memiliki kendaraan, jadi kita harus naik angkutan umum sambil menggendong anak kami dengan jarak pengobatan yang begitu jauh”. Apalagi semenjak suami mengalami

stroke pada tahun 2007 itu kita sudah tidak pernah berobat lagi.” (A) “Tantangannya yaitu kita harus selalu mengawasi dia terus karena kadangkala dia bisa tiba-tiba jatuh dari kursi dan terguling. Terus yang kedua itu tantangan dari luar rumah, kayak orang omong-omong tentang dia kayak ini tidak bisa buat ini itu yang buat jadi pikiran, tapi yah kita yang jalani jadi mereka tidak tau apa yang kita rasakan.” (YK) “Misalkan kalo rawat dia, dari dia kondisi 1-2 tahun mungkin kita masih bisa bawa keluar gendong bawa kemana-mana, tapi disaat dia bertambah usia, bertambah berat badan, ini juga kayak kita urus dia dengan dia punya kondisi begini, mau bawa ju sudah sulit, misalkan dia mau dibawa ke tempat permainan begitu, dulu kan lebih mudah, tapi kalo sekarang kan kita susah bisa bawa dia kalo tanpa kursi roda.” (IR) “Kalau dia sudah mulai sakit itu kami sudah mulai stress karena pasti dia akan hela dan badannya kaku trus sarafnya terganggu.” (NK) “Kalau dari saya sih kalau dia sakit tu nanti saya kerja di kantor su tidak konsen dan tidak fokus lagi itu, maksudnya dia kan beda dari adik-adiknya yang lain to jadi butuh perawatan ekstra untuk jaga dia jadi otomatis kita harus kasih perhatian lebih ke dia.” (MR) Participants who received negative stigma from neighbors because the participant had a child with special needs which made the participant feel hurt and resigned. This was expressed by the participant as follows: “Awalnya mereka mengolok waktu kita masih di rumah yang lama, adik laki-laki saya sering membela juga karena yah kondisi ini juga bukan kami yang Minta.”^b Stress/pressure This feeling of stress is also related to the theory of psychological well-being developed by in the dimension of life goals, namely someone who does not have a sense of meaning in life in the future or does not have confidence in the future, has a low score in the dimension of life goals in the theory of psychological well-being. This is based on the pressure or stress obtained by parents, stress itself arises because parents lose independence and control over their lives because a lot of time and energy is spent on raising and caring for their children. This was expressed by the participants as follows: “Kita stress juga, tapi mau stress juga tidak ada yang bantu jadi yah kita cuma bisa ikhlas dan terima saja dan selalu berdoa, apalagi semenjak bapaknya sakit ini jadinya saya yang urus semuanya, mulai dari kasih makan, harus disuap satu-satu.” (A) “Memang kita jaga seperti ini juga kita merasa tertekan seperti mau marah juga percuma, jadi dia juga banyak mau makanya kita juga harus selalu mengikuti apa maunya dia karena kalau tidak pasti dia ngambek.” (YK) “Kalo tekanan yang terlalu ini ju tidak sih, stres juga ya saat itu saja kalau kelelahan sa kayak kita hadapi ini kita kayak bilang tidak terima, kenapa dia punya anak begini, tapi kembali juga nanti kita bilang eh jalani saja sudah pokoknya berusaha ikhlas saja.” (IR) “Secara manusiawi ya pasti stress nya ada tapi saya tidak dibawa itu stress karena saya pikir ya mungkin ini ujian dari Tuhan juga kan. Prinsip saya ya apa yang kamu tabur ya itu yang akan kamu tuai. Jadi kalau saya pikir saya dibawa stres nanti siapa yang mau jaga mereka lagi, siapa yang cari nafkah lagi.” (MR) “Kalau dari saya juga stres pastinya, jadi kalau pas dia sakit tuh kan kita pikiran tapi saya tetap usaha untuk berobat dia sendiri sebisa saya, baik itu obat yang dikonsumsi maupun saya urut dia.” (NK) Participants have anxiety about the future of their children where parents will not live forever with their children so they are afraid that their children will not be able to be independent in the future. This was expressed by the participants as follows:

“Khawatir, karena dengan keterbatasan fisik itu pasti orangtua

pikiran. Nanti dia berkeluarga seperti apa, apakah dia punya pasangan betul-betul menerima dia, sayang dengan dia.” (MS) “Iya itu pasti khawatir, karena kalau besok-besok kita sudah mati ini nanti siapa yang rawat yang jaga mereka lagi, tapi untungnya sekarang dia sudah cukup mandiri juga. Tapi sekalipun ada saudara, ada paman dan bibinya tapi kan cara mereka merawat dan menjaga tidak akan sama seperti kita. 1 2 hari mungkin orang akan sabar tapi kalo lama-lama kan pasti mereka akan cape juga, harap bantuan orang juga pasti mereka akan bosan.” (IR) “Iya saya punya kecemasan pastinya, kalo sekarang dia masih butuh, misalkan mau ke wc dia masih butuh bantuan orang, dia belum bisa mandiri, kalo untuk makan dia bisa pelan-pelan.” (YK) “Kalau kecemasan ini jelas ada ya karena banyak hal yang dia masih ketergantungan kan dengan kita, tapi saya tetap pantang menyerah untuk bantu ajar dia dan motivasi dia untuk hal kecil-kecil yang mungkin dia bisa buat. Jadi saya memang cemas tapi saya berharap suatu saat dia bisa melakukan banyak hal begitu.” (NK)

Coping Stress

In carrying out coping strategies, parents need to develop self-acceptance, build positive relationships with others, maintain autonomy, master their environment, find a purpose in life, and continue to grow personally, as explained in Ryff's psychological well-being theory which includes 6 dimensions. This was expressed by the participants as follows:

“Diam, tarik napas panjang dan biarkan semua berjalan tapi baiknya orang rumah itu sudah paham jadi kalau saat saya sudah diam itu nanti 65 mereka yang ambil alih. Terus kalau cape juga yah saling cerita dan berbagi pikiran dengan suami juga, jadi kita saling suportif.” (MS) “Saya sholat, ambil wudhu terus baca al-quran.” (A)

“Tetap tenang dan mungkin berdoa saja sih supaya jangan terlalu terbawa suasana.” (IR)

Social Support

This social support is in line with the theory put forward by namely the dimensions of independence, positive relationships with others and mastery of the environment. Family The existence of social support from the family allows parents to develop themselves and achieve their maximum potential to achieve life goals and have self-acceptance of their child's condition and of themselves, in accordance with the dimensions of independence and self-acceptance put forward by [14-18]. This was expressed by the participant as follows:

“Kita bersama-sama rawat, kalau saya kerja berarti bapa yang jaga, begitu pula sebaliknya, ada juga opa dan oma mereka yang turut membantu menjaga secara bergantian juga.” (MS)

Community Environment

Based on the theory of psychological well-being dimensions from Ryff (1989), participants already have good environmental mastery values because participants have a sense of mastery and are competent in managing the environment. This was expressed by the participants as follows:

“Alhamdulillah tetangga tidak mengejek atau mengolok, mereka malah memberikan dukungan positif kepada kami.” (A) “Lingkungan kami selalu memberi respon positif terhadap kami. Malah tetangga kami yang nonmuslim itu sangat akur dengan

kami.” (A) “Kalau tetangga sekitar menerima keberadaan dia dengan baik, karena dia sering keliling juga dengan menggunakan kursi roda bersama saya.” (YK) “Kalo stigma negatif kayaknya dari tetangga tidak ada sih, malah justru mereka kalo liat malah mereka kasi saran begitu, kayak kasi saran berobat kesini kesitu lah ke (F).” (IR) “Selama ini tidak ada sih, malahan tiap kali kita lewat dengan (N)tu mereka selalu puji dia dan kasih dia motivasi begitu.” (MR) “Bahkan kayak saya story dia di whatsapp tu mereka komenya baik semua, bilang tambah cantik ya, pokoknya komen positif lah.” (NK)

School Environment

Social support at school is related to the theory of dimensions of psychological well-being according to namely positive relationships with other people, parents have warm and trusting relationships through good communication with teachers, allowing parents to have low levels of anxiety, because they already have trust in teachers at school [19].

“Anak-anak dekat dengan guru, sangat dekat sehingga saya sebagai orang tua merasa anak aman selama di sekolah meskipun dengan kondisi keterbatasan fisik anak (F).” (IR)

Discussion

This acceptance process refers to the attitude of not accepting the child's condition, understanding, and finally accepting the condition of the child with special needs and physical disabilities. Participants expressed that accepting and letting go of their child's existence did not take years, because participants had learned to live and be grateful as time went by.

This acceptance process also reflects the dimensions of self-acceptance and personal development based on the theory of developing dimensions of psychological well-being according to which involves the ability of parents to see and accept all aspects of themselves and their children's physical limitations including good and bad qualities of life in the past and present [20].

Participants have the view that being a parent with a child with special needs and physical disabilities is a tragic situation when you first find out. Tragic circumstances refer to the sad situation for participants who have children with special needs, namely physical disabilities.

Participants viewed that feelings of gratitude were felt when they saw their children had developed and this sense of gratitude was also obtained over time by remaining patient and accepting things as they are because everything is a gift from God. stated that parents who have children with special needs with high gratitude are able to realize that everything that happens in their lives is a gift from God. Participants also revealed that caring for children with special needs will drain a lot of energy and time, therefore parents really need something called having a positive relationship with other people, be it from family members and friends, it can be in the form of emotional support or practical support.

The challenges faced by parents of children with special needs are very diverse, it can be from within the family itself or from the outside environment. Participants revealed that having a child with special needs has great challenges and hassles be-

cause they have to give a lot of time to take care of their children which makes children continue to depend on their parents because they have limited abilities so that it greatly affects the physical aspects of the participants which results in fatigue for the participants. In addition, challenges in the form of social aspects such as negative stigma and discrimination were also felt by one of the participants. revealed that the difficulties and challenges faced by parents of children with special needs are the amount of time that must be spent, so that it will hinder parents from developing their potential, working, earning income, or activities needed for the welfare of the parents themselves. This is also in line with the dimensions of the theory owned by namely the dimensions of independence and personal growth. The difficulties and challenges faced by parents who have children with special needs make parents more vulnerable to disruption of their psychological well-being, one of the factors is experiencing stress.

Participants expressed that the stress they experienced caused participants to always think and become tired and participants also had pressure in the form of anxiety about the future of their children which made it difficult to interpret future life goals for their children. define parenting stress as being seen from excessive anxiety related to the interaction and role of parents with their children. Based on the participants' answers, there is a dimension that is primarily related to the theory of psychological well-being developed by in the dimension of life goals, namely someone who does not have a sense of meaning in life in the future or does not have confidence in the future, has a low score in the dimension of life goals in the theory of psychological well-being.

Based on the literature research conducted by the author, the results were found to explain that parents of children with special needs experience pressure in accepting the condition of children with special needs in the care process. This is different from the results of the research findings which explain that one participant did not feel pressure when he found out about the condition of the child with special needs because the participant already had good acceptance. The acceptance was obtained by the participant because he already had a high sense of gratitude and social support from the family, also from the beginning knowing that his child had physical limitations. There were several obstacles experienced during the research, namely the difficulty of arranging interview schedules because each participant had different working hours.

Conclusion

Overall, this research shows that the psychological well-being of parents who have children with special needs who are disabled is influenced by the parents' ability to accept the child's condition, develop effective parenting strategies, and receive adequate social support. Through a process of acceptance, nurturing, and social support, parents can achieve better psychological well-being despite facing various challenges.

Suggestion The advice that can be given is through the process of acceptance, care, and social support, parents can achieve better psychological well-being despite facing various challenges, and parents are expected to strengthen gratitude and do activities together such as doing hobbies together with children and

Usually every small development in children by giving positive affirmations to themselves and those closest to them. For school institutions, it is expected to increase active communication with parents of all students with special needs, not only physically disabled. So that it helps reduce parental anxiety about the condition of children at school. Participants are also advised to manage stress and anxiety through spiritual coping techniques such as praying and praying together to increase emotional closeness with children.

Further researchers suggest that research be conducted on the topic of the influence of spiritual care on the psychological well-being of parents who have children with special needs.

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