



Penny, E., & Malpass, A. (2019). Dear Breath: using story structure to understand the value of letter writing for those living with breathlessness- a qualitative study. *Arts and Health*.
<https://doi.org/10.1080/17533015.2018.1555178>

Publisher's PDF, also known as Version of record

License (if available):
CC BY-NC-ND

Link to published version (if available):
[10.1080/17533015.2018.1555178](https://doi.org/10.1080/17533015.2018.1555178)

[Link to publication record in Explore Bristol Research](#)
PDF-document

This is the final published version of the article (version of record). It first appeared online via Taylor & Francis at <https://www.tandfonline.com/doi/full/10.1080/17533015.2018.1555178>. Please refer to any applicable terms of use of the publisher.

University of Bristol - Explore Bristol Research

General rights

This document is made available in accordance with publisher policies. Please cite only the published version using the reference above. Full terms of use are available:
<http://www.bristol.ac.uk/pure/about/ebr-terms>



Dear Breath: using story structure to understand the value of letter writing for those living with breathlessness – a qualitative study

Elsbeth Penny & Alice Malpass

To cite this article: Elsbeth Penny & Alice Malpass (2019): Dear Breath: using story structure to understand the value of letter writing for those living with breathlessness – a qualitative study, Arts & Health, DOI: [10.1080/17533015.2018.1555178](https://doi.org/10.1080/17533015.2018.1555178)

To link to this article: <https://doi.org/10.1080/17533015.2018.1555178>



© 2018 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 14 Jan 2019.



Submit your article to this journal [↗](#)



Article views: 49



View Crossmark data [↗](#)

Dear Breath: using story structure to understand the value of letter writing for those living with breathlessness – a qualitative study

Elsbeth Penny^a and Alice Malpass^b

^a2BU Productions, Blagdon, UK; ^bCentre for Academic Primary Care, Bristol Medical School, Bristol, UK

ABSTRACT

Background: Despite the prevalence of dyspnoea (the pathological term for breathlessness) amongst the general population and the diagnostic importance of dyspnoea for respiratory illness, public awareness of dyspnoea is poor with an estimated two million people with undiagnosed Chronic Obstructive Pulmonary Disorder in the UK. We explore whether therapeutic letter writing is a valuable arts health approach for those living with breathlessness.

Methods: Eighty (80) participants took part in 10 workshops held in community-based settings. The overall approach was qualitative. We analysed the data thematically.

Results: Informed by theories of story structure, our analysis explores letters written to the breath in terms of there being a protagonist, antagonist, a process of recognition and reconciliation.

Conclusions: Writing a letter to the breath facilitates new ways of relating to breathlessness. Letters create a personal narrative and workshops create a public story. Further research should explore whether therapeutic letter writing can support communication about breathlessness with clinicians.

ARTICLE HISTORY

Received 21 May 2018

Accepted 14 October 2018

KEYWORDS

COPD; qualitative data; therapeutic letter writing; story structure; public story

Introduction

Therapeutic letter writing

Interest in therapeutic letter writing, in which someone writes a letter as part of their treatment plan goes back to the 1960s with the development of humanistic psychology and person-centred psychotherapy and *The Use of Written Communications in Psychotherapy* (Pearson, 1965). The approach was developed during the 1970s and 1980s, largely by Australian social workers (White & Epston, 1990). Letter writing gained further ground therapeutically through its adoption by narrative therapy and family system therapy, for example in Canada as part of a family systems nursing intervention (Bell, Moules & Wright, 2009). More recently mindfulness based approaches in the UK have adopted letter writing (Bartley, 2012). In practice it has taken many forms. Letters may be written to an aspect of the self, never intended to be sent but kept by the letter writer (Bolton, 1999) or letters can be written to a future self which are then handed over

CONTACT Alice Malpass  a.malpass@bristol.ac.uk

© 2018 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group
This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

to the therapist, who at some unspecified time, will post the letter back to the letter writer (Bartley, 2012). Letters may be written to a person who has hurt the letter writer in some way, again never to be sent but may be read by a therapist or read out by the letter writer to a creative self-help writing group (Jolly, 2011), or letters may be written to oneself from the future as part of a counselling process (Kress, Hoffman & Thomas, 2008). The literature in this area has explored the potential benefits of letter writing for people with both physical and emotional long-term health conditions. For example, letter writing to address physical pain (Bolton, 1999), letter writing that explores grief associated with a deceased parent (Keane, 1996) or letter writing to an amputated limb (Nau, 1997). All these studies highlight the therapeutic benefits which lead to improved wellbeing yet there is no consensus in the literature on mechanisms of action – how reported or observed benefits come about (Wright & Cheung Chang, 2001).

Nearly 20 years ago, Smyth, Stone, Hurewitz, and Kaell (1999) conducted a randomised controlled trial study on the effects of writing (not letter writing) on symptom reduction in patients with asthma. They found patients with mild to moderately severe asthma who wrote about stressful life experiences had clinically relevant changes in health status at four months compared to those in the control group. Smyth and Stone do not describe if asthma patients wrote about their breathlessness as their nominated “stressful experience”, nor do they report any qualitative data on what patients felt about the experience of writing. Neither are we aware of more recent attempts to use therapeutic letter writing with those experiencing breathlessness and so this is the focus of the study reported here.

Therapeutic letter writing for breathlessness: prevalence and lived experience

Dyspnoea (the pathological term for breathlessness) affects over 10% of the general population with higher prevalence in specific groups (see <https://www.networks.nhs.uk/nhs-networks/impress-improving-and-integrating-respiratory>), such as those living with chronic obstructive pulmonary disease (COPD) (IMPRESS Report, 2014; Bailey, 2004). Dyspnoea may also be the first vital symptom of respiratory illness diagnosis (Banzett, 2014; Currow & Johnson, 2015). Despite this prevalence and the diagnostic importance of dyspnoea to illnesses such as COPD, public awareness is poor and there are an estimated two million people with undiagnosed COPD in the UK (NICE, 2011). Research shows that living with dyspnoea can lead to increased stress, distress, anxiety and depression (Scano, Gigliotti, Stendardi, & Gagliardi, 2013). Qualitative research describes a shrinking life world involving a preference for “safe spaces” and a calculated navigation of surroundings, including air quality, temperature and physical environment. Both are a way to avoid episodes of chronic breathlessness and the fear and stigma associated with not being able to breath (Gullick & Stainton, 2008).

We thought it would be beneficial to offer a letter writing workshop to those living with breathlessness, as well as those interested in exploring their relationship to their breath (perhaps because of undiagnosed experiences of breathlessness), in which they are guided through a series of creative breath related exercises, leading onto being invited to write a letter to their breath.

The authors are part of the Life of Breath project, a multi-disciplinary approach to breathlessness that takes into account its subjective, cultural, linguistic – as well as medical – significance in order to increase the awareness and visibility of breathlessness

(Oxley & Macnaughton, 2016). The current study extends Life of Breath's multi-disciplinary approach to include therapeutic letter writing from an arts health approach. The paper is informed by the authors training in anthropology, mindfulness, script-writing and directing. In our discussion we review the value of using story structure as a theoretical approach to the themes emerging in both the letters to the breath and the qualitative interviews with participants.

Research approach and methodology

Aim

The aim of this research was to examine whether offering workshops which involve writing a letter to the breath facilitates new ways of relating to the breath and breathlessness and exploring the potential for this to become part of a wider arts and health public awareness strategy.

Design

This was a qualitative study that included participatory observation of the workshops by both authors, recorded group discussion about the letters individuals had created, short qualitative interviews with individual participants and photographs of the letters. A qualitative approach was the most appropriate way to observe and explore with participants the impact of the workshop on their relationship to, and perception of, their breath and breathlessness.

It was important to make the workshops as inclusive as possible, for those with low literacy levels or not comfortable with writing. This was achieved by the following emphasis. Using written words was optional, with many choosing to make visual letters. There were no pens or biro's provided and we suggested participants use sticks and feathers because it was important to slow things down and encourage relational reflections (Sugerman, Doherty, & Garvey, 2000). The workshop was invitational, with each participant invited to gauge which activities felt right for them to participate in. The workshops were led with a sense of playfulness, we encouraged participants to make mistakes, to keep their crossings out. The workshops were as much about group process and building group dynamics as they were about individual exploration. Ethical approval for the study was given by Health Research Authority and the reference number is, 15/EM/0478.

Recruitment

We were interested in recruiting three groups: firstly adults already diagnosed with a respiratory condition, experiencing dyspnoea and attending an existing respiratory support group. Secondly, adults in the community who were curious about exploring their breath – often because it was a tool in their work. Thirdly adults who self-identified as struggling with their breath as a result of a breath-related trauma, for example, childhood asthma, panic attacks, sleep apnea. The authors contacted the British Lung Foundation with information about the study who cascaded this to chairs of Breath Easy

Groups in the South West including South Wales. AM collected participants consent forms at the beginning of the workshop after participants had asked questions about the study, including what would happen to any data collected. To recruit from the community, the authors booked rooms in various community-based buildings (Quaker halls, Yoga centres, Buddhist centres, workplaces and schools) and advertised through local noticeboards and social media (Eventbrite and Meetup).

The workshops

The 10 workshops varied in length slightly, between one to two-and-half hours long, with most being two hours long. Workshops began with each person remembering a letter received or sent and sharing this in pairs or in the group, depending on time constraints. This sharing was to introduce the emotive relationship we may have to receiving and writing letters: what work letters do for us as symbolic objects. EP began a creative story with one line, passed onto the next person to continue, until the whole group had creatively collaborated on a spontaneous story about the breath. EP invited participants to blow a breath across the room to another person. The instruction was to receive the air into the body in the same way the breath had been exhaled by the other participant. This practice encouraged careful observation of the breath and involved participants experiencing their whole body being involved in breathing. The practice also built rapport and was often playful. After sending and receiving the breath (authors initials) led another creative writing and sketching exercise to explore collaboratively some themes related to breathlessness and the breath. EP then invited each participant to take a piece of paper and write down their responses in words or images to five questions which explore the breath in terms of the five senses, for example “if you could touch your breath, what would it feel like”? AM or EP would then lead the group through a short mindfulness of breathing meditation before participants were invited to begin writing a letter to their breath.

EP gave minimal guidance to workshop participants for writing a letter to the breath, instead EP simply encouraged participants to be curious and playful with the range of materials on offer. Participants were told not to worry about having a fixed idea if none emerged straight away, but to see where playing with the materials could lead to unexpected places – in terms of images or words. At the end of the workshop participants were invited to share their letter with the group and group participants were invited to share their reflections on each others letters.

Data collection

AM and EP collected data in the room where the workshops were held and on the same day. EP took photographs of each letter as well as of the workshop. AM audio recorded on an encrypted digital recorder the group reflections of the letters. AM and EP invited participants to take part in short qualitative interviews at the end of the workshop. AM and EP recorded the interviews and were guided by the topic guide shown in [Box 1](#). Where workshops took place amongst existing groups, for example in the Breath Easy Groups or Singing for Lung Health groups, group leaders were invited to give

Box 1. Topic guide for qualitative interviews.

- Reflections on what has been written or created?
- Choice of materials and inks used, images or words
- Experience of the workshop
- Relationship to their breath (and experience of breathlessness)
- History of breathlessness

written feedback to the authors on how they perceived the workshop had gone, including observations of any changes in their group dynamics in subsequent weeks.

Data analysis

All the recorded data were transcribed verbatim by a professional transcriber. AM and EP read and re-read the transcripts of the interview data and letter text data to familiarise themselves with the content. AM and EP met to discuss the re-occurring themes in the letters. A theme may be a repeating word or phrase, a repeating image, or a repeating use of colour or material or approach (such as ripping or stapling the paper on which the letter is written). AM and EP also noted the isolated uses of words or phrases or images because qualitative approaches do not judge the importance of a theme necessarily by its repetition, but by the importance its meaning has for the scribe/creator of the letter or indeed the analyst.

AM then formally coded the transcripts thematically, looking for similarities and differences both within and across individual interviews. AM held a data sharing meeting with her local Theory in Anthropology group at Bristol Medical School. AM invited members of the group to view the letters to the breath and add their own observations through placing post-it notes around each letter and sharing these thematic ideas through group discussion, before AM shared her own initial coding and thematic analysis. AM's approach to thematic analysis is interpretative, which involves a close examination of the language used as well as mapping the relationship between language, images and materials represented in the letters.

AM and EP met again to explore how theories of story structure could be used as one possible way to frame and interpret the themes emerging in the letters to the breath.

Theories of story structure informing analysis

Our approach to analysis is informed by theories of story structure. This is appropriate as letters usually involve a narrative structure, in this case addressed to the breath and/or self. We discuss the relevance and limitations of this approach to analysis in our discussion.

Protagonist and antagonist

Protagonist, meaning main character, is a word that comes from the Greek words for "first" (protos) and "struggler" or "combatant" (agonists) (Cooper and Dancyger, 2005). So the protagonist is the main struggler in the story. In our analysis, we were interested in who letter writers framed as the protagonist in their letter. Similarly, the word antagonist comes from the Greek words for "against" (anti) and once more "struggler"

or “combatant” (agonists). The antagonist, whether another character, or a force of nature, or simply an aspect of the protagonist’s own character or bodily function is the force or obstacle with which the protagonist must contend. We were interested in whether the antagonist would be the breath or not. It is the story of the struggle between protagonist and antagonist that provides the plot. It is important to note, the stronger the antagonist, the stronger the conflict and the harder the protagonist must struggle to achieve his or her goal. The more there is at stake, the more dramatic the conflict. We were curious whether letter writers addressed their breath in terms of conflict and struggle or not? Whether the breath and the letter writer were in opposition or on the same side?

Dramatic action and climax

Dramatic action, or the “movement of spirit”, as Aristotle defines it in the Poetics (Cooper & Dancyger, 2005, p.48) is the life force, the heartbeat of any script. Psyche, the word he uses for spirit, meant both “mind” and “soul” to the ancient Greeks- the inner energy that fuels human thoughts and feelings, the underlying force that motivates us. The climax is generally the moment of greatest intensity for the protagonist and a major turning point in his or her dramatic action. We were interested in whether letter writers included descriptions of significant moments or events in their relationship with their breath and if so, what these moments were. Would they be unique to the individual or would there be a common theme of climax in the letters?

Recognition

Recognition, according to Aristotle, is “a change from ignorance to knowledge” (Cooper & Dancyger, 2005, p.48), and usually, closely precedes or follows the climax. It is the point at which the protagonist realises where the dramatic action has taken him or her through the course of the events that have made up the story. We were interested to explore in our analysis whether the workshops had facilitated any sort of shift from ignorance to knowledge, any sort of recognition. Did letter writers make friends with their breath, or agree to disagree or fall out once and for all? We were aware that there may not be a happy ending.

Confronting the antagonist and reconciliation

Once protagonists/characters have confronted the climatic action, which may involve confronting their weaker moments, there is classically a re-resourcing to finally confront the antagonist, which may lead to some sort of reconciliation. We were interested in whether the letter writers would join sides with the antagonist through a shared sense of struggle or not?

Creating a stage, an audience and dialogue

Finally, we were also interested to explore in our analysis whether the letter writers created a stage or set, or reflected upon ideas of audience when being interviewed about their letters. In addition to this, we looked at styles of dialogue emerging in the letters. Occasionally, a script may have no written dialogue, but communication takes many forms – from physical gestures such as breath, eye contact, touch or absence of

any of these things. So we looked at the tone of the dialogue in the letters, plus how this may be conveyed non-verbally through the use of materials.

Results

We present the results of our analysis thematically in terms of theories of story structure. Citations from letters are referenced with gender (M or F), diagnosis if disclosed during the workshop interviews (and ND where no respiratory/breath related diagnosis was given) and attributed the citation to a particular workshop and participant number. Excerpts from qualitative interviews (as opposed to excerpts from letters to the breath) are indicated in the text.

Overview of results

The stages of story structure mapped onto themes emerging in the letters. Both the breath and the letter writer were framed as antagonist. Dramatic action in the letters took many different forms, from descriptions of the breath as a universal vital life force to vivid descriptions of breathlessness. The stage of recognition mapped onto four main themes; entreaties for the breath to stay and not abandon the protagonist; viewing the breath (albeit an antagonist) as a teacher from which there is much to learn; confronting the breath as antagonist and offering reconciliatory words or gestures which for some led to a blurring of antagonist and protagonist identities. The results also explore the range and tone of dialogue style, the use of the materials to create the letter into a visual stage and the importance of the audience to the workshop experience.

Protagonist and antagonist

In our analysis, we identified a tendency for participants to identify their breath as an antagonist who could play different characters with different parts, for example, as a lover or parent:

I am very pleased we are getting to know each other better and to enjoy each others' company now that we have reached an understanding. (F, COPD, Workshop 1, Participant 12)

"Reaching an understanding" suggests the letter writer has not always been able to enjoy the antagonist's company. Other letter writers were more explicit about the extent of difficulty in their relationship with the antagonist:

I have lived with you for 83 years, the first 23 years were good, but you have been unkind for the past 60 years, starting with the birth of my son. Why? Is there a reason for this? I've forgiven you as I have survived though it has been a struggle. The struggle now continues through my son and his breath. (F, COPD, Workshop 1, Participant 8)

Agonists are "strugglers" and "combatants" in the protagonist life, as the above example demonstrates. The above letter writer demands to know why the breath has behaved as it has. The breath is given agency in these letters and asked to justify its combative nature. The breath is addressed as an "other" with whom the protagonist must contend.

Often the breath as antagonist is addressed as one who has deserted the letter writer, torturing through absence. This was true for workshops held with Breatheasy groups;

most of the time I love you and value you, sometimes I can't find you when you make me cough, but I need you to stay with me just as long as you can

(F, COPD, Workshop 1, Participant 5)

As well as in workshops with those who use the breath in their work:

and then you were gone. Scratched out, written over. Erased. We forget you're there. Then you remind me with your sucked away fading. Too fast. Not enough. (F, panic attacks, Workshop 2, Participant 3)

The breath was addressed in the letters as someone who can betray us, who is capable of being unkind and needs our forgiveness:

you have been unkind...why? Is there a reason for this? I've forgiven you. (F, COPD, Workshop 1, Participant 3)

as well as someone who is capable of being faithful, though often ignored, and so deserving of the letter writers' thanks:

So really it's a thank you. Left and right. In and out. Nostril to navel. When its that deep it feels sooo good . Soft. Like a pair of feathers. (F, panic attacks, Workshop 2, Participant 3)

Some letter writers made themselves the antagonist who needed forgiveness:

expel the toxins I have poisoned you with. Forgive my failings and help me to nourish you.

(F, smoker, Workshop 4, Participant 1)

For others who made themselves the antagonist, there was no request for forgiveness, no attempt at reconciliation:

air is beautiful and I make it bad

(M, bronchiectasis, Workshop 6, Participant 4)

The tone is without redemption, the breather made the beautiful air bad.

Dramatic action and climax

Dramatic action in the letters sometimes took the form of addressing the breath as life giver, the uncertainty that surrounds one's mortality and the role breath plays in this drama:

thanks for my life and keeping me alive

(F, ND, Workshop 5, Participant 5)

For some the uncertainty was linked to suicidal ideation:

You give me life. But is that what I want? But is that what I want? (F, ND, Workshop 5, Participant 7)

For others, the dramatic activity of continually living with the uncertainty of breathlessness would regularly reach a climax, a moment of greatest intensity for the protagonist:

Limiting. Can't work as hard as before. Gasping for breath. Short of breath. O₂ goes low. Heart and brain lack of oxygen. Dangerous!!! Organs don't work as well as they should. (M, COPD, Workshop 6, Participant 11)

In this above example, the letter is written in short gasped sentences, the writing style mirroring the experience being described. Other letter writers explored the drama of uncertainty in terms of their bodies' asthmatic tendencies not to let go of the breath, creating physical tension and emotional strain:

Dear Breath. Let go. Just let it go please. There is no need to cling on. You have been there for me throw (sic) the toughest times. With me. In and out of me. Around and over me. But we are holding on to something. It is time to ease out of it, out of the body. Something crushing. Something stuck. You make my head spin. Where are you? Where do you disappear to? I can trust you to come back can't I?

(F, asthma, Workshop 7, Participant 1)

For others the dramatic action was about empowering the breath with the ability to bring about freedom:

Untangle me from my web of thoughts. Set me free. (F, ND, Workshop 8, Participant 10)

Echoing the earlier personification of the breath as lover or parent, the drama was often about feeling conflicted in relation to the "other", a desire to be released, set free versus a desire to be brought in close:

Release me, draw me into you. (M, ND, Workshop 8, Participant 6)

Recognition

Recognition in terms of theories of story structure is akin to finding a resolution after a struggle. We were interested in our analysis to see to what extent the letter writing facilitated a resolution for those who addressed their breath or themselves as antagonist. Did the letter writer and their breath make friends, or agree to disagree or fall out once and for all? The most common re-occurring theme in terms of recognition, was an entreaty for the breath to stay, to not abandon the letter writer:

I would like you to stay with me all the summer and together we shall enjoy the garden and walking in the woods -if you can manage to stay happily that long. (F, COPD, Workshop 1, Participant 7)

Again we can see the breath as antagonist being addressed in terms of a lover or parent:

Stay with me. (F, COPD, Workshop 6, Participant 2)

Stay with me just as long as you can. (F, COPD, Workshop 1, Participant 4)

Don't leave me, please. (F, ND, Workshop 5, Participant 3)

Recognition didn't need to be Aristotelian, in terms of a journey from ignorance to knowledge, to mean an important shift had occurred. For some the workshop facilitated a deeper understanding of the breath:

It has been an enlightening way to understand better how I breathe. (M, COPD, Workshop 9, Participant 14)

For most participants, the journey from ignorance to knowledge was subtle, with the journey being about learning, and the breath as antagonist, as being someone from whom we have much to learn:

Do you remember when I was a baby in the womb? Ah then it was my mother's breath (sic). I swear I can hear it now. And when it was my time to have a baby, breath that was the first time I really studied you. (F, ND, Workshop 3, Participant 7)

the lesson has been a long one. After eighty five human years I'm just learning to let go and let YOU breathe ME. We are very close now. (M, COPD, Workshop 1, Participant 1)

Confronting the antagonist and reconciliation

Most participants expressed recognition in their letters through confronting the breath as antagonist and offering words of reconciliation:

I've chosen this pretty paper to remind us what my life and being used to be like. Sadly my reaction to your affect (sic) on me since our illness has made me into a sad, grumpy, worn out woman. Medication is helping to keep us going but how I wish you and I could feel happy for more than we do. Remember that sweet little girl we were? Couldn't we work together to be a happy, positive body? How can we do that? (F, COPD, Workshop 1, Participant 2)

In theories of story structure, once characters have confronted their weak moments there is classically a re-resourcing to finally confront the antagonist, which may lead to some sort of reconciliation. In some of the letters, we see this pattern playing out, where letter writers become united with the breath as antagonist through a shared sense of struggle:

sorry you have to struggle with your lungs but I'm struggling too. I take medication to help us both. (M, COPD, Workshop 1, Participant 4)

I wish I could make it easier for you, I can't, but together we will battle on

(M, COPD, Workshop 1, Participant 6)

For others reconciliation came about through a merging of the protagonist and antagonist as one:

for you are me and I am you – lets (sic) work together in harmony

(F, ND, Workshop 4, Participant 3)

Reconciliation is not an expected or inevitable stage of the workshop. Not all participants were ready to engage with their breath in this way and the workshop was an important opportunity to simply view the breath, or themselves, as an antagonist for the first time.

Creating a stage, an audience and dialogue

The workshops opened up opportunities for dialogue. For many, even those attending established Breathe Easy groups, the letter writing workshop was the first time participants had shared the very private experience of living with breathlessness, including quieter members of the group. We witnessed disclosures of low mood from male participants who up to that point (according to group leaders) had put on a brave face in relation to living with breathlessness; stories of guilt and stigma at having caused their illness or let their families down, or stories of being verbally abused by the public because of needing to use a mobility scooter. Feedback with group leaders confirmed that sharing the personal experience of breathlessness had affected group dynamics in subsequent weeks, with leaders noticing members arriving earlier and staying later than before and being more talkative.

In most narratives, the audience is very important. The group operated during the workshop as an important audience. A participant whose letter included the phrase “this is me struggling to breath (*sic*)” was asked how she felt looking at her letter after talking about it to the group, she replied:

I feel quite good about it actually now. Because people don't want to keep hearing about this. And having something like this makes you unload abit. Because who do you talk to? You can't keep talking to your family about it. They don't want to know. (F, COPD, Workshop 6, Participant 5)

The letters reveal a range of styles and types of dialogue between the protagonist (self) and antagonist (breath), ranging from argumentative:

I wonder what you get up to when I'm asleep, because I don't know. What do you get up to? Ok fine don't tell me. (M, ND, Workshop 8, Participant 2)

To beseeching,

flow, don't be afraid. (M, ND, Workshop 4, Participant 7)

Reconciliatory,

dearest breath, breath me always. (F, ND, Workshop 4, Participant 9)

And thankful:

thank you for calming me down when I start to panic I appreciate everything, lots of love. (F, ND, Workshop 5, Participant 2)

Differences in types of dialogue reveal the letter writer is perhaps focused or involved in different stages of the story structure. For example, argumentative dialogue is used during early stages of dramatic action, when the protagonist is beginning to wrestle with their relationship to the breath, whilst reconciliatory dialogue is used during stages of Recognition, where a shift from ignorance to knowledge has occurred in relation to the suffering endured by breathlessness. Thankful dialogue often expresses a stage in the story structure where the protagonist views the breath not as antagonist but as saviour:

you are my saviour...everyday through thick and thin, you continuously ground me, allow me to rely on you and keep me calm and sane. (M, ND, Workshop 3, Participant, 4)

Despite the importance of dialogue and its tone, for some participants it is not the words they use but how they create the whole letter, the materials they choose. One participant saw another participants' letter as:

a stage set. With the silver, the curtain just opening, two mountains below, maybe some forests on the left. But it's just waiting then for the action. Maybe that's what the breath allows us to do: create a space where the actor can arrive. (M, ND, Workshop 2, Participant 9)

This comment preceded any idea amongst the authors of using story structure to inform analysis, but we can see in this comment, participants were themselves viewing the letters as a stage on which the breath (breathless or not) can step and express itself to its creator through words and images.

Discussion

Our results have shown that offering workshops which involve writing a letter to the breath can facilitate insights into how participants are currently relating to their breath and breathlessness. Using theories of story structure was a helpful theoretical lens through which to view, clarify and organise the qualitative findings. Our secondary aim to explore the potential for this approach to form part of a wider arts and health process of increasing public awareness about breathlessness is harder to assess. The workshops certainly offered a platform on which to share (often for the first time) with others the difficulty of living with breathlessness, helping to create a public story and going some way to make the experience of breathlessness less isolating and less invisible.

The approach in the workshops was about encouraging those living with breathlessness – the protagonists – to have a dialogue with themselves, with their “breathing antagonist”, facilitating them to write their own scripts, re-write their own lines through a creative writing process of recognition. Once participants begin to talk to their breath through letter writing, we see the workshops as supporting those living with breathlessness to have a dialogue with their doctors about their own treatment. A dialogue about how they treat themselves and how they are treated by others.

Jolly (2011) explores why letter writing is therapeutic in terms of contemporary ideologies of the self. Unsendable letters work because, according to Jolly, they “perform internal dialogue” (p.48). Ideas of letters as performative texts, as dialogues with a part of our unwell self, clearly has resonance with our use of story structure which analyses letters in terms of creating a stage for the actor “breath” to speak its part. This is because the stages of story structure we have used in our analysis map fit quite neatly onto general tenets of therapeutic process. Therapeutic process involves being able to stand back from (the part of us that causes) our suffering and see it differently, it “implies the conceptual division of the self” (p.48), the breath as antagonist (as we have presented it) is in Jolly's article the part of us which is “given a personality with its own needs and will” (p.48). The stages in story structure of recognition, confrontation and reconciliation that we have presented in our analysis resonates with Jolly's theoretical description of “a reintegration of the self's two parts...a self which needs to become conscious of its internal conflicts to bring them into relationship and eventual harmony” (p.48).

The literature on therapeutic creative writing, and therapeutic *letter* writing, has to date struggled to theorise why it is effective or ascertain mechanisms of action (Pennebaker,

2004; Wright & Cheung Chang, 2001). Our use of story structure in this article provides one way to illuminate why therapeutic letter writing is beneficial to wellbeing for those living with long-term chronic conditions, such as breathlessness. Jolly (2011) notes that therapeutic writing has been most favoured by constructivist therapies that see suffering residing in the story or narrative of the self rather than in underlying psychic structures. This makes sense to the analysis we have presented here-with letters to the breath revealing participants at different stages in their own story of reconciliation.

Technologies of self: writing or creating letters?

Though we have called this an arts and health based intervention, the approach of “writing a letter to the breath” sits between two therapeutic practices – creative writing and visual collage. Participants did not have to write or use words, though most did. Letters were not written with biros or normal ink pens or pencils. Instead participants in our workshops were encouraged to slow things down and use sticks or feathers dipped in inks that made the writing process slow and embodied. Our approach contrasts, then, to the rise in electronic-based-blogging which has become an important resource for self-help groups (Suler, 2005). Whilst both therapeutic letter writing and blogging involve creating an audience for performative texts, the technologies involved are at polar opposites. The workshops we describe may not involve any written words or text at all. It would perhaps be more accurate to say “creating” instead of “writing” a letter to the breath. Others have also emphasised the importance of colours, fonts and stationery, “that relates to the spirit the clients wish to convey”, to the therapeutic process (Jress et al., 2008, p. 114).

Therapeutic private narrative but public story

Jolly (2011) critiques the rise in therapeutic letter writing, particularly that associated with self-help resources which encourage writing letters to family members to achieve better intimacy, more co-operation etc. Jolly views these resources as one expression of wider societal trends in therapy culture that “reduces (other) people to projections of the self rather than real correspondents in mutual pursuit of authenticity or healing” (p.53), leading to the diminishment of authentic co-operation and connection. One key difference between the workshops we offer and the online or self-help resources is the importance of group context and what we have discussed in our analysis in terms of creating a stage and audience. The therapeutic effect of the letters to the breath also goes beyond the individual letter writer, benefitting the audience/readers as much as the letter writer. Group leaders fed back that the workshop had improved individuals’ relationship to their own breath but also group dynamics, increasing communication and rapport between members. Participants valued the opportunity to share their experience of the breath and breathlessness with others and be heard.

In a collaboration with a visual installation artist we have developed the letters into a visual art installation, Suspended Breath <https://lifeofbreath.org/2018/01/gasp-making-breathlessness-less-invisible-through-the-creative-arts/>. The installation is part of our strategy in knowledge translation, creating a public story about breathlessness, a visible reminder of the unseen suffering that breathlessness evokes. We have already exhibited Suspended Breath at the national Being Human festival and plan to incorporate the piece

in a series of workshops targeting school children living in areas of poor air quality (Catch your breath) as well as adults living in low social economic areas with breathlessness (Gasp! Rediscover the Breath: a 6 week arts health course). The letter writing workshops form part of a wider project to raise public awareness about lung health and breathlessness. In this way, we have utilised therapeutic letter writing in a way that goes beyond the therapeutic benefit for the individual letter writer and the group: we have utilised it as a research tool to generate knowledge about what it is like to live with breathlessness as well as a tool of knowledge translation, by using the letters as a starting point for an art installation and in the future a piece of theatre, entitled Gasp!.

Yet we also envisage the letters extending into the more immediate circle of influence of the letter writer too. The letters, though written to an individual breath, are viewed as a starting point for opening up dialogue with clinicians with the end goal of challenging some of the existing medical perceptions of breathlessness. This, we think, is what Jolly (2011) may have in mind when she advocates “reframing it (therapeutic letter writing) to activate latent forms of citizenship...measuring the growth of relationships, public as well as private, might be a better basis for measuring ‘efficacy’ rather than the diminishing of (individual) pain” (p.55).

Therapeutic letter writing, delivered in community-based group settings, is a valuable arts health approach for those living with breathlessness. Further research should explore to what extent therapeutic letter writing can support communication about breathlessness with family members and clinicians. An advocate of using letters as a clinical tool within the clinical relationship is Steinberg (2000). Resonating with our use of story structure in our analysis, Steinberg talks of drama and draft scripts:

if the therapeutic process is perceived in terms of roles and drama, the letter is like a draft script or ‘treatment’ inviting the comments of the other participants. (p. 119)

In contrast to Steinberg, our future research will focus on the patient as the dramaturg, exploring the possibility of co-writing scripts in the public recognition and clinical treatment of breathlessness.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

Dr Alice Malpass gratefully acknowledges the funding support by the Wellcome Trust provided through the grant 'Life of Breath' [with grant reference number 103340] which enabled her to write this article.

References

- Bailey, P. H. (2004). The dyspnoea-anxiety-dyspnoea cycle—COPD patients' stories of dyspnoea: “It’s scary/when you can’t breathe”. *Qualitative Health Research*, 14(6), 760–778.
- Banzett, R. B., & O'Donnell, D. (2014). Should we measure dyspnoea in everyone? *European Respiratory Journal*, 43, 1547–1550.
- Bartley, T. (2012). *Mindfulness-based cognitive therapy for cancer*. Oxford: Wiley Blackwell.

- Bell, J. M., Moules, N. J., & Wright, L. M. (2009). Therapeutic letters and the family nursing unit: A legacy of advanced nursing practice. *Journal of Family Medicine*, 15(1), 6–30.
- Bolton, G. (1999). *The therapeutic potential of creative writing*. London: Jessica Kingsley Publishers.
- Cooper, P., & Dancyger, K. (2005). *Writing the short film*. Burlington, MA.
- Currow, D. C., & Johnson, M. J. (2015). Distilling the essence of breathlessness: The first vital symptom. *European Respiratory Journal*, 45, 1526–1528.
- Gullick, J., & Stainton, F. M. C. (2008). Living with chronic obstructive pulmonary disease: Developing conscious body management in a shrinking life-world. *Journal of Advanced Nursing*, 64, 605–614.
- IMPRESS: Improving and Integrating Respiratory Services. (2014). Responding effectively to people with long term breathlessness. Retrieved 07 April 2017 from <https://www.networks.nhs.uk/nhs-networks/impress-improving-and-integrating-respiratory>
- Jolly, M. (2011). What I never wanted to tell you: Therapeutic letter writing in cultural context. *Journal of Medical Humanities*, 32, 47–59.
- Keane, F. (1996). Letter to Daniel. [Blogs.glowscotland.org.uk](http://blogs.glowscotland.org.uk)
- Kress, V. E., Hoffman, R., & Thomas, A. M. (2008). Letters from the future: The use of therapeutic letter writing in counselling sexual abuse survivors. *Journal of Creativity in Mental Health*, 3(2), 105–118.
- Nau, D. S. (1997). Andy writes to his amputated leg: Utilizing letter writing as an interventive technique in brief family therapy. *Journal of Family Psychotherapy*, 8(1), 1–12.
- NICE. (2011). Chronic obstructive pulmonary disease costing report: Implementing NICE guidance. London. Retrieved 22 March 2017 from <http://www.nice.org.uk/nicemedia/live/13029/53292/53292.pdf>
- Oxley, R., & Macnaughton, J. (2016). Inspiring change: Humanities and social science insights into the experience and management of breathlessness. *Current Opinion: Supportive and Palliative Care*, 10, 256–261.
- Pearson, L. E. (1965). *The use of personal communications in psychotherapy*.
- Pennebaker, J. (2004). Theories, therapies and taxpayers: On the complexities of the expressive writing paradigm. *Clinical Psychology: Science and Practice*, 11, 138–142.
- Scano, G., Gigliotti, F., Stendardi, L., & Gagliardi, E. (2013). Dyspnoea and emotional states in health and disease. *Respiratory Medicine*, 107(5), 649–655.
- Smyth, J. M., Stone, A. A., Hurewitz, A., & Kaell, A. (1999). Effects of writing about stressful experiences on symptom reduction in patients with asthma or rheumatoid arthritis. *Journal of American Medical Association*, 281(14), 1304–1309.
- Steinberg, D. (2000). *Letters from the clinic: Letter writing in clinical practice for mental health professionals*. London: Philadelphia, Routledge.
- Sugerman, D. A., Doherty, K. L., & Garvey, D. E. (2000). *Reflective learning: Theory and practice*. US: Kendall Hunt.
- Suler, J. (2005). Equest: Case study of comprehensive online program for self study and personal growth. *CyberPsychology and Behaviour*, 8(4), 379–386.
- White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. New York: Norton.
- Wright, J., & Cheung Chang, M. (2001). Mastery or mystery? Therapeutic writing: A review of the literature. *British Journal of Guidance and Counselling*, 29(3), 277–291.