

## PEER REVIEW HISTORY

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### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Being normal, not vulnerable – case study of a two-day residential programme for young adults with cancer
<b>AUTHORS</b>	Martins, Ana; Taylor, Rachel; Morgan, Sue; Fern, Lorna

### VERSION 1 - REVIEW

<b>REVIEWER</b>	Lena Wettergren Karolinska Institutet, Sweden
<b>REVIEW RETURNED</b>	03-Jan-2017

<b>GENERAL COMMENTS</b>	<p>This is a well-written manuscript that reports results of an evaluation of a two day residential program for teenagers and young people with cancer. With a qualitative design the study aimed to conduct a process evaluation of the “Find Your Sense of Tumor”, an educational, social and peer-to-peer support program directed to those over 18 years of age. Study results are based on observations of interactions between young people and interviews, face-to-face and over the telephone, with 26 professional participants (professionals from hospitals, program organizers and people from the steering committee). Four key outcomes for the participating young people were identified: Positive attitudes, belonging, recreation, and increased knowledge. Furthermore, three interlinked influencing factors were found: being with other young people, the professionals accompanying young people to the program, and the conference program. The findings are somewhat expected from a program of this kind with a schedule and content thought through and well planned. It is still of great interest to evaluate care actions in this format as they are underreported from a scientific point of view and may be a value to patients and their families. However, the described methodology and results lack some information to be able to fully grasp and judge the manuscript.</p> <ol style="list-style-type: none"><li>1. Study results are based on interviews with professionals and observations of interactions between young participants having had or having cancer and it is not explained why not the participating young people with cancer are interviewed? Are their experiences planned to be presented elsewhere or why are they not of interest? This is a crucial question to answer.</li><li>2. Almost no information is presented about the attendees. I suggest the authors to add descriptive information such as sex, age, diagnoses and educational status/working situation.</li><li>3. In “strengths and limitations” following the abstract one of the bullets state that “attendance at the residential program is free to young peoples and so limits socioeconomic bias”, a statement not backed by facts.</li><li>4. The introduction’s first three sentences included 18 references. Please choose only key references (exclude at least half of them),</li></ol>
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	<p>and use updated publications published no more than 8 years ago especially for areas currently under change such as sexuality.</p> <p>5. The authors describe that even if a number of programs exist, evaluation of what works is lacking. However, the text (last paragraph page 4) presents several outcomes in line with your own findings and it is not totally clear how your study adds to the body of knowledge. Please clarify the knowledge gap and rationale for the study. Furthermore, the last sentence on page 4 is not understandable and needs to be clarified.</p> <p>6. It is stated that an independent researcher attended and observed the program. How was she selected? What was her preunderstanding and experience of childhood cancer? She is described as having 10 years' experience working with children and young people, in what context? This is crucial information as this will reflect the analysis and understanding of the results.</p> <p>7. Why were so many professionals approached for possible participation (N=75)? Did any of those who chose not to participate mention a reason for withdrawing? Even if no ethical clearance for analyzing non-responders existed maybe approached possible participants spontaneously expressed causes for their decision.</p> <p>8. The data analysis is described as a framework approach analyzing transcripts and observation field notes with content analysis in five key stages. Please describe each of these stages with a concrete example. I suggest a figure with boxes to show how text/observation (one example from a transcribed interview text and one example from an observation) was worked through the 5 steps.</p> <p>9. The authors call the interviews they conducted deep but according to how they are described they do not appear to be deep. I suggest that the label deep is deleted.</p> <p>10. The discussion is in large a justification of the results and a deeper discussion including a reflection of the study's limitations is lacking. The second paragraph on page 16 states: "note taken throughout the residential programme were descriptive and no interpretations were made until analysis." It sounds as you do not understand that the choice of interactions to record is the start of analysis. The authors are asked to describe their view of qualitative methodology in the method's section with a reference.</p>
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<b>REVIEWER</b>	O Husson Radboud University, Netherlands
<b>REVIEW RETURNED</b>	19-Feb-2017

<b>GENERAL COMMENTS</b>	<p>This manuscript presents the process evaluation of an educational, social and peer-to-peer support residential program for young people affected by cancer and identified key outcomes for these young people. The manuscript is well written and clear. I only have some minor comments:</p> <p>The authors should describe more clearly in their abstract that this study is focused on the perspective of the professional</p> <p>Please provide a rationale for not including patients in this process evaluation</p> <p>Add the fact that patients are not included as a limitation of this study</p> <p>In their introduction the authors focus on adolescents and young adults, while this study focuses on a program for young adults (18+). Please remove the term "adolescents". And change the title of the manuscript accordingly.</p> <p>The exact role of the professionals is not described and not clear in</p>
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	the results section.
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## VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Reviewer Name: Lena Wettergren

Institution and Country: Karolinska Institutet, Sweden

Competing Interests: None declared

This is a well-written manuscript that reports results of an evaluation of a two day residential program for teenagers and young people with cancer. With a qualitative design the study aimed to conduct a process evaluation of the “Find Your Sense of Tumour”, an educational, social and peer-to-peer support program directed to those over 18 years of age. Study results are based on observations of interactions between young people and interviews, face-to-face and over the telephone, with 26 professional participants (professionals from hospitals, program organizers and people from the steering committee). Four key outcomes for the participating young people were identified: Positive attitudes, belonging, recreation, and increased knowledge. Furthermore, three interlinked influencing factors were found: being with other young people, the professionals accompanying young people to the program, and the conference program. The findings are somewhat expected from a program of this kind with a schedule and content thought through and well planned. It is still of great interest to evaluate care actions in this format as they are underreported from a scientific point of view and may be a value to patients and their families. However, the described methodology and results lack some information to be able to fully grasp and judge the manuscript.

1. Study results are based on interviews with professionals and observations of interactions between young participants having had or having cancer and it is not explained why not the participating young people with cancer are interviewed? Are their experiences planned to be presented elsewhere or why are they not of interest? This is a crucial question to answer.

Thank you for your comment and we agree that capturing the experiences of young people is crucial to the evaluation of the conference. The results presented in this manuscript provide the foundation on which we designed a longitudinal evaluation of the conference from the perspective of the young people attending, significant others and professionals involved in their care who attend the conference. The evaluation involving young people began in November 2016 for young people attending that conference with data collection occurring at five times over 13 months. The evaluation survey was informed by the study presented here and retention rates at second data collection point are 100% which we think reflects the understanding of the conference gained during this study. Although the experiences of young people attending the November 2015 conference were not examined extensively two of the steering committee members interviewed were young people who attended the November 2015 conference and a further two young people from the steering committee had attended previous conferences.

2. Almost no information is presented about the attendees. I suggest the authors to add descriptive information such as sex, age, diagnoses and educational status/working situation.

We have added Table 2 which details the self- reported demographic details of the young people attending the residential programme. During the event young people participate in an electronic survey ‘Have Your Say’ (see appendix 1), participation is voluntary and young people consent to have their answers used to inform research and strategy.

3. In “strengths and limitations” following the abstract one of the bullets state that “attendance at the residential program is free to young peoples and so limits socioeconomic bias”, a statement not backed by facts.

Thank you for your comment. We have amended the statement to illustrate the purpose of free

attendance for all young people is to promote inclusiveness for those who may not otherwise be able to attend. The costs of accommodation, travel to and from the venue, food and all residential programme activities including workshops are covered. Thus, the residential programme aims to reduce the financial restrictions imposed by those from lower socioeconomic background. We have also added this to Table 1 which describes the structure of the conference.

4. The introduction's first three sentences included 18 references. Please choose only key references (exclude at least half of them), and use updated publications published no more than 8 years ago especially for areas currently under change such as sexuality.

We have edited the manuscript as you have suggested. Thank you for your observations.

5. The authors describe that even if a number of programs exist, evaluation of what works is lacking. However, the text (last paragraph page 4) presents several outcomes in line with your own findings and it is not totally clear how your study adds to the body of knowledge. Please clarify the knowledge gap and rationale for the study. Furthermore, the last sentence on page 4 is not understandable and needs to be clarified.

Thank you for your comment. On reflection we agree this paragraph would imply that our work is not novel and acknowledge we have not described these studies fully. The studies referenced refer to children, families and young people with a range of diseases.

ref 19: children with cancer and families (review of 20 papers), ages: 8 to 19 years

ref 26: Youth with cancer, ages: 8–14 years

Ref 27: Adolescents: ages 15–18 years

Ref 28: 13-18 years (M=15.7, SD=1.5) with cancer

Ref 29: adolescents, ages, spectrum of disease - youth aged 14–15 with cancer, sickle cell disease, HIV/AIDS, or metabolic diseases

Our study is first study of a homogenous population of young adults aged 18-24 with cancer. This is an important population to study as they present with unique needs as reported in a review of social wellbeing referenced in the introduction "young people with cancer reported greater challenges in social functioning compared to the general population and when compared to younger and older cancer patients [1]". It is also novel in that it provides a triangulation of perspectives from the programme organisers, professionals attending and the young people on the steering committee in addition to the observations.

We have edited the last sentence on page 4 to ease readability.

6. It is stated that an independent researcher attended and observed the program. How was she selected? What was her preunderstanding and experience of childhood cancer? She is described as having 10 years' experience working with children and young people, in what context? This is crucial information as this will reflect the analysis and understanding of the results.

The independent researcher was selected to be part of the research team due to her experience working with children and young people in different projects, including child abuse and neglect, adolescents in residential care settings, children and young people with acute and long term conditions and children and young people with cancer. Her understanding and experience of childhood cancer was deepened in a 3-year longitudinal study evaluating the role of a nurse specialist key worker role for children with cancer and their families. This mix-methods evaluation included interviews with professionals, parents and children about their experience of care. Furthermore, as stated in the methods the analysis was also validated by other team members who have extensive experience in a range of research methods and particularly with young people and cancer.

7. Why were so many professionals approached for possible participation (N=75)? Did any of those who chose not to participate mention a reason for withdrawing? Even if no ethical clearance for analyzing non-responders existed maybe approached possible participants spontaneously expressed

causes for their decision.

In order to be inclusive all professionals attending the 2015 residential programme were invited to participate by an 'opt-in' process. Only those who consented to having their contact details shared were contacted by the researcher to arrange an interview (n=19). We did not collect any information on those who did not want to participate and all those who consented completed an interview. We have added this detail to the manuscript for clarification.

8. The data analysis is described as a framework approach analyzing transcripts and observation field notes with content analysis in five key stages. Please describe each of these stages with a concrete example. I suggest a figure with boxes to show how text/observation (one example from a transcribed interview text and one example from an observation) was worked through the 5 steps.

Thank you for your comment. Appendix 4 has a figure detailing how the analysis was developed through the 5 phases with examples from the transcribed interview and observations.

9. The authors call the interviews they conducted deep but according to how they are described they do not appear to be deep. I suggest that the label deep is deleted.

We are unclear what the reviewer refers to as we describe our interviews as in-depth not deep. Nevertheless, we have change to 'semi-structure interviews'.

10. The discussion is in large a justification of the results and a deeper discussion including a reflection of the study's limitations is lacking. The second paragraph on page 16 states: "note taken throughout the residential programme were descriptive and no interpretations were made until analysis." It sounds as you do not understand that the choice of interactions to record is the start of analysis. The authors are asked to describe their view of qualitative methodology in the method's section with a reference.

Thank you for your comment. We have added a description of our view of qualitative methodology in the method's section with a reference; we have changed the title of the manuscript to reflect this. We feel the discussion is a true reflection of our results in the context of available research evidence for young people with cancer. However, we acknowledge that limitations were not described fully and we have added this to the text. For example, that although our protocol detailed that notes taken throughout the residential programme were descriptive and no interpretations would be made were made until analysis, we acknowledge that the process of recording is in itself an interpretation and set some strategies to capture as many experiences as possible (e.g. the researcher visited all settings within the residential programme). We have added this to the discussion in the manuscript. We have also added that the voice of young people is largely missing from this study and their views are currently being captured in a longitudinal study.

Reviewer: 2

Reviewer Name: O Husson

Institution and Country: Radboud University, Netherlands

Competing Interests: None declared

This manuscript presents the process evaluation of an educational, social and peer-to-peer support residential program for young people affected by cancer and identified key outcomes for these young people. The manuscript is well written and clear. I only have some minor comments:

The authors should describe more clearly in their abstract that this study is focused on the perspective of the professional

We have added to the objectives that the observations are from the views of professionals attending and four patient representatives who sit on the steering committee and have attended the conference

at least twice.

Please provide a rationale for not including patients in this process evaluation

Thank you for your comment and we agree that capturing the experiences of young people is crucial to the evaluation of the residential programme. The results presented in this manuscript provide the foundation on which we designed a longitudinal evaluation of the conference from the perspective of the young people attending, significant others and professionals involved in their care who attend the conference. The evaluation involving young people began in November 2016 for young people attending that residential programme with data collection occurring at five times over 12 months. The evaluation survey was informed by the observation study presented here and retention rates at second data collection point are 100% which we think reflects the understanding of the conference gained during this in-depth observational study. We have added this to the text.

Although the experiences of young people attending the November 2015 conference were not examined extensively two of the steering committee members interviewed were young people who attended the November 2015 conference and a further two young people from the steering committee had attended previous conferences.

Add the fact that patients are not included as a limitation of this study

Thank you, this has been added to the discussion.

In their introduction the authors focus on adolescents and young adults, while this study focuses on a program for young adults (18+). Please remove the term “adolescents”. And change the title of the manuscript accordingly.

Thank you for your comments on reflection we agree that the paper is focussed on young adults and have changed the title accordingly and updated the manuscript throughout.

The exact role of the professionals is not described and not clear in the results section.

Thank you for your comment and we feel the role of the professional is described in the section ‘Support and guidance from professionals’ on page 14 of the manuscript, we also mention in Table 1 under ‘group leaders: patient ratio’ the purpose of the professionals is to safe guard young people and provide support and we have added further text under ‘participants’ which now includes the sentence ‘The role of the professionals at the conference is to provide safe guarding and support for the young people attending in their group.’

## VERSION 2 – REVIEW

<b>REVIEWER</b>	Lena Wettergren Karolinska Institutet, Sweden
<b>REVIEW RETURNED</b>	30-Apr-2017
<b>GENERAL COMMENTS</b>	The authors have satisfactorily responded to my questions and made the necessary changes to the manuscript. I think this is an interesting paper that adds to the literature regarding survivorship of adolescents and young adults with cancer.