Psychological distress on childhood cancer: a concept analysis

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ABSTRACT

Stress is the imbalance of situation, whereas there is not balance between a demand and ability perceived by individual during respond to it. Psychological distress is seen as an incongruence between the ideal self and the self, it will be different for children particularly they who have cancer. It also provides confusion for nurses in managing to taking care of children who have experience psychological distress. The aims of this concept analysis are to clarify the concept psychological distress in term of pediatric nursing cancer practice, the second is defining the term psychological distress concept in children perspective based on Walker and Avant’s (2011). The criteria that identifies the attributes, antecedents, and consequences of psychological distress based on the literature review, with addition, the empirical references and construct cases are identified and presented. Methods. A literature search was conducted using CINAHL, Scholar, ClinicKey, and PubMed Lit databases over the last 20 years. Findings. Content analysis of the literature showed, concept analysis has clarified psychological distress definition in term of pediatric area with three main components of the attributes including negative emotional, unpleasant feeling, and difficult to cope the stressor, then the the consequence was negative. The presentation of attributes related to the concept, antecedents and consequences should enable to defining this concept and useful to identify psychological distress in children. Conclusions. Psychological distress is also happened in children with disease such as cancer and caused a serious problem for children, parent and nurse as a healthcare provider. Nursing research to explore the psychological distress of childhood cancer is needed, again intervention studies also needed to reduce the consequence of psychological distress of children.

INTRODUCTION

The most common of cancer among children was leukemia with approximately 30% of all childhood cancers, mostly approximately 70%-75% of Acute lymphatic leukemia (ALL) (Hatfield, 2008). The diagnosis of cancer is destroying, it change the child and family’s emotional states especially related to feelings and fears, especially during the first learn that a child has leukemia and during chemotherapy. Family members live in anxiety and worry...
related to the child’s life will be very limited, failure of the remission tretment, and child will be has a relapse and is finally the possible death of child (Hatfield, 2008; Pilliteri, 2010). It is a stressful and frustrating situation and cause the psychological distress not only for children but also the parent and all of family members. Children is unique, its different than adult, they have limited understanding and cognitive ability, and number of coping mechanisms (Pilliteri, 2010), thus, they have different responses than adult with no exception psychological distress.

Stress is the imbalance notion, it is a situation whereas there is not balance between a demand and ability perceived by individual during respond to it (McGrath, 1970) (Walker, et al, 2004). Stress perceived while certain situations stressful, otherwise he or she is unfamiliar and does not understand how to respond. Arvidsdottter et al (2016) identified Psychological distress is seen as an incongruence between the ideal self and the self, it is potential breaks down a person’s self-esteem slowly.

The purpose of this concept analysis to clarify the concept psychological distress in term of pediatric nursing cancer practice, the second is defining the term psychological distress concept in children perspective.

SEARCH METHODS
This analysis used literature review method, some databases from Google Scholar, ClinicKey, CINAHL, and PubMed were searched for the past 20 years used key words such as psychological distress, mental distress, distress, and psychological, cancer, children, and leukemia. The most information written in English dan have content related or dealt with human psychological distress or stress. The excluded references were not available in English, psychological distress unclear explained with only psychological level examination, and the content was out of context psychological distress. The sources were reviewed more than 30 articles.

CONCEPT ANALYSIS
This concept analysis methodology was used Walker and Avant’s (2011) framework for some reasons. First, the method from Walker and Avant is organized logically and easy to follow. Second, the end product of concept analysis is always tentative, so that although the concept analysis of psychological distress was available, but in fact, the come up analysis has somewhat different attributes. The framework contains an eight step process: (1) select a concept, (2) determine the aims or purposes of the analysis, (3) identify of all uses of the concept that can discover, (4) determine the defining attributes, (5) identify a model case, (6) construct borderline, related, and contrary cases, (7) identify antecedents and consequences, and (8) defining empirical referents (Walker & Avant 2011, p. 160).

Psychological distress comes from two words, they are psychological and distress, otherwise the psychological is come from psychology. Psychological distress mostly used and referenced in health care literature, especially in psychology area and medicine, but, it also related many areas in the world such as education area, economy, and and animal. All of them defined psychological distress quiet different. Psychology is the study of human behavior, emotions, and thought processes. It can influence people understanding of theirselves, and their relationships with other people (Walker et al, 2004). Distres is a feeling of worry extremely, sadness or pain; a situation in which you are suffering or are in great danger and therefore in undanger need of help (Dictionary.cambridge.org). The concept of psychological distress is not clearly and easily understood. The psychological distress usually is used to observe human response not only to illness but also to many aspects in the live resulting stress dan depressed, in overal stage of age including children.

PSYCHOLOGICAL DISTRESS
Psychological distress is regularly discussed in psychological, medical, nursing, education and social science literature (Arvidsdotter et al. 2016, Dyrbye 2006, Stallman 2010). Humanistic Psychology Dictionary defining the concept of
psychological distress is the final result of factors, psychogenic pain, internal conflicts, and external stress that prevent a person from self-actualization and connecting with 'significant others'. Ridner 2004, described psychological distress is negative feelings or emotions that affect one’s level of functioning and interfere with activities of daily living. Psychological distress is a mental health outcome typified by psychophysiological and behavioural symptoms that are not specific to a given mental pathology (Marchand & Durand, 2011). Psychological distress are the exposure to a stressful event that threatens the physical or mental health, the inability to cope effectively with the stressor and the emotional turmoil that results from this ineffective coping (Horwitz, 2007). Psychological distress is viewed as an emotional disturbance that may impact on the social functioning and day-to-day living of individuals (Wheaton, 2007). Drapeau 2012, psychological distress as a normal emotional reaction to a stressor raises the issue of delineating “normality” in different populations and different situations. In a study conducted by Shelby et al (1998) of children during and post treatment, found that anxiety and depression occured more often in children with leukemia than their peers, with the prominent problems were about expressing external feelings, and adapting to social situations. Jaisoorya et al (2017) studied psychological distress in 7560 students from 73 schools, they reported that 10.5% students suffered mild psychological distress, moderate distress was 5.4%, and severe distress was 4.9%. Students who experienced psychological distress had a higher risk of reporting academic failure, alcohol and tobacco use, suicidality, and sexual abuse. These findings demonstrated that consequences of psychological distress occur mostly on negative.

Defining attributes

Defining attributes is the core of concept analysis, it is clustering of attributes that are the most frequently related to concept (Walker & Avant 2011). Psychological distress has three defining attributes: (1) negative emotional, (2) unpleasant feelings, and (3) difficult to cope with the stressor.

Negative emotional
During experience psychological distress, a people is perceiving anxiety, stress, worry, and panic (Chad-Friedman et al, 2017). The psychological distress is denoted the lack of control, crying, anger, hopelessness, despair, decreasing the tolerance level, easily frustrated, the emotions became colder, less empathetic, and the tend to refuse love (Arvidsdotter, et al, 2016), the children also frequently stated irritability and sleep disturbances (Wolfe et al, 2015), even suffered mood disturbances (Erickson, et al, 2013). In addition, children whose leukemia also showed feeling such as shame, sad, withdrawal, and labil emotion (Hermalinda, Rustina, & Novieastari, 2015), and the most common was becoming angry. Sitaresmi, M. N., Mostert, S., Purwanto, I., Gundy, C. M., Sutaryo, & Veerman, A. J. (2009). Chemotherapy-related side effects in childhood acute lymphoblastic leukemia in Indonesia: parental perceptions. Journal of Pediatric Oncology Nursing, 26(4), 198-207

Unpleasant feelings
A people is perceiving unhappy feeling such as afraid, fear (Chad-Friedman et al, 2017, Mirowsky & Ross, 1989), also panic (Thienkrua et al, 2006). Arvidsdotter et al (2016), described unpleasent feeling perceived as a feeling inferior to others and losing one’s grip on life, suffering and poor self esteem. Social isolation was described as feelings of loneliness and exclusion. Feeling sad and nervousness were perceived by children with cancer that denote the psychological distress (Hedén, et al, 2013; Wolfe, et al, 2015; Collins, et al, 2000), additionally, feeling bored, annoyed, fear, and homesick also perceived by adolescent with cancer (Hayati & Wanda, 2016).

Difficult to cope with the stressor
Psychological distress is experienced an individual whereas he or she perceive an inability to cope with the stressor.
Arvidsdotter et al (2016), described people feel struggling to cope with everyday life, felt confused and forgetful. The avoidance of medical treatment or nursing interventions is another way to express coping difficulty (Thienkrua et al, 2006).

**Model Case**
Model case is an example the concept using that covers all of the defining attributes (Walker & Avant 2011). Dewi, a 5-year old, study at kindergarten, recently, she was diagnosed with high risk leukemia, at the beginning when she arrived at ward room, she was cry loudly for long time, refused to be administered IV therapy, yelling, kick the nurse and her mother, rejecting others. She rejected to communicate with the nurses for several days, cried when the nurse or doctor came to the ward. She also didn’t sleep on the bed, but on the lap of her mother, always told want to back home so much, asked her friends and her cats, she also want to play at the kindergarten. After 2 days, she still looked unhappy, hopelessness, withdrawing from others, quiet without crying, and exhibiting apathy, depression, lack of interest in play and food, and overall feelings of sadness. This case demonstrates some defining attributes of psychological distress: negative emotional, unpleasant feelings, and difficult to cope with stressor. Negative Emotional was denoted by kick the nurse and her mother, cry loudly for long time, yelling, apathy, depression, and lack of interest in play and food. Unpleasant Feelings showed through hopelessness, unhappy, overall feelings of sadness. Difficult to cope with the stressor came from withdrawn, refuse to be administered IV therapy and do communication with the nurses for several days, want back home so much, asked her friends and her cats, slept on lap of mother.

**ADDITIONAL CASES**
Borderline cases consist of several defining attributes, related case is instance of another concept that related to the concept, contrarily, the case does not reflect the concept (Walker & Avant 2011). An example of each follows.

**Borderline case**
Bejo, a 6-year old, study at elementary school, come from poor family. After diagnosed with thalassemia, this moment he was in ward room for received first time blood transfusion. At the beginning, he was cry and tearful for an hours, looked sad, and yelled, run when looked the needle, but when the parent hold him, he was obey to administered the IV therapy. After lunch, he looked smile to her mother, he said that i like here, because the meal was delicious, i never eat it before. This case demonstrates some defining attributes of psychological distress about negative emotion and unpleasant feeling, but not demonstrate the difficult to cope the stressor, it is a borderline case.

**Related Case**
Jono, his age was 14 years, diagnosed by brain tumor, and regularly did hospitalization for radiotherapy after his brain surgery 3 month ago. He said he felt worry about his condition, and fear for any medication everytime. He routinely asked the nurse to take a time prior to do injection, he took the deep breath, close his eyes and pray. After injection time, he go around in the ward room, and tell to another patients about his experience and how to cope the situation during hospitalization. This is an instance of stress concept, Jono was stressed, but he did not show negative emotion, unpleasant feeling and he also still cope the stressor and solve his problem correctly.

**Contrary Case**
Oni, 7 years old, was diagnosed with leukemia, she is cheerfull girl, smart and friendly, and when she will be adult, she want to be a doctor. This moment she got fever and finally the doctor diagnosed her with leukemia, she looked calm, cooperative during medical treatment although sometimes she cried when medical treatment cause pain, but just a few minutes. She asked many things about leukemia to the nurse and doctor, she feel unsad, she said that “i still can walk, read and play, i saw a girl in other ward room couldn’t walk and eat”.

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This is contrary case, Oni did not denote perceived difficult to cope the stressor, there was not negative emotion and still feel better and pleasant.

**ANTECEDENTS AND CONSEQUENCES**

Antecedents are the requirement conditions before the concept occurs, and consequences are effects of the concept having occured (Walker & Avant 2011).

*Antecedents*

Psychological distress occred by the exposure to a stressful event, it threatens the physical or mental health (Horwitz, 2007). Raising the stressor also cause Psychological distress (Drepau, 2012). Distress can occur if any stressor can be threat, any an awareness or perception of the stressor, and any response including cognitive, emotional, behavioral and physiological changes. Some people find unfamiliar situations and do not know how to respond it become stressful stimulation (Walker et al, 2004), posttraumatic stress disorder (PTSD) also related to poorer quality of life and increased the psychological distress of survivor childhood cancer (Meeske, et al, 2001). General sources on distress in Walker et al 2004, are (1) illness and hospitalization, (2) life events, such as loss of a spouse, death, trauma or job loss, (3) daily hassles, (4) traumatic events and post-traumatic stress disorder horror, (5) organizational stress, such as long working hours, low social support at work, insecure job, interpersonal conflicts, bad organisational justice, bullying, threats, and violence at work. 

An example of a study conducted by Zeltzer et al 2009, found that childhood cancer survivors are at high risk for psychological distress, the leukemia survivors denoted increasing rates of psychological distress, during patient adolescence, the leukemia survivors suffered high level of depression, anxiety, and social-skills deficits. Moreover, brain tumor survivors demonstrated got more psychological distress, including depression, somatization, and more symptoms of fatigue and daytime sleepiness. Another study, completed by Chen et al, 2000, they found that Higher levels of pain sensitivity were associated with greater anxiety, it mediated the effects of intervention on distress. Stallman 2010, found that the university students had been estimated have higher of prevalence for mental health problems than general population, whereas, full-time status and financial problem was a predictors of psychological distress.

*CONSEQUENCES*

Psychological distress are the exposure to a stressful event that threatens the physical or mental health, the inability to cope effectively with this stressor and the emotional turmoil that results from this ineffective coping. The consequences of psychological distress be viewed on negative (figure.1). Ridner 2004, stated that the psychological distress affected one’s level of functioning and interfere with activities of daily living. In addition, it has impact on the social function and daily living of individuals (Wheaton 2007). Psychological distress also can slowly breaks down a person’s self-esteem (Arvidsdotter et al, 2016). Stallman 2010, found that psychological distress was related to disability and lower academic achievement in university students in Australia. This study almost similar with Jaisoorya et al, 2017 and Deasy et al, 2014, they stated that students who underwent psychological distress had a higher risk of reporting academic failure, alcohol and tobacco use, suicidality, and sexual abuse. Similar with childhood cancer, the Psychological distress predicted bad health behaviors : smoking and alcohol use, for instance, also caused fatigue and sleep alteration (Zeltzer, et al, 2009).

Another study stated that the cancer patients who had experience psychological distress and fatigue can be predicted fall to risk of recurrence and death, even of the clinical and histopathological variables (Groenvold, 2007). Furthermore, during the diagnosis and treatment of leukemia, the children who had high levels of psychological distress potentially at a high risk for posttraumatic stress symptoms (PTSS) (Best, et al, 2001).
Another aspect of psychological distress based on Olive et al 2016, they found from six hundred and seventy-six children, aged 8 years in Australia, that a child who identified with more symptoms of depression and stress was likely to be less fit and less physically active.

**Antecedents**
- stressful event:
  - Illness & hospitalization,
  - Life events, daily hassles, traumatic events & PTSD,
  - pain

**Psychological Distress Reflected by Defining Attributes:**
- Negative Emotional
- Unpleasant Feeling
- Difficult to cope the stressor

**Consequences**
- Negative

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**Figure 1. Relationship between concept of psychological distress**

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**EMPIRICAL REFERENTS**
Psychological distress can be examined by several tools. First, Psychological Screening for Young Children aged 3 to 6” (PSYCAa3-6), it is a simple scale for children 3 to 6 years old administered by non expert or specialist, to screen the general level of psychological distress in young children during crises situation. It is including of 40 items concerning child behavior in the form of easy questions reported by the parent or caregiver through an interview. The content of PSYCa 3–6 including a psycho-traumatic component, it can conclude the psychological difficulties and their major expression such as depression, phobia, anxiety, regression, psychosomatic complaints, and posttraumatic disorder. The PSYCa 3–6 is still need further studies to replicate and validate the PSYCa 3–6 in other populations (Marquer, 2012).

Second, Pediatric Emotional Distress Scale (PEDS), it has 21-item parent-report measure used for children 2-10 years, it was designed to rapidly assess and screen for elevated symptomatology in children following exposure to a stressful and/or traumatic event. It consists of behaviors with experiencing traumatic events and consists of 17 general behavior items and 4 trauma-specific items. The measure yields scores on the following scales: 1) Anxious/Withdrawn, 2) Fearful, and 3) Acting Out. Likert rating scale used in 4-item: 1) Almost Never, 2) Sometimes, 3) Often, and 4) Very Often (Saylor et al, 1999).

Third, The Pediatric Quality of Life (PQ)-Memorial Symptom Assessment Scale (MSAS), it evaluate 24 physical and psychological symptoms for teenagers (age 13 years or older), for children ages 7-12 years only answer eight items (PQ-MSAS 7-12) with another questions (16 items) are answered by the parents or caregiver (PQ-MSAS 7-12-proxy-supplement). In addition, all items are answered by the parents (PQ-MSAS-proxy-full) for children ages 2 to 6 years (Wolfe, et al, 2015).

**CONCLUSION**
This concept analysis has clarified psychological distress definition in term of pediatric area. The antecedents of children with cancer mostly came from the its illness and hospitalization, and pain, while the attributes of the psychological distress were negative emotional, unpleasant feeling, and difficult to cope the stressor. Interestingly, the consequence of this concept only negative, it was different with analysis before in other context that psychological distress can be positive or negative effect. The presentation of attributes related to the concept, antecedents and consequences should enable to defining this concept and useful to identify psychological distress in children.
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