

CHAPTER TWELVE

PARENTSKNOWLEDGE OF HEALTH EDUCATION: DETERMINANT FACTOR FOR WELLNESS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

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Introduction

One of the most tedious services is the provision of care for persons with developmental disabilities. Mere observation will revealed that there are several persons with severe developmental disabilities in Nigeria. However, most of them are cared for by their parents and family members at home while others reside in home/schools or centres. Observation has suggested that poor health of the caregivers can contribute to poor care service provision, and this is one of the main reason parents look for out-of-home placements for persons with these conditions. The health of parents is very significant in determining the quality of care provision for persons with disabilities generally. Study by Zahaika, et al. (2021) on challenges facing caregivers of children with disabilities during Covid-19 in Palestine revealed that majority (88.5%) of the caregivers felt physically exhausted, about (75.4%) had decreased living standards, and (86.2%) indicated that caregiving is taking their strength.

Disability is a complex challenge that greatly limits the performance of daily life activities and the ability to integrate with individuals. It poses burden to the person as a result of the inability to perform one or more of the functions that are essential in daily life. Disabilities occur as a result of several reasons which may be an injury, congenital abnormality, genetic factors or environmental problems. The primary caregivers to individuals with disabilities are their parents and immediate family members, by facilitating their daily activities. Good health of individual with developmental disability is an important factor in the provision of quality education for them as unhealthy learner cannot learn effectively. May and Kennedy, (2010) had observed that the individual's quality of life and ability to function objectively is premised significantly on his/her health status.

Developmental disabilities are those disorders that originated between ages zero to twenty-two (0-22 years). These disorders affect the ability of the individuals to live independent life, thereby subjecting the affected persons to depend on others for everyday daily living activities, such as eating, bathing, general grooming and

many more. Among conditions under developmental disabilities include intellectual disability, Autism Spectrum Disorders, Down syndrome, Asperger syndrome, Spinal Bifida, Cerebral Palsy, Hydrocephalous, Attention Deficit Hyperactivity Disorders and Microcephalous among others (Pinals, Hovermale, Mauch et al, 2021). Lack of ability of ability to live independent life by individuals with developmental disabilities has overriding effects on their wellness and that of their parents who serve as primary caregivers.

Wellness is a day-to-day activities that is associated with choice, action and intentions in the pursuit of optimum state of well-being and health. It is about the overall health of an individuals which incorporates several dimensions that can work in harmony and far beyond physical health alone. The Global Wellness Institute (2000) explained that wellness involves action of choice, activities and lifestyles toward a complete health. Key tenets of wellness as ancient practices include preventive and holistic health for individuals. However, wellness has evolved in the present days to include spiritual, diet, self-help, fitness, self-care and nutrition practices (Global Wellness Institute, 2000). Enhancing wellness in human can only be achieved through effective health education.

Health education is a process of educating people about wellness which encompass social, physical, intellectual, emotional and spiritual health (McKinze, et al. 2009). Donatelle, (2009) also explained that health education is the way by which people learn the behaviours and manner for conducive promotion, restoration and maintenance of personal health. It is the combination of planned learning experiences based on sound practices that provide individuals the opportunity to gather information and the skills necessary to make quality decisions for sound health. World Health Organization (1998) also defined Health Education as “comprising of consciously constructed opportunities for learning, involving some form of communication designed to improve health literacy, including improving knowledge, and developing life skills which are conducive to individual and community health. It also fosters confidence, motivation and skills that will encourage needed actions to improve personal and community health. Knowledge of health education by the parents would allow for the improvement of health condition of parents and automatically affects care provision and by extension, increase the overall well-being of individuals with developmental disabilities (Raina et al. 2007).

The thesis statement of this paper therefore focused on some thematic areas such as categories of developmental disabilities, challenges facing parents of children with developmental disabilities, wellness, rationale of knowledge of health education for care-givers and children with developmental disabilities, benefits of health education knowledge to the individuals, programs of health education for parents of children with developmental disabilities, implication of the article to special education, conclusion and suggestions.

Categories of developmental disabilities

Institute of Medicine (US), Committee on Nervous System Disorders in Developing Countries (2001) described developmental disabilities to include functional deficit as a result of disorders of nervous system development which appears at early stage of child growth resulting in failure to attain developmental milestone and inability to perform in some domains such as hearing, vision, behaviour, speech, motor performance and intellectual functioning. Though, there are specific types of developmental disabilities, most of them demonstrate significant level of cognitive impairment (intellectual disability). Major categories of developmental disabilities include but not limited to the following:

Cognitive Disabilities:This includes intellectual disability and specific learning disabilities. Intellectual disability is defined as sub-average intellectual functioning (intelligence quotient [IQ] below 70), with by deficits in adaptive behavior. Specific learning disabilities is as a result of impairments in one or more of the specific “processes of spelling, speech, reading, language, arithmetic or writing which may originate from cerebral dysfunction. Other associated conditions to cognitive disabilities include Down syndrome, fetal alcoholic syndrome and micro cephalous (Institute of Medicine, 2001).

Motor Disabilities:Motor disabilities include limitations in the ability to walk and in using upper and lower limb. Motor disabilities can also affect swallowing and speech. Childhood motor disabilities can include cerebral palsy, which originates from damage to developing brain motor tracts; paralysis resulting from conditions such as poliomyelitis and spinal cord injury; acquired and congenital abnormality of the limbs; and progressive disorders, such as spinal muscular atrophies and muscular dystrophies. The severity of the motor disabilities can range from mild to profound. Among other related conditions to motor disabilities are spinal bifida and hydrocephalous (Institute of Medicine, 2001).

Behavioral Disorders:Developmental disabilities underbehavioral disorders include but not limited to Attention Deficit Hyper Activity Disorder (ADHD), Attention Deficit Disorder, emotional and behaviour disorder. These disorders can have profound effects on academic achievement and on families generally (Institute of Medicine, 2001).

Autism Spectrum Disorders (ASD):Spectrum which implies characteristics that are similar but with variance in actual patterns of behaviours is the key word in the term “Autism Spectrum Disorders”. ASD as a developmental disability is always evident before age three with significant effect on social interaction and verbal and non-verbal communication skill. Engagement in unusual stereotyped movements and repetitive activities, unusual response to sensory experiences and resistance to environmental changes is other features of ASD. ASD affects how human brain processes information. ASD is a diverse set of five syndromes; Autism, Asperger syndrome, Pervasive Developmental Disorder-Not-Otherwise Specified, Rett syndrome and Childhood Disintegrative Disorder (CDD) (Institute of Medicine, 2001).

Dimensions of wellness

Murdock, (2022) create a distinction between wellness and health as he describes health as the end-goal while wellness is a process of actions to achieve health (the goal). Health is state of the body being free from diseases while wellness is seen as the overall balance of a man's social, emotional, physical, occupational, intellectual, spiritual and environmental well-being. Wellness is described as an individual pursuit and responsibility for personal lifestyle, choice and behaviours which is determined by environmental, cultural, physical and social factors (Global Wellness Institute, 2000). School of Nursing and Health Profession, Rowan University, (2022) identified six dimensions of wellness.



Six dimensions of wellness, adapted from School of Nursing and Health Profession, Rowan University, (2022)

- Spiritual: It involves the search for true understanding of higher purpose in human life.
- Emotional: This entails the acceptance and demonstration of individual's feelings and comprehension of other people's feeling through proper awareness.
- Physical: The process of using proper sleep, exercise and diet to make body healthy.
- Mental: Mental alertness through creativity, learning and problem-solving.
- Environmental: Preparing natural environment to enhance individual health.
- Social: Healthy and meaningful interpersonal within the communities.

There is distinction between healthcare and wellness. Healthcare involves process of a person with poor health seeking treatment to his/her ailment, while wellness is a proactive process of developing lifestyle that helps to prevent diseases and maintain sound health and quality life. Wellness is a self-approach to achieve and maintain good health by the individuals (Global Wellness Institute, 2022).

Therefore, wellness of children with developmental disabilities is subject to the ability of their parents as the primary caregiver to develop and maintain attitude and lifestyle that can help prevent these children from contracting diseases and maintain sound health by providing them with balance diet and observe other health measures.

Rationale of knowledge of health education for care-givers

Health education programmes are designed towards assisting individuals, families and communities to develop positive health behaviours with the aim of preventing diseases and enhance the quality of life. Knowledge of health education by parents as caregivers should be integral part of training in order to enhance their quality of health and by extension, enhance the wellness of persons with developmental disabilities (Akpeli, 2019). According to Patterson and Vitello (2006), the relevance of health education to human generally cannot be over-emphasised. They maintained that several situations in human society require the knowledge of health education to ensure the overall health conditions of individuals and the general community. Patterson and Vitello, (2006) identified rationale of knowledge of health education to include:

- Most health challenges are related to individuals and group behaviours and lifestyles. Knowledge of health education is meant to address those health challenges by equipping individuals with needed information on how to effectively prevent or manage any ailment objectively.
- Newly emerged ailments such as HIV/ AIDS and Corona Virus can only be effectively tackled by equipping every citizen with the knowledge of transmission, prevention and management mechanisms.
- In most cases, health education activities and promotion are often carried out by untrained workers in health education and who often are less committed to the service. However, if care-givers are well-informed about health education, the inefficiency of the health promotion workers will be less damaging.
- General health promotion and provision may be less effective if individuals are not well equipped with needed skills and knowledge to maintain personal health. Knowledge of health education will bring about substantial improvement in the practices of health promotion which is more individualised and be result-oriented.
- Knowledge of health education is to promote health habits in individuals and bring about the practice of healthy lifestyles and environmental modification and further strengthen the existing health for better quality of life.
- Achieving and sustaining all inclusive health for all is a global goal that requires the inputs of all, therefore, knowledge of health education will help in bring the sustainable goal on health into reality (Patterson and Vitello, 2006).

Benefits of health education knowledge to the individuals

Health education enhances health promotion process which helps to enable people to improve and increased the control over, and thereby improves their health. It is very important because it allows people the opportunity to know how to take care of themselves. Joint Committee on Terminology (JCT, 2001) has identified specific areas of benefits of health education to individuals which by extension is applicable to parents of persons with developmental disabilities. These benefits include but not limited to the followings:

- Knowledge of health education helps by motivating people based on individual areas of interests in improving and enhancing their personal living conditions.
- Knowledge of health education assists in the development of a sense of responsibility for self-health conditions as individuals and as family members of every given communities.
- Knowledge of health education helps in the appraisal of knowledge of individual about emerging diseases, assessment of attitudes of the individual relative to the spread of the diseases, and the preventive measures.
- Knowledge of health education helps to improve health by teaching prevention as well as basic health knowledge, and also re-shape people's habits with unhealthy lifestyles. This also helps to inculcate good health habits in the future generation, thereby, brings about healthy society.
- Knowledge of health education helps people to develop healthy strategies in managing situations of extreme anxiety, stress, depression and other emotional psychosocial problems associated with daily challenges and reduce the negative effects of these challenges (JCT, 2001).

Benefits of knowledge of health education to the family

As knowledge of health education is beneficial to individuals, so it is helpful to the families as a whole. Knowledge of health education helps in the creation of awareness on wellness and prevention of illnesses among family members. JCT, (2001) summarized the benefits of knowledge of health education to the families to include:

Promoting support for the family: knowledge of health education helps to promote family support by strengthen positive informal social networks through community based programmes and services information. Family-life is not always easy. Life events such as death, birth of a child with disability, illness, depression, redundancy, financial challenges, abuse, or family separation put stress on family and relationships. These knowledge help to provide information on the easiest way to deal with the problems.

Promoting healthy child development: knowledge of health education to provide health care for children with developmental disabilities such as early interventions and care that can reduce the burden of the disability.

Promoting mental health: knowledge of health education helps to promote emotional wellness and mental health among individuals. Mental health is a state of well-being whereby individual realizes own potential, copes with the life stresses, be productive and fruitful at work, and able to contribute to the society at large.

Promoting healthy nutrition: knowledge of health education helps in promoting healthy diet habits such that can enhance health of individuals.

Promoting safety and injury prevention: knowledge of health education can help to promote safety and bring about injury prevention. Safety and injury prevention is a component of safety and public health, and its goal is to improve the health of the population by preventing injuries and hence improving quality of life. This can be effectively enhanced with full knowledge of health education by individuals in the community.

Programmes of health education for parents of children with developmental disabilities

Programmes of health education for parents of children with developmental disabilities can come in different forms based on the need of the parents, their children, families and communities in general. Centre for Disease Control and Prevention [CDC] (2007) identified some of such relevant programmes which include the following:

Home health promotion: Developing necessary health potentials and skills of children with developmental disabilities requires parents and other family members to be promoters of wellness themselves. Every parents is a role-model to their children. Words and actions of parents can have great influence on the health behaviours of their children.

Child health and development: Health education emphasised that the most important stage of child development if early period. This includes all domains of development; language, emotional, social, cognitive, and physical domains.

Injury prevention programmes: Process to maintain healthy lifestyle and prevent injuries is inculcated through this programme.

Fitness programmes: Through this programmes, individuals are helped to improve their physical and health conditions through the ability to perform daily activities, sports and occupations.

Blood pressure control programmes: People are helped to manage their blood pressure through stress management strategy, eating habit and exercise.

Food and nutrition services: Balance diet is very important in child development. Parental knowledge of nutrition goes a long way to enhance the wellness of children with developmental disabilities.

Drug counseling programmes: To avoid substance abuse by parents and individuals with developmental disability, counseling services are often provided to help people overcome the dependency of becoming drug addicts.

First aid training programmes: These are meant to train parents on how to give first hand assistance to individuals experiencing sudden injuries or illness, so as to prevent worsening condition and also preserve life.

Healthy home environment: A safe home environment can effectively promote wellness and enhance personal growth and development of the individuals. This programme helps to equip parents with necessary skills to make their home safe and disease-free.

Family, school and community partnerships: To maintain unity, cooperation and foster general health, the complementary efforts of all stakeholders is required. Children with developmental disabilities can only live a worthy life if parents/families, community and school can work together as one.

Implication of this article to special education

Poor health is an inhibiting factor to effective learning. Individuals with developmental disabilities are already faced with the challenge of disability which automatically affects their overall growth and development. Effective care-service delivery for persons with developmental disabilities is premised on the overall wellbeing of parents as the primary caregivers. Psychological wellbeing, medical wellbeing, economic wellbeing and physical wellbeing are all significant and imperative for the overall health of the parents of children with developmental disabilities, and this will automatically determine their productivity. Health education is a pro-health and integral part of complementary health promotion approaches that can help in shaping health-oriented attitude and health skills acquisition of parents of children with developmental disabilities, thereby influencing the overall health of individuals with developmental disabilities (Pizybylska et al. 2014). Provision of quality education for individuals with developmental disabilities can only be possible if these individuals are healthy. In order to enhance effective learning for individuals with developmental disabilities, their overall health must be well enhanced and this can only be achieved when their parents are in sound health. This will enable teachers and other special education service providers to be more effective and productive.

Conclusion

There are well-documented health challenges associated with care services for persons with disabilities, with significant short-term and long-term implications on the overall health of the parents and the persons with developmental disabilities. Care services provision is stressful and it increases the psychological distress which in turn may reduce productivity among caregivers. Effective and efficient care of children with developmental disabilities is premised on the health status of their parents. Effective management of their health will

significantly improve their service delivery and further enhance the living condition of persons with developmental disabilities. Knowledge of health education by caregivers will help them to maintain good health and thereby make them effective service providers. It is therefore important that necessary health education training be provided for all parents of persons with disabilities generally, and developmental disabilities in particular, so as to make them more efficient and productive.

Suggestions

The impact of care services provision for individuals with developmental disabilities on the health of the caregivers, especially the parents who are the primary caregivers, is often negative as most caregivers always experience health challenges, thereby makes them less productive in their service provision. This can consequently affect the health of individuals with developmental disabilities and their ability to learn effectively in schools. In order to enhance the health of the caregivers and consequently improve their productivity to enhance overall well-being of these individuals, employers of labour in the various special homes and schools for persons with developmental disabilities should provide regular health training for their caregivers. Parents that are primary caregivers to their children with developmental disabilities should regularly seek for health information from professional health education workers as this will improve their health and the health status of their children.

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