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Quality of Life in Adolescents with Cancer

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Abstract

There is no current universally accepted definition for quality of life (QOL). One source defined the concept of QOL as how an individual measures the goodness of different aspects of their life. These assessments include one's emotional reactions to life events, disposition, sense of fulfillment, and satisfaction with personal relationships and work (Theofilou, 2013). Another definition encompasses the person's level of functioning and overall satisfaction and well-being of their life (Lavdaniti & Tsitsis, 2015). QOL can be influenced by many factors, including physical health and certain disease processes. One disease in particular that can significantly affect one's QOL is cancer. Cancer can be physically and psychologically wearing both during treatment and even in survivorship. In cancer survivors, QOL encompasses physical, psychological, social, and spiritual well-being (Lavdaniti & Tsitsis, 2015). A particularly vulnerable group of cancer patients that may struggle more with QOL, both during and after treatment, are adolescents. As survival rates increase for adolescents with cancer it is important to measure outcomes such as health related QOL (Russell, Hudson, Long, & Phipps, 2006). Paying attention to health related QOL in adolescent cancer survivors is relevant due to the number of adolescents diagnosed each year. Based on statistics from 2014, 10,380 children younger than 15 years old and 5,000 adolescents between the ages of 15 and 19 will be diagnosed with cancer (America Society of Clinical Oncology, 2014). The aim of our literature review is to further explore the QOL of adolescents going through cancer treatment. Furthermore, we are determined to suggest strategies to improve this QOL based on reliable research. Through the literature, we will explore quality of life in general, effects of cancer on adolescent patients, both physically and psychologically, and examine which methods would be most beneficial in helping to improve an adolescent with cancer's QOL. This information will be

presented as the thesis project for the Lee Honors College for the researchers Alexis Guastella and Molly Ryan.

Purpose and Background Information

The purpose of this literature review is to determine the current research on QOL of adolescents going through cancer treatment and to establish effective techniques to improve it. This area is of importance to research because over 80% of pediatric oncology patients live at least five years after being diagnosed (National Cancer Institute, 2014). With that being said, they will be living longer and ultimately desire to live a satisfying and healthy life. It is known information that patients that are actively in treatment have a compromised QOL (Monteiro, Torres, Morgadinho, & Pereira, 2013). Cancer treatments are typically painful and psychologically weakening. These issues should be taken into consideration when measuring QOL. Factors that lead to low QOL of life include nausea, pain, anxiety, perceived physical appearance, worry, and fatigue (Hsu & Tu, 2013; Scarpelli et al., 2008). The focus of most health care providers is to treat the pain and physical side effects, while the psychological side effects are often overlooked. Rarely are oncology and hematology patients assessed for symptoms other than pain (Strömngren, Niemann, Tange, Farholt, Sonne, Ankersen, ... & Kurita, 2014). Treating the patient holistically, both physically and psychologically, will lead to the best patient outcomes.

Literature Review

Quality of life is a broad concept used to emphasize an individual's emotional reaction to life occurrences, disposition, life fulfillment and satisfaction and satisfaction with work and personal relationships, otherwise known as "well-being" (Theofilou, 2013). Due to the fact that QOL is such an individualized and subjective perception, it is hard to have a universal definition.

With that being said, when measuring QOL it may be helpful to narrow down the area of focus. For example, health QOL is specifically concerned with health aspects while also accounting for basic QOL components (Theofilou, 2013). Health related QOL can be measured utilizing instruments with questions related to psychological, physical and social well-being, self-determination, independence and satisfaction with control of the disease process. Instruments can include questionnaires, interviews, patient report and rating scales. Measuring QOL may be especially unique for the adolescent and young adult (AYA) population. The instrument used must be specifically applicable to the AYA population to include but not limited to emotional resilience, adaptation, physical, emotional and social functioning and influence of others (Hinds, 2010). Furthermore, it is important to shift from parent report to AYA individual report to acquire a more accurate QOL measurement. For an AYA experiencing cancer treatment, specific points of care such as curative effort to end of life care should also be considered when assessing QOL in order to receive the most precise rating (Hinds, 2010).

Adolescence is a particularly important stage between being a child and an adult. People in this stage are commonly not addressed as their own population. AYAs need to be treated as a subspecialty, as they experience a different journey than pediatric and adult patients (Szalda, Kim, Ginsberg, 2014; Williams, 2013). Neither pediatric nor adult care is appropriate to meet AYA needs (Szalda, Kim, Ginsberg, 2014). The separate needs of the AYA population are often not fully addressed. Unmet needs are a vast source of anxiety, depression, and distress. Examples of these needs include lack of information (on disease process, treatment, nutrition, exercise, alternative therapies, and relapse), pain management, physical and occupational therapy, and in-home nursing care (Williams, 2013). Concerns that are not addressed after treatment include fertility (which may be glanced

over due to their younger age), risk of relapse, impaired body image, weight, loss of hair, scars, and fitting in with peers. If these issues are not addressed, the patient could carry them on into adulthood. Be aware of their physical and emotional needs throughout their entire care with long-term monitoring (Williams, 2013).

AYAs are going through vital physical, psychological, and social developments. It is a time of growth and development of independence, confidence, and gaining a sense of self. Cancer can interrupt AYA's maturing autonomy, values, and relationships, including intimate relationships (Williams, 2013). This in turn could cause a decrease QOL for the patient. According to one study, AYAs who are currently receiving active cancer treatment have impaired cognitive and social QOL (Monteiro, Torres, Morgadinho, & Pereira, 2013). This impaired social QOL can inhibit an AYA going through the average life experiences for their age group. AYA are going through a time where personal experimentation, forming new relationships, discovering sexual awareness, and witnessing or participating in risk-taking behavior are essential developmental tasks (Szalda, Kim, Ginsberg, 2014). These are important milestones for every AYA to go through, regardless of health status. Missing out on these can lead to psychosocial issues, therefore decreased QOL.

Due to the cancer process being extremely physically taxing, most medical attention is paid to physical symptoms and preventing recurrence of the cancer. Rarely are oncology and hematology patients assessed for symptoms other than pain (Strömngren, Niemann, Tange, Farholt, Sonne, Ankersen, ... Kurita, 2014). Pain and anxiety are common symptoms during cancer treatment (Phillips & Jones, 2013; Szalda, Kim, & Ginsberg, 2014; Thrane, 2013). Evaluating and treating pain is essential to improving one's QOL, but should not be the only focus. Even though QOL is affected by level of pain, it also involves several other

factors. The main factor affecting QOL in cancer patients during and after their treatment is fatigue (Hsu & Tu, 2013; Szalda, Kim, & Ginsberg, 2014). Fatigue inhibits functional status and increases depressive symptoms. In cancer patients, fatigue may be increased due to chemotherapy, radiation, and surgery, and affects their QOL throughout the disease (Hsu & Tu, 2013). Nausea, lack of appetite, and psychological distress are other factors that can negatively affect AYA QOL (Szalda, Kim, & Ginsberg, 2014). Aside from the physical effects of cancer and treatment, childhood cancer survivors are more likely to have depression, post-traumatic stress disorder (PTSD), and risk for negative social, behavioral, and physical outcomes (Phillips & Jones, 2013). These physical and psychological factors working together can negatively affect one's mind and body, which may inhibit them in achieving positive QOL.

With all of the physical and psychological distress placed on AYA cancer patients there may be negative repercussions regarding health behaviors. The frequency of substance abuse is alarmingly high in everyday adolescents and young adults with between 8.5% and 25% reporting recent cigarette smoking, binge drinking, marijuana and illicit drug use (Szalda, Kim & Ginsberg, 2014). While the time of adolescence and young adulthood already present a high incidence of substance abuse and experimentation, a cancer diagnosis may increase the risk for these behaviors. AYA cancer patients may use these health-harming behaviors for fun, coping, or as a result of desiring to fit in with peers. Not only do these substance use behaviors pose the regular health risks, these may be intensified in an AYA cancer patient. Due to different types of treatments or medications they may be on, the risk for hepatotoxicity, pulmonary toxicity, cardiac toxicity, drug-to-

drug interactions, development of secondary cancers or other serious effects increases (Szalda, Kim & Ginsberg, 2014).

Recommendations

Because AYA do not fit into the mold of a pediatric nor adult patient, this population should be recognized as separate. Nurses and health care teams should be well educated on the separate needs of these particular patients. Assessing needs is essential so the proper interventions can be established. One way of assessing the needs is through the Cancer Needs Questionnaire-Young People (CNQ-YP). The CNQ-YP is the first multi-dimensional measure for unmet needs that has been made specifically for AYA cancer patients. There are 70 items with six overall categories (treatment environment and care, feelings and relationships, daily life, information and activities, education, and work) (Clinton-McHarg, Carey, Sanson-Fisher, D'Este, & Shakeshaft (2012). This tool has a good internal consistency and is reliable when assessing needs in treatment, feelings and relationships, day-to-day life, information, work, and education (Williams, 2013). This is one way to assess the patient before initial treatment, so that the patient's baseline QOL is known, before moving on to the next recommendations. If more nurses are educated on this tool and the tool is made available to nurses, hopefully more AYA will be screened for QOL issues before they become a problem.

AYA should be supported and engaged in normal tasks and milestones (Szalda, Kim, & Ginsberg, 2014). One way the health care team can achieve this is by working around the AYA the best they can. If an adolescent has a special event such as prom or graduation coming up, every effort should be made for them to be there. If an AYA is hospitalized, health care providers should work around their sleep schedule to the best of their abilities to give them a

sense of normalcy. Friends and family should be encouraged to visit whenever possible to make the AYA feel included and not isolated.

Establishing a sense of normalcy is key in relation to the patient's psychosocial care. The AYA should stay involved and meet with other AYA, family, and friends (Williams, 2013). Peer support groups are important to decrease isolation and increase integration (Phillips & Jones, 2013). The patient should be made aware of these groups, whether they ask about them or not. They may feel embarrassed to bring it up, so making the information available to them regardless can bypass this issue. Furthermore, the health care team should prompt the patient about who the AYA would like to have with them. Adolescents with cancer, probably never being in a hospital much before this life event, may not realize they are allowed to have visitors or invite friends to see them. Support from peers and family is essential (Hinds, 2010; Williams, 2013). One way family can be involved is by participating in family therapy to develop strategies for communication (Nelson, Hase, Kupst, Clarke-Steffen, & Brace-O'neill, 2004). If the AYA is able to have an open communication line with their family, they may voice more fears or concerns. If the family knows how to respond to these concerns, the patient may feel more supported.

On a more individual level, the AYA with cancer should get involved with personalized health counseling and the practice of health promoting behavior (Szalda, Kim, & Ginsberg, 2014). In a study done by Matthews, Glackin, Hughes, & Rogers (2014), there was a strong, positive correlation between counseling and QOL. Another type of support to consider is whether or not the patient belongs to a religious group. Religion and spirituality is a factor in QOL and can decrease depression and increase overall well-being (Hsu & Tu, 2013). The patient and their family should be made aware of the chaplains available to them in the hospital.

Furthermore, if there are events with this community the patient would like to attend, the health care team should do their best to let the patient be able to attend.

Holistic patient care is important for the AYA population (Williams, 2013). One study showed that holistic modalities had a positive impact on children aged 1-18 with cancer. These modalities include hypnosis, mind-body techniques (breathing exercises, distraction, positive coping behaviors, and relaxation techniques), virtual reality, creative arts therapy (dance and movement, music, and art therapy), and massage (Thrane, 2013). These modalities can work as distraction to the patient and a way to express themselves through their difficult time. Creative arts therapy especially had a significant effect on decreasing pain (Thrane, 2013). Another possible modality to consider is adventure therapy. Adventure therapy is a holistic method through doing activities like ropes courses, hiking, journaling, and reflection to build trust and confidence. It provides long-term follow-up care for pediatric cancer survivors to improve emotional and learning problems, increase self-esteem, life skills, teamwork, and leadership qualities (Wynn, Frost, & Pawson, 2012). Each patient should be assessed individually to determine the best holistic care option.

In regards to issues with substance abuse, interventions, prevention, and education are essential for AYA cancer patients. Every AYA cancer patient should be screened for substance abuse frequently throughout his or her care. More time since diagnosis and higher rating of QOL may be protective against health harming behaviors such as substance abuse (Szalda, Kim & Ginsberg, 2014). With that being said, increasing AYA cancer patients QOL may help in avoiding health-harming behaviors. Forming a trusting relationship with AYA cancer patients is the key to preventing health harming behaviors. Being able to communicate openly with these patients will allow discussing substance use to be easy. AYA

patients with cancer need to be counseled on how substance use can impact their health more seriously than others due to their treatments and medications. In the case that substance use has already started to occur, proper services and treatment should be offered to them in order to prevent any additional damage to the patient's health (Szalda, Kim & Ginsberg, 2014). Health care providers must be aware of possible health harming behaviors such as substance abuse in their AYA cancer patients.

Overall, the AYA should always be involved in their care and informed of any changes with their care. The health care team should address every aspect of their care, tell them when anything in their plan of care changes, and answer all the questions the AYA may have. They should be allowed to have a say in their treatment decisions. One way to make this possible is by promoting self-efficacy so the AYA can stay independent, active, up to date on their health care information/decisions, and to better cope with treatment side effects physically and psychologically (Williams, 2013). Education is very important for these patients. Informing the AYA patient about what they are going through and their disease process may make them feel more comfortable during treatment. This in turn may decrease overall stress and make them feel more in control.

Conclusion

With both cancer diagnosis and survivor rates growing, the amount of attention paid to QOL in AYA should also be high. Many aspects of an AYA cancer patient's treatment or diagnosis can affect QOL. Although health care providers may not be able to stop the disease, there are ways the health care workers can help to improve the QOL of an AYA cancer patient. The vital take away is to make these recommendations available to the patient in order to have the best possible QOL outcomes. Each patient should feel as if they are being treated as an

individual. For example, if the patient wants to go to a religious service, but their white blood cell count is too low, maybe there is a way to stream the service to the patient. The health care provider should be creative with their solutions with this sub-group. There should be special measures taken to make their life as normal as possible, utilize techniques that are helpful to them to reduce stress or manage symptoms, individual or family counseling, and any other specific needs. Researchers should continue to discover the best possible ways to increase AYA with cancer's QOL.

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