Role of Community Nurses in Improving Caregivers’ Ability in Caring for Children with ARFID (Avoidant Restrictive Food Intake Disorder)

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ABSTRACT

Background: Community nurses have a vital role in improving the caregiver's ability to care for children with ARFID (Avoidant Restrictive Food Intake Disorder). Maternal and family beliefs about the potential risks and seriousness of their child who suffers from ARFID will result in their confidence.

Objectives: This study aims to illustrate the role of nurses in improving caregiver skills in caring for children with ARFID based on Johnson’s Behavioral System Model (JBSM), Health Belief Model (HBM), and Parents-Child Interaction Model (PCIM).

Method: This research is a literature research of electronic databases using keywords of "community nurse", "carer", "ability", "Avoidant Restrictive Food Intake Disorder", "caring", and "role". The article used in this review is primary research article with no limiting method of research.

Results: The results of the data analysis obtained seven themes which were mutually open, related and connected to each other. They were (1) Attachment-affiliative, (2) dependency, (3) ingestive, (4) eliminative, (5) sexual, (6) achievement, and (7) aggressive / protective relationships.

Conclusion: The development of caregiver skills in caring for children with ARFID will be very useful in preventing childhood malnutrition. Caregivers in this case the mother or caregiver can develop constructive behavior in accompanying children with eating disorder.

Keywords: role, community, nurse, carer, ability, caring, avoidant restrictive food intake disorder

INTRODUCTION

Community nurses have an extremely vital role in promoting the ability of caregivers in caring children with ARFID (Avoidant Restrictive Food Intake Disorder). A number of theories that can be developed by community nurses in this case include Johnson’s Behavioral System Model (JBSM) and Health Belief Model (HBM). JBSM empirically refers to the nursing care carried out for facilitating an individual (caregiver) in effectively and efficiently behaving when nursing children with ARFID. The effective and efficient behavior in HBM is translated as the ability of a caregiver in predicting preventive measures, conducting screening, or controlling the condition of children with ARFID (Glanz, Rimer, & Viswanath, 2008; Goong, Ryu, & Xu, 2016; Purwanta, 2012).

ARFID is a new term for describing eating disorder in infancy and early childhood (toddler) with the characteristics of: refusing to eat, poor meal times, low eating skill which does not fit with the stage of child development, lack of interest in eating, avoidance based on
sensory characteristics of food such as: food appearance, food aroma and taste, fear to eat like dysphagia, fear to swallow food (Fisher et al., 2014; Kostro, Lerman, & Attia, 2014; Nicely, Lane-Loney, Masciulli, Hollenbeak, & Ornstein, 2014), and failure in meeting appropriate nutritional and energy need. (Katzman, Stevens, & Norris, 2014), which later causes one or more signs of significant weight loss, nutritional deficiency, high dependence on enteral feeding and oral nutritional supplements, and interference with psychosocial functioning (Berlin, Davies, Silverman, & Rudolph, 2011; Sharp, Volkert, Scahiil, Mccracken, & Mcelhanon, 2016). Feeding difficulty in children is a serious problem as it has an impact on their future life cycle (Ágh et al., 2015; Campbell & Peebles, 2014; Segovia, 2015; Uher & Rutter, 2012).

Some clinical symptoms shown by children with feeding difficulties can be in the form of picky eating behavior with prevalence of 12% - 50% (Garg, Williams, & Satyavrat, 2015), food allergies with prevalence of 17.3% (Edition et al., 2015), and other symptoms. Research results reveal that 58% of children aged 1 – 5 suffer from feeding disorder with the following complaints; eating only less than one third of the portion (27.5%), refusing to eat (24.8%) and being fretful, unpleased, or angry (22.9%), only liking one kind of food (7.3%), only willing to drink milk (18.3%), taking > 1 hour to eat (19.3%), and taking something into mouth as to suck it (15.6%). As much as 72% complaints have been experienced for more than 6 months, 50% showing complaint of weight gain disturbance, 22% being fretful, 12% suffering from epigastrium pain, 10% suffering from back arching, and 6% suffering from swallowing pain and frequent vomiting (Soedibyo & Mulyani, 2009). There have been 11% (Nakai et al., 2017), 12.4% (Fisher et al., 2014), 22.5% (Nicely et al., 2014), 5% - 23% (Strandjord et al., 2016) children reported to have suffered from ARFID.

The nutritional problems of Indonesian children in 2010 are evident from the prevalence of Low Birth Weight (LBW) of 8.8%, prevalence of under-fives categorized into being stunted of 35.6% (7.6 million out of 23 million under-fives) and prevalence of thin children of 13.3% (Coordinating Ministry of People’s Welfare, 2012). The prevalence of children suffering from eating disorder is 15% in female children and 3% in male children (Hay & Claudino, 2012), 30% in female children and 15% in male children (Campbell & Peebles, 2014), 5% - 14% and potentially increase to 22.5% (Katzman et al., 2014; Norris & Katzman, 2015). Among six-to-fifteen-month-old infants, it is reported by caregiver that 6% of them suffer from eating disorder and this figure will increase to 25 – 40% in the following stage of development (Sacrato, Pellicciari, & Franzoni, 2010).

The eating disorder in infants and toddlers is caused by several factors, including: genetic and biological factor, environmental and sociocultural influences, and psychological stress (Campbell & Peebles, 2014; De Luca & Napoletani, 2015), mother and family factor (Allen et al., 2014), and dysfunctional interaction between mother and child (Goulding et al., 2014; Gueron-Sela, Atzaba-Poria, Meiri, & Yerushalmi, 2011; Kröller & Warschburger, 2009; Sacrato et al., 2010; Squires, Lalanne, Murday, Simoglou, & Vaivre-Douret, 2014). The prevalence of affectionate tension between parents and child is 13 – 82%, depending on the risk factor in the family such as negligence or maltreatment to the child (Skovgaard Væver, Smith-Nielsen, & Lange, 2016).

The improvement of the ability of caregivers becomes an extremely significant variable in nursing children with ARFID by considering some causing factors such as genetic-biological factor, environment, psychological stress, mother and family factor, and interaction between mother and child (Frank, Roubal, Breitzer, & Godin, 2016; Masse, McNeil, Wagner, & Quetsch, 2016; Shumaker, Ockene, & Rieker, 2009). Very strong environment influence will disturb the balance of behavioral system and will threaten one’s stability in behaving (Dovey, Isherwood, Aldridge, & Martin, 2015; Sidor, Fischer, Eickhorst, & Cierpka, 2013; Yoo, Popp, & Robinson, 2014).
Psychological stress factor and mother-family factor may influence the belief of mother and family. The belief of the mother and family on the risk potential and the level of seriousness in children suffering from ARFID will yield in the belief of impeding threat. The interference on this threat will impact on the belief of the mother and family to have positive behavior in nursing children with ARFID (Dong et al., 2016; Gueron-Sela et al., 2011; Poortaghi et al., 2015). The factor interaction between mother and child can be described as the sensitivity between mother and child in capturing the existing signals or clues from ARFID case, which may cause effective and efficient behavior (Colegrove & Havighurst, 2016; Merwin, Advisor, & Gray, 2010). The idea of this research aims to describe the role of a nurse in promoting the ability of caregivers in nursing children with ARFID based on Johnson’s Behavioral System (JBSM), Health Believe Model (HBM) and Parents-Child Interaction Model (PCIM) theories.

METHOD

This research is a literature research of electronic databases using keywords of "community nurse", "carer", "ability", "Avoidant Restrictive Food Intake Disorder", "caring", and "role". The article used in this review is primary research article with no limiting method of research. Results The results of the data analysis obtained seven themes which were mutually open, related and connected to each other. They were (1) Attachment-affiliative, (2) dependency, (3) ingestive, (4) eliminative, (5) sexual, (6) achievement, and (7) aggressive / protective relationships.

RESULTS AND DISCUSSION

Johnson’s Behavioral System Model concept in promoting the ability of caregivers in nursing children with ARFID

Nurses significantly contribute toward the facilitation of effective patient functional behavior before, during and after illness (Tomey & Alligood, 1998; Tuneh, 2016). There are 7 internal subsystems that are open, related and connected to each other, namely: attachment-affiliative subsystem, dependency subsystem, ingestive subsystem, eliminative subsystem, sexual subsystem, achievement subsystem, and aggressive/protective subsystem).

Attachment-affiliative subsystem

Attachment-affiliative subsystem refers to the behavior required to achieve security needed to survive, such as social inclusion, intimacy and forms for maintaining social cohesion (Fawcett, 2017), something that is essential and basic from all social organizations (Tomey & Alligood, 1998), as an early response to the development of an individual (George, 1995; Madlala, 2015). The social cohesion created in the environment covers the relationship with family and friends (Tuneh, 2016). The purpose of attachment-affiliative system is to protect one from danger (George, 1995; Milberg & Friedrichsen, 2017). The affection from parents will have a long-term role in the neurological development of the child (Lavallée, Aita, Bourbonnais, & De Clifford-Faugère, 2017). The ability of a child in coping with stress and managing negative emotion becomes the outcomes of social competence, moral and empathy development, and academic achievement (Skovgaard Væver et al., 2016).

Dependency subsystem

Dependency subsystem refers to the behavior of providing help/assistance as a response to the nursing given in the form of attention and acknowledgement and physical
assistance (Fawcett, 2017). As to dependence, it is defined as “...its clearly not in control of itself” (Groarke, 2016). Dependency subsystem may help improve behavioral response to mutually give and care. Dependency subsystem is highly influenced by attachment-affiliative subsystem. The provision of affection from the caregiver to the child is the response given from the dependency behaviors shown by the child.

It is difficult to separate the dependency subsystem from affiliative or attachment subsystem because without someone invested in or attached to the individual to respond to that individual’s dependency behaviors, the dependency subsystem has no animate environment in which to function (George, 1995)

Dependency is a state of relying on or needing someone for aid, support reliance confidence or trust (Madlala, 2015) 

...it deals with the presence of people around the patient, the physical contact, group therapy is also good to create system to give patients support through their ordeal (Tuneh, 2016)

Dependency subsystem is defined as succoring behavior that calls for a response of nurturance as well as approval, attention or recognition, and physical assistance (Fawcett, 2017).

Children has a high dependency upon their parents or caregivers associated with the fulfillment of food needs (Hansson et al., 2016; Herschell, Scudder, Schaffner, & Slagel, 2016). Children with eating disorders are strongly influenced by dependency (Ben-Porath, Federici, Wisniewski, & Warren, 2014), so that in order to create good eating behaviors, parents or caregivers need to continuously improve children's independence in meeting their own needs (Cullinane & Novak, 2013).

**Ingestive / eliminative subsystem**

The ingestive subsystem is associated with a sense of satisfaction in food intake. This behavior is related to social, psychological, and biological considerations. Ingestive is related to how, when, how, and how much to eat and drink as a behavioral subsystem. This is considered as a source in maintaining integrity and achieving pleasure in achieving environmental recognition. The ingestive subsystem is also related to the behavior of food intake (Fawcett, 2017; Tomey & Alligood, 1998).

On the other hand, the eliminative sub-system is associated with behavioral satisfaction in terms of a person's elimination system "... the excretion of waste products form the body" (George, 1995). This elimination system is related to the ability to dispose of body waste metabolism. Satisfaction is linked very strongly with security, trust, and confidence and it also influenced by personal opinions, beliefs, expectations, and experiences (Condelius & Andersson, 2015). Family satisfaction is a protective factor in children with eating disorders (Allen et al., 2014).

**Sexual subsystem**

The sexual subsystem describes the behavior associated with procreation (affectionate / loving). In sexual subsystems, there are two functions, they are procreation (giving love / love) and gratification (mutual give satisfaction). The key words of this sexual subsystem is that in all communities having the same goal which is behavior that is acceptable by the larger community (Tomey & Alligood, 1998).

Sexuality is an issue related to a quality in life. JBSM provides direction related to sexual behavior in several components including: communication, appearance, desire, stimulation, activity level, technique and orgasm. Communication is defined as a verbal conversation with a partner. The appearance is conceptualized as a physical appearance between the two that is when dressed or when not dressed. Desire is an interest to engage in
sexual acts both alone and with a partner. Stimulation interpreted as a physical manifestation of desires such as lubrication of the vagina. Activity levels are defined between both initiation and frequency of sexual activity. Techniques are the various positions which are used during sexual activity. Orgasm is defined as the ability to get the peak of pleasure (Wilmoth & Tingle, 2001).

**Aggressive subsystem**

Aggressive subsystem is a form of self-defense mechanism or protection from various threats in the neighborhood (Tomey & Alligood, 1998), protection or self-preservation and social behavior (Fawcett, 2017). Protecting behavior and maintaining this behavior will result in a therapeutic relationship between caregivers and children (Curcio, 2017). In cases of children with ARFID who are depressed, they need help from family members or carers to provide protection, direction, and family support (Cismaru & Pioufle, 2016).

**Achievement Subsystem**

Achievement is the level of achievement through creative skills in the one's life behavior. Achieving control or self-control or the environment through the search for some standard of perfection, such as physical, social, or creative skills. Mothers who are relatively young will have limited educational experience and low incomes (Catherine et al., 2016). This factor is associated with increased injury to children and development of low cognitive behavior in children.

**The concept of Health Belief Model (HBM) in improving caregiver skills in caring for children with ARFID**

HBM is one of the theories used to determine the ability of a person to take a preventive action measures against disease and health promotion (Akey, Rintamaki, & Kane, 2013), explaining on why a person changes or maintains specific health behaviors (James, Pobee, Oxidine, Brown, & Joshi, 2012; Poortaghi et al., 2015), explaining on why a person fails to participate in activities which are aimed to detect or to prevent disease (Borowski & Tambling, 2015), predicting a person to take action in prevention, screening, or controlling sickness Glanz et al., 2008). To sum up, HBM is the underlying theory of caregivers to behave well in the level of prediction, to take action, and to change the behavior in caring for children with ARFID.

The main concepts in HBM include five health-related attitudinal factors namely: perceived susceptibility, perceived severity, perceived benefit, perceived barrier and perceived self -efficacy) (Glanz et al., 2008; Rahmati-najarkolaei, Rahnama, Fesharaki, & Behnood, 2016; Shumaker et al., 2009). Perceived susceptibility is a belief about the probability of gaining illness or disease conditions (Glanz et al., 2008). Confidence in vulnerability is associated with risk as health conditions develop (Borowski & Tambling, 2015). Carers or families who are caring for children with ARFID often do not realize or deny that their children have a health problem. This parents’ rejection in eating disorders’ cases is equivalent with low perceived susceptibility which will ultimately lead to the caregivers’ unenthusiastic to look for changes.

Perceived severity is related to the difficulties or consequences of individual beliefs resulting from the conditions occurring. More difficulty levels or negative consequences about a condition will lead a person to take precautions over his condition (Borowski & Tambling, 2015). The combination of perceived susceptibility and severity will lead to the new terminology which is perceived threat (Abuadas, Petro-Nustas, Albikawi, & Nabolsi, 2016; Glanz et al., 2008; Shumaker et al., 2009).
Perceived benefits is defined as the emergence of perceptions to change behavior because of one's awareness to their vulnerability of the seriousness of their health condition (perceived threat) (Sarver, Cichra, & Kline, 2015; Surdej, 2016; Thomson, Buckley, & Brinkworth, 2016). This behavior is a useful behavior to reduce the risks or threats of children with ARFID. Perceived barriers are potential negative aspects of health-promoting actions. Acceptance of barriers becomes the most significant predictor of action (Borowski & Tambling, 2015). Cues to action is a modifying factor that will influence the behavior directly and indirectly through perceived threats and perceived benefits (Hanson & Benedict, 2002). Perceived self-efficacy is defined as a belief for success in carrying out behaviors that lead to results to be achieved (Colditz et al., 2015; Dawson, Mullan, & Sainsbury, 2014).

CONCLUSIONS

The development of caregiver skills in caring for children with ARFID will be very useful in preventing childhood malnutrition. Mother may develop constructive behavior in accompanying children with eating disorder. This will contribute to support the Sustainable Development Goals (SDGs) program. Nutrition policies in SDGs include reducing the incidence of stunting and wasting failure and reducing child mortality and morbidity due to infectious diseases related to nutritional disorders (Knowles et al., 2015). Further development of a study is the needs to analyze: a) the influence of the caregiver's behavioral system (affection, dependency, ingestive / elimination, sexual, aggressive, attainment of caregiver's behavior in caring for children with ARFID, and b) the influence of caregiver behavior (vulnerability beliefs, beliefs Seriousness, confidence of barriers, beliefs of benefit, self-efficacy) towards the upgrading of caregivers in caring for children with ARFID.

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