

VIVO3 - Visualising your cancer to help you cope

Poole, J. ¹Furber, L.² M. Dean, L.² Morris, M²

1. University Hospitals of Leicester NHS Trust. 2 De Montfort University. 3. Nottingham University Hospitals. 4. Teenage Cancer Trust

Introduction

Less than 1% of cancer diagnoses occur in teenagers and young adults (TYA) between the ages of 13 and 25 years every year (Cancerresearchuk.org). The most common types of cancer experienced in this subgroup of patients are lymphomas, germ cell cancers, brain tumours and bone cancers, such as osteosarcoma or Ewing's sarcoma. Initial consultations with healthcare professionals in cancer services suggest that this subgroup of patients would benefit from being able to visualise their own personal tumours in an abstracted, three-dimensional form. It is anticipated that 3D printed visualisation tools could help TYA patients understand their diagnosis and enable them to develop coping strategies.

Methods

TYA patients (N=11) from across the East Midlands consented to take part in a pilot study designed to explore whether or not having a visual, three-dimensional representation of their own personal cancer would help them to understand their diagnosis and come to terms with their disease. In addition, 2 parents were also present during one focus group and their opinions were also captured.

A number of proto-type 3D-printed tumours, made from a plastic compound were constructed, and molecular models of growth and metastasis were designed. These proto-types were used to aid discussions with two groups of TYA patients in two separate focus group discussions. Each focus group lasted approximately 90 minutes and were held in the Teenage Cancer Unit social room at each participating hospital.

The research question was:

Can 3D printed visualisation tools help cancer patients understand their diagnosis and enable them to develop coping strategies:

- By providing them with a sense of perspective of the size and site of the tumour
- By helping them to understand the different treatment options (i.e. surgery) available to them and aid their decision-making
- By providing patients with a tangible object to help them understand and explain their disease to friends and relatives
- By "abstracting" the form of the tumour, to aid parents in helping their children to cope, either with their own cancer or that of a close relative

The qualitative data was analysed using a thematic analysis approach to analyse the data using the following steps, data familiarisation, data coding, theme development and revision (Braun & Clarke, 2006).

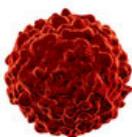
Results

Visual representation



There was a strong opinion amongst the two groups that they wanted to see their scan images to help them visualise their cancer; to help them understand what was wrong with them. Some doctors didn't appear to want to show scan images to patients but participants felt that if they were requesting to see the images then their wishes should be respected, regardless of whether the cancer had grown or not. Seeing the scan image was empowering.

Introducing the 3D Model



It was generally agreed that a member of staff could discuss the option of having a 3D model with patients individually and the 3D model could be discussed on Facebook. TYA patients also wanted the option to call a nurse and ask them about this directly, particularly if their friends already had one. They would prefer it though if their doctor gave them the 3D model so that the patient could ask them questions about it. Some people would like the option of having the 3D model at the point of diagnosis whilst others felt that they might want one a few months after diagnosis or when they went into remission. It was agreed that the decision was very individual and would depend on how well they were coping with their diagnosis.

Therapeutic Aid



Participants spoke of wanting to do a number of things with their 3D model which in some way would be therapeutic to them. Several participants spoke of smashing the 3D model to destroy it, whilst others suggested that a 3D image in a softer material would be helpful as they could then squeeze the 3D Model repeatedly at times of stress or anxiety. Some spoke of keeping the 3D model in their memory box so that they could look back at it in the future and remind themselves that they had beaten this cancer. There was a consensus of opinion that what you chose to do with the 3D model would depend on what stage your cancer was and how you were coping with your diagnosis.

Communication Aid



There was a general consensus that the 3D Model would help them to integrate with their peers when first diagnosed (particularly if they named it). The model could be used to help them engage in conversations with their family and friends and would be a focal talking point. Additionally, some described how the model might help educate them about their cancer more so than being presented with written information and told to go away and read it.

I have just been diagnosed for the 4th time and I have asked consultants to see the scan and they say 'well...it isn't about the size' and I'm thinking well it kind of is, please show me my scans and explain how big it is. (F)

It helps me to understand what I am dealing with. (F)

I think at diagnosis because I didn't really understand what cancer was and I think to actually have an image right in front of me...would have been a lot easier to deal with (M)

When told my diagnosis, I was in denial. So I don't think I would want this then or if I did I wouldn't have wanted it until a few months after my diagnosis. (F)

I think if you were at peace with it, you'd want to keep it...it's not that much of a threat anymore, but if you are still trying to get through it you might be more prone to destroy it. (F)

If it was like a stress ball, you could squidge it, then it would go back and...if you are really stressed out you could have a go at it again. That would be awesome (M)

We could have a ceremonial smashing when we got the all clear. (M)

Look at what I have got?... Like an ice-breaker, when you meet someone new, this is mine....(F)

...it would help my parents understand what happened to me. It would be beneficial depending on which member of the family you are talking to. (M)

Conclusions

The majority of TYA patients that attended the focus groups felt that being able to visualize their cancer would help them and their families/ peers to come to terms with their diagnosis. They also felt it would enable them and families/peers to understand their cancer.

Further questions need to be answered amongst medical professionals with regards to their engagement in the study and whether they would be happy to give the 3D model to patients in their consultation. Will this add more time to the consultation? If so is this feasible?

Further work needs to be done around the time points of when best to give patients the 3D model and which healthcare professional is best placed to do this?

This is an innovative and exciting project that could be used in all groups of patients with a cancer diagnosis.

Literature cited

Cancer Research UK
Braun V., Clarke V. (2006) Using Thematic Analysis in Psychology.
Qualitative Research in Psychology, 3(2) 77-101

Acknowledgments

We would like to thank the patients and parents who participated in this pilot study. We would also like to thank the Teenage Cancer Trust Youth Support Coordinators who helped us recruit participants to this study and helped organise the focus groups discussions.