



Coping with parental cancer



Mecheline van der Linden, PhD

Medical oncology/Medical psychology

VU medical center



Clinical experience

- Sammy 13 years old; *her grandmother does not approve putting teddy bears on the grave of her mother (died of breastcancer)*
- Victor 14 years old; *very introvert, misses his mother as a judge in hockey games (coloncancer patient)*
- Nick 12 years old; *involved in a fight in school (father is dying of coloncancer)*
- Lisa 9 years old; *intense worries about hereditary breastcancer and (mother is treated for breastcancer)*
- Tamara 11 years old; *problems at school with children yelling cancer words (mother incurable cervical cancer)*



What is known?

- The prevalence of children living with parental cancer is estimated on at least 75.000
- Increased risk to develop adjustment problems; emotional, behavioral, social, physical and cognitive problems
- Adolescent internet use has grown exponentially in the last decade





Study objective/research questions

- To investigate the use and content of web-based peer support in children coping with parental cancer. Is internet an effective tool in supporting children who have to cope with parental cancer?
 - Check clinical experience; do we have to adjust the psychosocial care for children and in what way?
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- To explore the topics and reactions on the web-site for children who are confronted with parental cancer





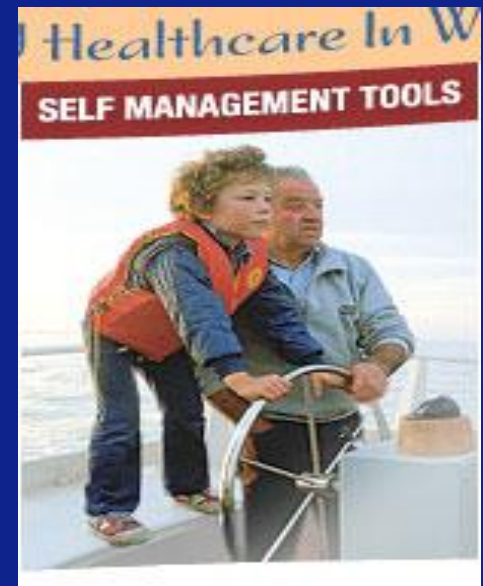
Method: the website

- Since 2001 the website www.kankerspoken.nl is initiated by the Dutch Cancer Society to inform children and to create a place to get in contact with others dealing with the same situation
- Information on cancer and forum discussions for three age groups: children <12 years, children > 12 years, adults.
- Closely monitoring of the site by the Dutch Cancer Society



Method; quantitative analysis

- Data: all complete messages posted in a three month period 1 January till - 1 April 2005
- Focus on forum discussion of children older than 12 years (no age limit)
- Age and gender
- Number of forum discussions each participant
- Preliminary categories are composed on support groups in adults
- Three categories were added for the children group in this study:
 - Seeking contact outside the website
 - Offering help
 - Asking for help





Method; qualitative analysis

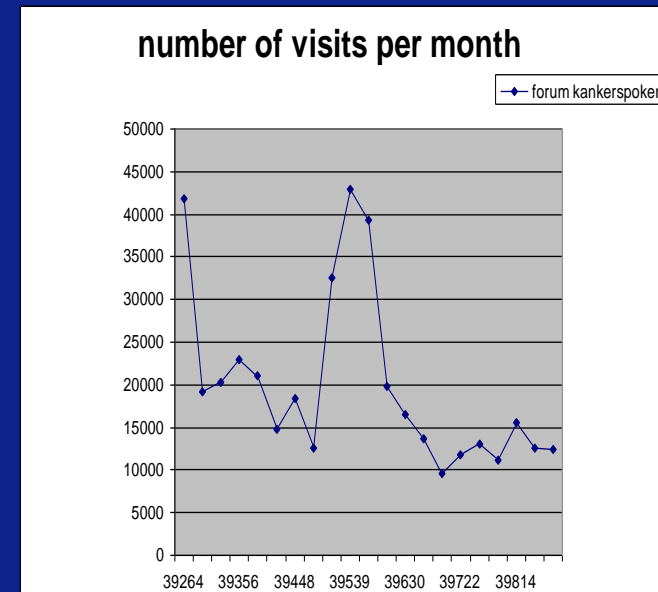
- Content analysis of each separate discussion was carried out with respect to topics children discussed
- Resemblances and differences between the separate discussions were compared
- Three major categories were established:
 - I. Experiencing/expressing emotions
 - II. Problems facing parental cancer
 - III. Types of advice children give each other





Quantitative results

- During the 3 month period 129 children and 8 adults participated in 158 forum discussions (1581 visits)
- Majority girls (80%)
- Mean age 15 years and 3 months old (median age 14)
- Mean number of days of online participation per person 2.96 days
- On average a person started 1.15 discussions and participated in 4.42 discussions
- Main activities on the site:
 - Sharing personal experiences, providing support and seeking contact outside





Quantitative results

Frequency of categories occurring in the 158 forum discussions

Categories	Frequency	Percentage
Personal experience	117	74.1
Encouragement/support	92	58.2
Seeking contact outside the site	56	35.4
Providing advice	41	25.9
Providing personal information	23	14.6
Personal opinion	21	13.3
Words of thanks	20	12.7
Offering help	18	11.4
Asking for help	16	10.1
Seeking advice	14	8.9
Prayer/ hope	9	5.7
Seeking personal information	6	3.8
Humor/ jokes	4	2.5
Providing factual information	4	2.5
Seeking factual information	2	1.3



Qualitative results

- Fears and uncertainties centered on:
 - Losing a loved one
 - Results of medical tests
 - Heredity of cancer
- Several problems
 - Lack of support, especially their peers
 - Lack of understanding
 - Hide feelings and withdraw
 - Concentration problems
 - Other children call names using the word cancer
 - Celebrating birthdays in absence of a beloved person





Main topics and examples of citations resulting from content analysis

I. Expression of emotions

- Sadness
"Sometimes want to cuddle up to my father and cry till my tears run dry".
- Fear
"My father always thinks in worst case scenarios and so do I"
- Uncertainty
"How long will it take...? Does mommy have a lot of pain....? Will she be alright? I don't want to lose her yet... "
- Anger
"It felt terrible to be so helpless, I can't take the cancer away. It makes me angry".
- Guilt
"Last summer my father died. He had been ill for a long time. I was the one that cried least of all. I feel guilty about that".



Main topics and examples of citations resulting from content analysis

II. Problems facing parental cancer

- Lack of social support
"I can't talk about it with my parents, I'm afraid of causing them even more sorrow".
- Lack of receiving understanding from environment
"The outside world thinks we're doing okay, but they don't see the misery our family is going through".
- Hiding feelings
"...I never talk about it with other people, it would make me cry and I hate crying".
- Concentration problems
"I'm not doing well at school as I can't concentrate".
- The word cancer used as a term of abuse
"I think it's stupid to call names using the word cancer. You don't want anybody to suffer from cancer".



Main topics and examples of citations resulting from content analysis

III. Giving advice

- To write down problems
"I think it might help you to write down your problems, It certainly helped me".
- To talk about feelings
"Try to phone the child-line or talk to the school social worker.. "
- To seek contact with fellow sufferers
"This forum is a nice place for talking to fellow sufferers about having a sick parent/brother/neighbour, etc. My mum is suffering from breast cancer and I am pleased with a site like this where you can tell your own story, give vent to your feelings and talk about your emotions".
- To look for distraction
"Try to play a sport, do not lie down on the couch all day"



Conclusion

- Web-based support is an easy and accessible option in psychosocial care; it offers a window into the child experience of parental cancer
- Primarily exchanging personal feelings and experiences concerning the illness (in contrast with online support groups for adults: information)
- Clinical experience corresponds with the findings of child expressions on the site; information for teachers and parents (Sammy, Nick and Tamara), how to get in contact with children (Victor and Lisa)
- Further prospective studies are needed to investigate efficacy of web-based peer support





Discussion

- Unclear whether the emotions are temporarily or structural
- Closely monitoring of the site is advisable; foundation 'Sadness in your head'. Revised website ready end 2009.
- We must improve and expand the site to meet the needs of children

