EXPLORING THE COMFORT EXPERIENCE OF ADOLESCENTS WITH METASTATIC CANCER

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OBJECTIVES

1. Discuss the purpose of the research study.

2. Describe the results of the study.

3. Explain the nursing implications of the study.
BACKGROUND

Adolescent cancer is challenging

Adolescents are in distress from painful procedures and treatments

Most of the publications were drawn from the parents’ and staff perspectives

Adolescents can offer significant insights into their needs
PURPOSE of the STUDY

What is the meaning and significance of comfort experienced by adolescents with metastatic cancer?

SPECIFIC AIMS
1) To explore the meaning of comfort experienced by adolescents diagnosed with metastatic cancer.
2) To explore the significance of the experience of comfort as described by adolescents diagnosed with metastatic cancer.
IMPLEMENTATION

Phenomenology

Eligible patients – adolescents 15 to 21 years old with metastatic or progressive disease

Setting – children’s cancer hospital of a large tertiary cancer institution

Purposive sampling – 14 signed consent, 13 interviewed
REACTION TO THE STUDY

Most of the participants wanted to start the interview right after signing the consent.

Most of them (except one) were candid and openly answered the questions.

All of them were teary-eyed or crying/sobbing.

Discussion about death was very emotional.
REACTION TO THE STUDY

Two patients were told by Oncologist they have limited time left, the possibility of death is near

Three of the seven whose parents were divorced had substance abuse or suicidal attempts
# DEMOGRAPHICS

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sample</th>
<th>N = 13</th>
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<tbody>
<tr>
<td><strong>SEX</strong></td>
<td>MALE = 7</td>
<td>FEMALE = 6</td>
</tr>
<tr>
<td><strong>MEAN AGE AT DX/INTERVIEW</strong></td>
<td>AT DIAGNOSIS = 15</td>
<td>DURING INTERVIEW = 17</td>
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<tr>
<td><strong>DIAGNOSIS</strong></td>
<td>SOLID TUMOR=11</td>
<td>HEME = 2</td>
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<tr>
<td><strong>NUMBER OF SIBLINGS</strong></td>
<td>1-3 = 5</td>
<td>&gt; 3 SIBS = 3</td>
</tr>
<tr>
<td></td>
<td>&gt; 5 SIBS = 3</td>
<td>&gt; 5 SIBS = 3</td>
</tr>
<tr>
<td><strong>NUMBER OF PEOPLE IN HOUSEHOLD</strong></td>
<td>2-3 = 7</td>
<td>4-5 = 4</td>
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<tr>
<td></td>
<td>&gt;5 = 2</td>
<td></td>
</tr>
<tr>
<td><strong>ETHNICITY</strong></td>
<td>CAUCASIAN = 7</td>
<td>HISPANIC = 4</td>
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<tr>
<td><strong>ETHNICITY</strong></td>
<td>ASIAN = 1</td>
<td>ARABIC = 1</td>
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<tr>
<td><strong>PAIN MGT.</strong></td>
<td>DRUGS ONLY = 13</td>
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<tr>
<td><strong>CANCER TREATMENT</strong></td>
<td>CHEMO ONLY = 6</td>
<td>COMBI = 7</td>
</tr>
</tbody>
</table>
THEMES

WHO AM I?: Physical changes

WHY ME?

WHAT WOULD IT BE NOW?

WHERE DO I STAND AND BELONG?
THEMES

HELP FROM HIGHER BEING

EXISTENTIAL WELL BEING

MY SOCIAL SUPPORT

THIS IS WHERE I BELONG
WHO AM I? PHYSICAL CHANGES

POOR SELF-ESTEEM

“I feel different from them”

“I lost the centimeter of self-esteem that I had left”

“I was no longer me”

“I lost what made me different from others”

“The pain and other symptoms were distressing... it’s not me”
WHO AM I?

DISTORTED BODY IMAGE

“ I look like a monster “

“I do not want to see my friends and people...”

“ Losing your hair, worst is losing your eyebrow is horrible...”
WHY ME?

SHOCK/ANXIETY/ANGER

“It is unreal and upsetting”

“I was suffering even without treatment... I told them to stop repeating the word cancer
WHAT WOULD IT BE NOW?

UNCERTAIN FUTURE

“What would happen to me?”

“How about my friends and family?”

“Will I be able to have children?”
WHERE DO I STAND/BELONG?

ISOLATION

“I feel like one African American in a sea full of white people ... you feel alone”

“I just wanted someone to be with me”

“I feel like I’m in a cage, a lab rat, back in the cage when they are done, they pull me in a leash”

“They (friends) graduated and I’m left behind in high school”
WHERE DO I STAND AND BELONG?

AUTONOMY VS. DEPENDENCY

“He (oncologist) ignores me, he just go straight to my parents... don’t go to my parents, they do not know what is going on, talk to me... I’m 16”

“I prefer straight talk from my doctors”
WHERE DO I STAND/BELONG?

OVERPROTECTIVE PARENTS

“I feel like a child, you want me to be independent but difficult... he tells me to do this, do that”

“My parents did all the calls and referrals for other treatment, I just go with them...
HELP FROM HIGHER BEING

FAITH AND TRUST IN GOD

“My mother taught me how to pray, I have strong faith in God”

“God gave me a second chance”

“God did this for a reason. I place a lot of trust in him”

“My mom took me to a place in...we have to get down on our knees and pray...”
HELP FROM HIGHER BEING

HOPEFULNESS

“I know there are miracles, it inspire me to never give up”

“I know I will be healed, I trust in the doctors here in the US”.
HELP FROM HIGHER BEING

FEAR OF DEATH

“I talked to my parents about death, I’m still afraid but I had so much time to think about it I don’t mind so much anymore, I guess…”

“I talked death with my friends... they told me to think positive”

“I beat it (cancer) once, will I beat it again?”
HELP FROM HIGHER BEING

PERSISTENCE TO FIGHT

“I do think positive you know, I want to live”

“I’m fighting but you have to face reality”
EXISTENTIAL WELL BEING

MEANING OF LIFE

“I want to be happy and live life to the fullest”

“I’m tired of being alone. I’m tired of treatments”

“I want to be a teen-ager again”
EXISTENTIAL WELL-BEING

LEAVING LEGACY BEHIND

“Want to teach them (nieces/nephews) to value a person not material things”

“I was able to help others who are afflicted with the disease through my foundation....”

”I’m happy being able to rescue dogs; it’s actually been a big part of my life now
MY SOCIAL SUPPORT

ROLE OF FAMILY/FRIENDS

“My mother is there all the time with me”. “I feel secured when mom is there with me”

“My family cheers me up and motivates me to keep fighting”

“My friends would visit; we watch movies, talk about school”. “I was doing normal things with my friends”

“I was very happy to see everyone from school...
MY SOCIAL SUPPORT

ROLE OF HC STAFF/SCHOOL

“My oncologist here is amazing; he is flexible with my chemo”

“My nurses treated me like their sister...”

“My teachers understood my treatment schedule; they are flexible with my school work”
MY SOCIAL SUPPORT

INTIMACY

“I broke up with him (boyfriend) when I was diagnosed, was probably the hardest thing I ever had to do in my life”

“People say teenagers cannot fall in love but I definitely think that they can…”

“My boyfriend is like my little counselor”
THIS IS WHERE I BELONG

SUITABLE PLACE FOR TREATMENT

“ I prefer Pediatric staff, more welcoming, they relate with you, they know what to do, they understand you are younger and have different emotions”
“The long waits in the hospital annoys me”
“I like games, drawing and use of creative expressions”
“The waiting room and hospital room were crowded”
“Hospital rooms are boring; need to make it more colorful and happy”
“The things that a patient would like to have in their rooms”
CONCLUSION

Meaning of comfort: holistic care

Significance:
Comfort promotes well being and hopefulness
Hopefulness – essential component in their ability to positively cope; motivation and will power to continue living
Energize them to continue treatment even if the disease is metastatic or progressive
NURSING IMPLICATIONS

Active involvement of adolescent in every discussion

Address distressing symptoms expeditiously

Consult pediatric palliative care early—uncontrolled symptoms

Evaluate presence of psycho-spiritual, social, and environmental distress aside from physical distress. Identify those with psychopathology from the disease.
NURSING IMPLICATIONS

Consult child psychologist at the time of diagnosis

Peer support and involvement, if desired by patient

Provide developmentally appropriate artwork in the patient room

Unit policies that will cater to the needs of adolescents
RECOMMENDATIONS

Conduct similar research in a broader adolescent population with chronic diseases.

Interviewer without direct relationship with the patients.

If study is for cancer patients only, include patients with primary CNS malignancy (ideal however very difficult).
REFERENCES


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