Validation Of "Caregiver Berdaya" Module to Optimize The Independence of Disabled Individuals

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ABSTRACT

Disability is complex. The problems experienced by disabled people can be categorized into two, namely internal and external problems. The internal problems include low independence and low self-esteem. In addition, problems such as emotional control, environmental interactions, and communication with other people are also commonly encountered by disabled people. This study aimed to create and perform a content validation of the "caregiver berdaya" module to optimize the independence of disabled individuals. The present research used a content validity by professional judgment involving 6 experts. The results of the Aiken's V analysis on each aspect showed a V score between 0.825 – 0.90625. Meanwhile, in a percentage, the content validity of the module was 89.50%, meaning that the module has a good content validity and feasible to be used for the next stage, i.e., an empirical validation.

Keywords: caregiver, disabilities, module

Introduction

Many terms are used to refer to special needs, such as disability, impairment, and handicap. According to the World Health Organization (WHO), the definition of each of the terms is as follows: Disability is a restriction or lack of ability (resulting from impairment) to perform activities in the manner or within the range considered normal; this term is usually used at the individual level. Impairment is a loss or abnormality in psychological or anatomical structure or function: this term is usually used at the organ level. Handicap is an individual's disadvantage resulting from an impairment or disability that limits or prevents the fulfillment of a normal role for the individual. Although the terms impairment, disability, and handicap are sometimes used interchangeably, the three of which are not the same (Desiningrum, 2016).

Disability occurs when a disorder restricts one's ability to perform certain tasks (for examples walking, seeing, reading). According to Law of the Republic of Indonesia Number 8 of 2016, disabled people are any person who has physical, intellectual, and/or sensory restrictions for a long period of time in making interactions with the environment and may encounter obstacles and difficulties to fully and effectively participate with other citizens in accordance with equal rights. In addition, the World Health Organization (WHO) mentions that there are three criteria for disability, namely: (1) problems with physical or mental functions, (2) restrictions such as hearing, walking, etc., (3) difficulties in performing daily activities, such as work or activities in the social environment (Desiningrum, 2016).

Disability is complex. The problems experienced by disabled people can be categorized into two, namely internal and external problems. The internal problems include low independence and low self-esteem. In addition, problems such as emotional control, environmental interactions, and communication with other people are also commonly encountered by disabled people. The external problems may come from the family or the surrounding community, i.e., lack of social support for disabled persons. Families are the main support for disabled people, especially for disabled children.

Family as a microsystem for disabled people plays a crucial role. Nevertheless, the family as a caregiver also faces its own challenges. Based on the results of an initial interview with the Director of Pinilih Disability Family Forum, it was found that parents with disabled children at Pinilih Disability Family Forum feel guilty over the restrictions faced by their children, causing them to have overestimation, loss of self-esteem, guilt, confusion, and embarrassment, so they prefer not to be engaged in social activities. The restrictions experienced by disabled children cause these children to be more dependent on their parents than normal children. The dependence of the disabled children then creates stressor for their parents (Musatto, 2004; Desiningrum, 2016).

On the other hand, families who have disabled children who live in rural areas, in which most of the population have low education levels, lower economic status, and limited access to information, tend to face various stigma (Neely-Barnes & Dia, 2008). Some examples of the stigma faced by disabled children are: they are considered unable to be independent, they always need help from the surrounding environment (Diwan, Chovatiya, & Diwan, 2011), and they burden the family. Such stigma has a psychological effect on parents as the caregiver of disabled children, causing them to be ashamed of the children’s condition (Setyaningrum & Nur’aeni, 2019).

Raising children does require various resources; parents with disabled children even need much more resources in terms of finance, education, treatment, and health (Zahaika, et al., 2021). Parents with disabled children also face greater challenges than parents with non-disabled children because disabled children need more attention and support in terms of independence such as eating, moving, wearing clothes, maintaining personal hygiene, and learning (in this case understanding instructions). This is likely to cause parents to have problems with sibling, education, and lack of time with other family members (Norliza, Azmi, Liana, Ainnunazlee, Zarina, and Zaim, 2019).

Caregivers are those who help disabled individuals or patients who are usually families or people who care about them. Spouses, parents, guardians, children, or relatives who take care of disabled family members encounter burden of care such as physical or psychosocial problems, difficulties, or impacts. Several things that affect the caregiver's burden are the needs of the disabled individuals (daily activities or medication), type and severity of symptoms, patient disability, relapse, or the caregiver's financial ability. This brings a negative effect not only on the caregiver but also on the patient, other family members, and the health care system. The caregivers will experience physical, emotional, and financial problems, which directly affect the care of the disabled individuals (Rafiyah, 2011; Meilani & Diniari, 2019).

In addition to family problems, disabled people often face discrimination, where their rights cannot be properly fulfilled. This is in line with the findings of a study that the social welfare problems faced by disabled people from low-income families in relation to the fulfillment of their rights showed relatively similar characteristics and difficult conditions, in the context that the disabled people are at a great risk of various forms of discrimination and neglect of rights. This includes the nonfulfillment of the need and accessibility of disability rights that they should be entitled to as citizens, including the right to social rehabilitation that allows them to achieve independence and participate in all aspects of community life. Nine problems related to the fulfillment of disability rights in poor families were found, namely: 1) the right to education, 2) health, 3) employment, 4) social security, 5) information and communication, 6) mobility, 7) emergency situations, 8) sports, culture, recreation, and entertainment, and 9) equal legal and political rights. The fulfillment of and access to the nine rights for disabled people have not been fully achieved (Cahyono and Probokusumo, 2016).

Based on the abovementioned problems, this research tried to formulate and validate the Empowered Caregiver Module which was developed based on an understanding of humans in the indigenous context, so the research results expectedly truly reflect pure understanding of Indonesian humans and can be applied according to the context of the Indonesian culture, instead of only an adaptation of theories developed in other countries.

Several studies have developed caregiver training modules that are limited to one skill, so caregivers are not empowered to be able to assist the development of disabled individuals in certain period of time as in a study by Kasari, et al. (2020) which developed a caregiver-mediated intervention (CMM) on autism caregivers where the intervention focuses on providing training for caregivers to assist children with autism. In addition, Fieldston (2013) focused his research on the effectiveness of education/ knowledge-based interventions for caregivers for children aged 7 months to 5 years who have physical illness, while Kasari & Wong (2010) developed interventions for caregivers for children (toddler, aged 21-36 months) with autism in making interactions using the "joint attention" method in children.

In Indonesia, however, a model for a comprehensive module that provides not only knowledge and skills to caregivers, but also psychological support to caregivers has not been available. Therefore, this study tried to develop a model based on the understanding of humans in the indigenous contexts, so the research results expectedly truly reflect pure understanding of Indonesian humans and can be applied according to the context of the Indonesian culture, instead of only an adaptation of theories developed in other countries.

In conclusion, this study aimed to create and perform a content validation of the “caregiver berdaya” module to optimize the independence of disabled individuals. The research expectedly can contribute to producing a comprehensive module that can empower caregivers in assisting the development of disabled individuals

Methods

The empowered caregiver module was developed based on several stages. The first stage was to assess the research subjects to explore various constructs, including the psychological conditions of the caregivers for disabled individuals, characteristics, and development of disabled individuals, to design an intervention stage to be described in the empowered caregiver module. The assessment method used observation and semi-structured interviews. Based on the results of the assessment, it was found that the main problem was independence, so the empowered caregiver module was developed in a way that expectedly could help disabled individuals become more independent. To achieve this goal, this module contained various materials, namely group counseling, psychoeducation on disability and caregivers, and training on stress management, assertive communication, and independence.

The materials of the module were divided into three sessions, namely group counseling, psychoeducation, and training with a duration of 7 hours 30 minutes. All the procedures were carried out indoor in three sessions. In the first session, participants were given the opportunity to share their problems, and interpret them together with the facilitator. In the second session, participants were given knowledge/information about the definition of children with special needs and caregivers, their problems, and things that can be done to cope with them. In the third session, participants were trained to apply effective communication techniques to children with special needs, so as to minimize the various problems that usually arise.

This was a descriptive study of the module by conducting a content validity of the empowered caregiver module. The content validity involved experts who had relevant competencies (Arip, Bakar, Ahmad & Jais, 2013; Wulandari, 2018) to conduct professional judgment (Supraktiknya, 2014; Wulandari, 2018). This study involved six experts for the professional judgment to examine and assess whether the concepts, principles, and techniques given in the module could help achieve the predetermined objectives. The six experts were selected based on their interests, competencies, and experiences related to disabled individuals.

Results

There are two important criteria in developing a module, i.e., content validation and the contribution of the module after tested (Noah & Ahmad in Rozubi & Li, 2015; Sugiyono, 2015; Wulandari, 2018). Russel & Johanningsmeier (1981) and Wulandari (2018) mentioned that the development of a module requires a content validation process and limited trials involving real subjects. This study focused on the content validation of the module before limited trials involving real subjects is carried out.

The research results were calculated using the Aiken's V formula to find the validity coefficient in each session. The following table presents the results of the content validation in each aspect using the Aiken's V formula:

Table 1. Results of Content Validation of “caregiver berdaya” Module Using Aiken’s V for Each Session

No	**Session**	**Validity Coefficient**
1	Counselling	0.825
2	Psychoeducation	0.875
3	Training	0.90625

Based on the assessment criteria using index V, the content validity score ranged between 0.825 - 0.90625 (see Table 1). It can be concluded that all the sessions in the “caregiver berdaya” module had a good content validity and feasible.

Table 2. Calculation Results of Content Validity of Module

Session	**Expert Judgement**					
	A	B	C	D	E	F
Counselling	5	4	4	4	4	4.8
Psychoeducation	5	4	4	4	5	5
Training	5	4	5	4	5	4.75
Total	15	12	13	12	14	14.55

Table 3. Results of the Overall Content Validation of the “caregiver berdaya” Module Using Percentages

No	**Expert**	**Percentage**	**Status**
1	A	100%	Highly Feasible
2	B	80.00%	Feasible
3	C	86.67%	Highly Feasible
4	D	80.00%	Feasible
5	E	93.33%	Highly Feasible
6	F	97.00%	Highly Feasible
Average		**89.50%**	**Highly Feasible**

To assess the overall content validity score of the module, the raw data were calculated using the formula: the total score given by an expert (x) divided by the total score (y). This calculation resulted in the validity of the research module, i.e., 89.50% (see Table 3). Based on the feasibility criteria of the content validity by Slavin (Ayriza, 2008; Arip et al., 2013; Wulandari, 2018), a validity score of 70%-80% (see Table 3) is categorized as feasible, and a validity score of 85%- 100% (see Table 3) is categorized as highly feasible. Therefore, it can be concluded that the "caregiver berdaya" module had a good content validity and feasible.

Discussions

A module is a learning package that contains a concept or material (Russell and Johanningsmeier, 1981; Wulandari, 2018). The present study aimed to develop and validate the contents of a psychoeducational training module which can be used, at a later stage, to improve caregiver skills in empowering disabled individuals to become more independent. A good module should have a good content validity (Russell & Johanningsmeier, 1981; Ahmad et al., 2008; Wulandari, 2018). In fact, the content validity referred to in this study was the conformity of the module with the contents that should be contained in the module.

Both the overall validity of the empowered caregiver module and the validity of each session in the module obtained good results. There are three main sessions of this module, namely counseling, psychoeducation, and training. In the counseling session, this module focuses on providing opportunities for participants to catharsis their daily activities. This counseling session is expected to be a good start for participants in seeking a stable condition to follow the next session.

In the psychoeducation session, this module focuses on providing material related to how to build good communication between participants as caregivers and patients. This psychoeducation session is expected to be a bridge between the participants' understanding and the training objectives in the next session. Finally, the training session. In this session, the module focuses on the application of good communication patterns between caregivers and patients.

The validity coefficient of each session of the module ranged between 0.825 – 0.90625. Azwar (2012) and Wulandari (2018) showed that a validity coefficient of 0.5 is acceptable and considered satisfactory. The overall content validity of the module was 89.50%. A content validation is categorized as high if the percentage is greater than 70% (Ayriza, 2008; Tuckman & Waheed in Arip et al., 2013; Wulandari, 2018). This means that the content validity of the empowered caregiver module was good and there was a conformity between the materials contained in the module and the objectives of the module.

The content validity score of the module was influenced by the stages taken by the researchers in developing the module. Russell and Johaningsmeier (1981) and Wulandari (2018) stated that there are six interrelated stages in designing, developing, and validating a learning module, namely determining the specific goals or objectives of the module, determining the appropriate competency measurement instrument, determining the characteristics of the subjects, determining the learning designs and methods, conducting experiments on the subjects, and assessing the learning process. The empowered caregiver module was developed by referring to the first, second, fourth, fifth, and sixth stages of a learning module development according to Russell and Johanningsmeier.

The theoretical contribution of this research is for the development and validation of a module to empower caregivers for disabled individuals based on the psychological needs of the caregivers, to develop the independence of the disabled individuals.

The practical contribution of this research is to produce a module that can practically help develop the independence of disabled individuals through empowered caregivers who attend all the sessions of this empowered caregiver module.

Conclusion

This study has developed a module with content validity which can then be applied to caregivers for disabled individuals. In the next stage, this module expectedly could be one of the solutions to the empowerment of disabled individuals through caregivers.

To meet the criteria as a good module, namely conformity with the objectives of the module, it is recommended for future researchers who will use this module to use it according to the existing stages.

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