

PEER REVIEW HISTORY

BMJ Paediatrics Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Fortune favours the brave: Composite first person narrative of adolescents with congenital heart disease
AUTHORS	Biglino, Giovanni; Layton, Sofie; Leaver, Lindsay-Kay; Wray, Jo

VERSION 1 - REVIEW

REVIEWER	Corno, Antonio University of Leicester Cardiovascular Research Center Leicester, UK Competing interests: None
REVIEW RETURNED	08-Aug-2017

GENERAL COMMENTS	<p>The Authors have to be congratulated for this fantastic initiative. They certainly are opening the mind of many of the caregivers involved with congenital heart defects.</p> <p>Few points to be considered in order to further improve the quality of the manuscript.</p> <p>1) Did you consider the diversities in this group of patients? Several studies carried on by the caregivers involved with the medium-long term follow up of these patients, generally involved with the requirement of the neurological and psychological issues correlated with congenital heart defects, have shown the different behaviours correlated with the characteristics of the parents in terms of ethnicity, social level, educational level, type of occupations, etc. The same has been seen for the social life style of the patients, their educational level and their education.</p> <p>It would be interesting to have more information on this respect for the group of patients examined in this study.</p> <p>2) these patients are evidently all "millennials". Did the research take in consideration the unique way used by the "millennials" to communicate and to learn, in comparison with the previous generation?</p> <p>"Millennials" have a different focus, attention span, limited memory for verbal communication, easy attention to written short messages (SMS, WhatsApp, etc.), and the same it has been demonstrated for the visually transmitted information.</p> <p>Maybe the authors should add a comment related to these characteristics of the "millennials" to better explain the results of their observations.</p> <p>Once again: congratulations to all Authors for this very interesting article, forcing the people to think outside the box.</p>
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REVIEWER	Phillips, Bob CRD, University of York Competing interests: None
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REVIEW RETURNED	20-Sep-2017
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GENERAL COMMENTS	<p>This is a clearly written report of a programme of artistic events with a small group of young people with congenital heart disease attending a central London (UK) quaternary hospital to reflect upon their identity and the place of CHD within this.</p> <p>The report then uses the professional authors views and experiences of these workshops to develop a single, composite, first person narrative of the experience.</p> <p>The concept, of using the experiences of patients explored through art to illuminate aspects of health and illness that HCPs may not appreciate is not new, but is uncommon, and is worth repeating.</p> <p>I am comments are that we do not understand</p> <ol style="list-style-type: none"> 1. how the single narrative was constructed - where did the co-authors negotiate, was there really one dominant writer or group authorship, what weight did the deviant elements from the workshops gain and what insight are we losing when the 'mess' is cleared up? to take a note from the paper - why is it being suggested that an overlay-meld of all Cézanne painting of the Montagne Sainte-Victoire overlooking Aix-en-Provence are better than examining the separate ones? 2. how was this narrative taken back to the participants to triangulate with their own experience of the workshops? 3. where can this be used in future and what pieces of the process were the ones which seemed to elicit the greatest insight (for use by HCP) or benefit (for the participants)?
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VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Comments to the Authors

The Authors have to be congratulated for this fantastic initiative. They certainly are opening the mind of many of the caregivers involved with congenital heart defects. Few points to be considered in order to further improve the quality of the manuscript.

[We thank the Reviewer for the positive feedback and for the constructive suggestions.](#)

1) Did you consider the diversities in this group of patients? Several studies carried on by the caregivers involved with the medium-long term follow up of these patients, generally involved with the requirement of the neurological and psychological issues correlated with congenital heart defects, have shown the different behaviours correlated with the characteristics of the parents in terms of ethnicity, social level, educational level, type of occupations, etc. The same has been seen for the social life style of the patients, their educational level and their education. It would be interesting to have more information on this respect for the group of patients examined in this study.

[We appreciate this aspect and, albeit the size of our sample is too small to comment on key variables known to have an impact on neuropsychological outcomes, we have added a note on participants being at the same level in terms of their education. We did not collect any information about the parents of the young people. With regards to the process itself, we have also added a qualitative observation on the potential role of the artistic process in creating a bond between participants.](#)

[Addition to manuscript \(p. 5\) - All patients were in the final two years of secondary education and were in the process of applying for university.](#)

Addition to manuscript (p. 13) – Variables including ethnicity, social status, level of education or type of professional occupation (including parental education) are known to affect neuropsychological outcomes in CHD patients [15]. In our study, the sample size was too small to evaluate differences in some of the key variables at play, but we note that participants were all at an equivalent stage in their education and engaged well during the workshop process. Furthermore, we would advocate that the artistic process contributed to creating a bond between participants which, qualitatively, was demonstrated by their high level of engagement, willingness to share their stories and returning for a second workshop.

2) These patients are evidently all "millennials". Did the research take in consideration the unique way used by the "millennials" to communicate and to learn, in comparison with the previous generation? "Millennials" have a different focus, attention span, limited memory for verbal communication, easy attention to written short messages (SMS, WhatsApp, etc.), and the same it has been demonstrated for the visually transmitted information. Maybe the authors should add a comment related to these characteristics of the "millennials" to better explain the results of their observations.

We hesitate to comment overtly on 'millennials', as according to definition millennials are born between 1977 and 1995 and our participants are just above the definition. Nevertheless, we have added a comment on the nature of the participants and their ways of learning and interacting.

Addition to manuscript (p. 13) – It is also important to consider character traits typical of a generation which tends to be techno-savvy and collaborative [16-17] in support of adopting a creative and visual approach in a workshop setting to explore patients' narratives.

Once again: congratulations to all Authors for this very interesting article, forcing the people to think outside the box.

Reviewer: 2

Comments to the Authors

This is a clearly written report of a programme of artistic events with a small group of young people with congenital heart disease attending a central London (UK) quaternary hospital to reflect upon their identity and the place of CHD within this. The report then uses the professional authors views and experiences of these workshops to develop a single, composite, first person narrative of the experience. The concept, of using the experiences of patients explored through art to illuminate aspects of health and illness that HCPs may not appreciate is not new, but is uncommon, and is worth repeating.

We thank the Reviewer for the positive feedback and for the constructive comments.

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1. how the single narrative was constructed - where did the co-authors negotiate, was there really one dominant writer or group authorship, what weight did the deviant elements from the workshops gain and what insight are we losing when the 'mess' is cleared up? to take a note from the paper - why is it being suggested that an overlay-meld of all Cézanne painting of the Montagne Sainte-Victoire overlooking Aix-en-Provence are better than examining the separate ones?

We have added clarifications with regards to constructing the narrative and the approach that was taken, in addition to what already mentioned in the Methods. We have also discussed more about the composite approach vs. individual accounts, as it was not our intention to communicate that the composite would be in any way *better* than individual stories, but rather an approach to protect participants' anonymity and creating a representative narrative, which does not in any way diminish the uniqueness and the importance of individual narratives.

Addition to manuscript (p. 8) – Three authors (GB, SL and JW) developed a narrative independently and differences in the approach, tone and key elements to be included were then discussed prior to creating a merged version, which resulted in the final 'composite'. This was then shared with the fourth author (LK-L) to further check the truthfulness of the re-presentation. As such, there was not a dominant writer but the approach was considered as a group authorship.

Addition to manuscript (p. 14) – Each individual account contains unique elements and should in itself be respected and hailed as significant [18]. A composite approach does not intend to dilute this uniqueness or suggest that singular images or expressions should be removed in an amalgamation of common traits. Rather, the composite approach was chosen as a way to protect individual stories and identities, by combining all of them into one. Indeed, it is suggested that this method could lead to a “more embodied” understanding of the phenomenon being re-presented, conveying its wholeness [8].

2. how was this narrative taken back to the participants to triangulate with their own experience of the workshops?

We shared the narrative via email with all participants and they were invited to comment on whether elements of it reflected their own individual narrative. Indeed, participants commented positively about the composite approach: “I really appreciate the personal aspect of the narrative but without compromising patient confidentiality”; or “It brought some of my family and friends to tears as they suddenly could feel the emotion from the perspective of a heart patient, which as an individual is hard to explain”. We have added this information in the paper.

Addition to manuscript (p. 8) – The final version of the composite narrative (presented in the Results section of this paper) was also shared via email with the workshop participants. They were invited to comment on whether elements of it reflected their own individual narrative and the feedback that we received from them indicated that this was indeed the case.

3. where can this be used in future and what pieces of the process were the ones which seemed to elicit the greatest insight (for use by HCP) or benefit (for the participants)?

We have added on this important point in the Discussion, on top of noting that “The exploration and assimilation of stories of illness has been advocated to lead to better understanding and, as a result, improvement of health care” (p.14).

Addition to manuscript (p. 13) – The workshop was framed as an artistic activity and not as art therapy. This is an important distinction, as the artist leading the workshop was focusing on using the creative tools to stimulate and hold the narratives. Participants’ benefit, nevertheless, could be inferred from the feedback received via email after the activities, mostly referring to the possibility of sharing their accounts and to the opportunity of doing it with peers who also have a form of CHD. One participant eloquently reflected on the approach being “very useful when going through the transition clinic” as “[i]t made me feel like I still mattered as opposed to feeling like I was being forgotten and passed on without much thought”, and that “[t]he work with the artist allowed me to actually reflect on what my condition meant to me and how it impacted me growing up; this was a good way to mark the transition into being an adult patient”.