

The Lived Experience of Inpatient Education among Parents with Children Newly Diagnosed with Acute Lymphocytic Leukemia



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Speaker Disclosure Slide

- **Jesusa Chua, MS, RN-BC, CPHON has NO industry relationships to disclose.**
- **She also will NOT discuss any off-label treatments in this presentation.**

Can we start at the beginning?

□ **Good Question....**



□ **This study all began with this burning question:**

How do we improve the delivery of education to parents who were just recently told their child had cancer?

□ **Then this novice's question led to another**

The Burning Question

What is the experience of Inpatient Education among parents with a child Newly Diagnosed with Acute Lymphocytic Leukemia?

How we went about with the study:

- All subjects were identified at a hematology/oncology floor of a Metro Phoenix hospital
- Parents were approached before discharge
- Parents were called post-discharge
- Parents were interviewed in the clinic
- Audio recordings were transcribed and analyzed
- Experts were consulted with the initial findings
- Parents were re-consulted with the results of the study

Thematic Clusters

▣ *Cancer gets personal*

▣ The maze of symptoms and consults

“They have this punch buggy game where they punch each other. So his brother punches him, and his bruise got, you know, black and blue. It was the most unusual bruise I ever saw. It just kind of seeped down and it lasted the entire time we were gone. And it looked very unusual to me, so again I said, ok, when we go to the doctor point out the bruise to the doctor.”



Thematic Clusters

■ *Cancer gets personal*

■ Fear of the Diagnosis

Investigator: how was that weekend for you???

Mom: it was hell...

Investigator: ahahh

Mom: cause one thing I didn't know for sure. One part of me is telling he does have it but the other part is "oh God, please no."

And I'm very shaken, I was very nervous about the whole thing. So upset but I wasn't crying and I just said, "*Son*, we have to go for further blood work because they are not sure at this point".

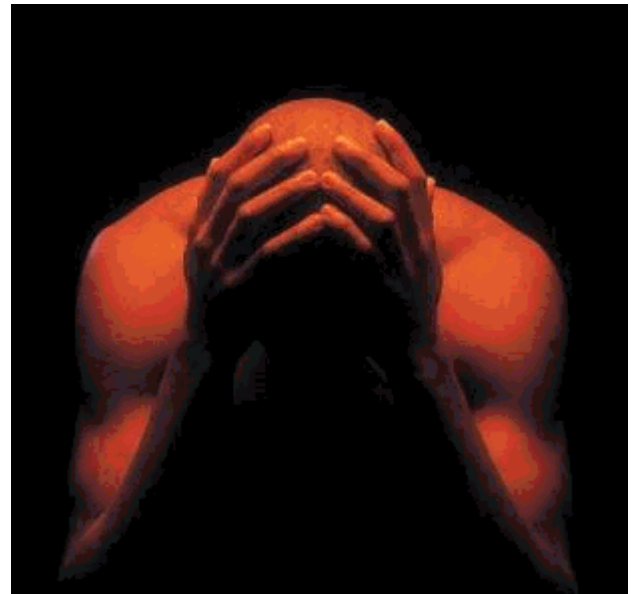


Thematic Clusters

▣ Overwhelming emotion

"I cry, I you know, so then I get frustrated and I lash out at everybody you know and it just hurts to see her like this you know. It's you know, I, I wish she wouldn't have to go through this, I wish it was me, you know, and because she's so young, and she's so you know, she's innocent. You know and I feel like what did I do wrong? You know, why my baby, why her, you know. I wouldn't want this to be on anybody else but you know, you know because she hasn't lived all her life, and I feel like. I feel like, I feel that... I did something wrong with her. (short pause) I put the blame in me. "

▣ A recollection of past experiences



Thematic Clusters

▣ *From Fear to Moving Forward*

▣ The learning begins

“But after Monday when she said it is leukemia, I was ok...let’s do this. What’s next? I want to know. And they gave me a lot of information.”

“when we knew what kind it was I was able to calm down. And I felt more confident about his prognosis, and so I think I was able to take everything in.”



Thematic Clusters



- *From Fear to Moving Forward*
- **Different strokes, same bottom line**

- **Getting the “Doctor Talk”**

I think it was because of the style that it was being offered to you, you know, the different, you know. You know I love all the doctors here, and they are all awesome, but I know they're busy, and a lot of times you ask them something and they just give you the, you know, doctor talk, you know (laughs). And for laymen just like me, I cannot understand. So a lot of times, for me, like in the hospital, I have better luck with, like the nurses and stuff, where they will actually sit down and take the time to explain it to me until I understood what they were talking about.

- **“I need more meat”**

I just think hmmm maybe the nurses were dumbing it down too, but then I thought, I don't expect the nurses to know what my level of education is, or my history or background. So... There was just a couple of occasions where I was kind of upset, they didn't seem like they were hearing me. It didn't seem like they heard me say that I had Hodgkin's disease myself, and you know, I have been through this before. I felt like they should have “upped it up” a little after that but it was still dumbed down.

- **“Dr. X sat with me for an hour”**

Thematic Clusters

▣ *The dilemmas of discharge*

- ▣ “You want me to do what?!”
- ▣ “I would really like to sleep in my own bed now”



Thematic Clusters

▣ *The dilemmas of discharge*

“It would have been nice if you guys talked to my husband”

I think I would have preferred that the doctor talk to him, because he doesn't always listen to me (laughs). I think I know as much as I do, I think he's just more receptive hearing it from a doctor.



Diving into the Depths of this Lived Experience

Perceptions that are at the core of this lived experience

- ▣ An unwelcome and dreaded world**
- ▣ A pre-occupation about it's cause**
- ▣ The comfort of hope**
- ▣ There is ALWAYS a resource**
- ▣ We have stepped into a new world**

Implications of Findings

- **The journey with cancer began way before admission**
- **We all come from our own life-worlds, what about the child and the care provider experiences?**
- **Remember, it is their journey... meet them there.**
- **We can anticipate the difficult phases parents go through**
- **Learn their definition of learning and teaching, meet these expectations**

More Implications

▣ Above all, repeat, repeat, repeat

And everything I've learned is something that I need to know. You know there has been times when I had so many people explain things to me, because just I don't understand. You know, and like one person will explain it to me, and they're like, so this is how it is, and blah,blah, blah (hands gesturing upwards, with eyes to looking towards the ceiling) and then they're off, you know. And I'm like... I still don't get it."

▣ Let us agree to say what we mean

▣ Consistency across settings, and among professions greatly help

▣ We support, we cannot judge

Some necessary considerations

- The investigator has her own 'being-in-the-world'
 - She followed the tradition of Heidegger's hermeneutics
 - She is immersed in the worldviews of scientific inquiry, adult education principles, traditional concepts of grieving, death and dying
 - She entered this experience with the initial goal of 'helping' patient education

Some final thoughts

- ▣ **A few statements before we conclude**
- ▣ **The themes gathered are a reflection of the experience of people interviewed within Metro Phoenix**
- ▣ **Addressing the gorilla in the room**
- ▣ **This study is a first step to tackling the issue of patient education**



Philosophers, as things now stand, are all too fond of offering criticism from on high instead of studying and understanding things from within -- **Edmund Husserl**

Giving Credit

- ▣ The very generous **parents** who re-lived their journeys with me
- ▣ My fearless leaders headed by **Ellen Hansen and Renee Connor**
- ▣ **Kathy Zeblisky and Linda Balk** for their patience with novices
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- ▣ **PCH** who continues to support nursing research

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