

**“You give me a name that I can’t say, but I have to explain what it is every day”;
the power of poetry to share stories from young people with a rare disease**

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Unstructured abstract

Qualitative research is about people’s lives; their stories, their thoughts, their feelings, and their experiences. Researchers continue to reflect on the best way to present other people’s stories in a way that stays true to their accounts and delivers the message in a manner which resonates. This article presents one such way, discovered through serendipity, which allowed the researcher to share findings from young people’s stories eloquently and passionately to audiences of healthcare professionals from different disciplines. The silence and raw emotion witnessed after the poetry delivery was akin to that often seen during childbirth when those around are stunned into thoughtful awe. The poetry, which was crafted entirely from young participant’s interview transcripts had two benefits; 1) sharing young people’s stories using their own words and 2) using a presentation format that demanded attention; so that people took notice, listened and reflected on the words and experiences being expressed.

Introduction

Qualitative research aims to understand people's thoughts, experiences and emotions (McCulliss, 2013). Whilst there are various methodologies and methods within the overarching umbrella term of 'qualitative', the researcher always undertakes to sift through, organise and present the data in a meaningful way to arouse an empathetic reaction in the consumer of research; hopefully leading to a deep, personal understanding of the individual or topic under study (Lietz, Furman, & Langer, 2006; McCulliss, 2013). Phenomenology is one such methodology which aims to slow the researcher down and hold his or her gaze as they bring the phenomena or lived experience of some focus under study to the front (Willis, 2002), but by doing so, reams of 'data' are gathered along the journey. In this paper I discuss a research project, where I discovered the potential power of poetry, an approach that was also new to my research team. The detail of the study, the recruitment process, methods and final results have been presented elsewhere (Livermore et al, 2019). The intention here, is to focus exclusively on the use of poetry, as a vehicle for the presentation and dissemination of research findings. The serendipitous 'stumbling upon' the value of utilising poetry within a phenomenological study is my particular focus; encouraging qualitative researchers to keep their minds open to new approaches when working with data. The intended purpose of this article is to demonstrate the powerful way of communicating data to a range of audiences, through the use of poetry.

Background to the study: emergence of the first poem

The study in question is the first qualitative phase of a sequential exploratory mixed-methods study, examining a health condition in children and young people called Juvenile Dermatomyositis. Juvenile Dermatomyositis (JDM) is a rare, rheumatological, systemic condition, defined by weakness in proximal muscles and characteristic skin rashes, often involving other body systems, with potentially life threatening consequences (Nistala & Wedderburn, 2013; Papadopoulou & Wedderburn, 2017). Diagnosed before the age of sixteen years and with an incidence of 2-3/million/year, it is more common in girls than boys (Huber et al, 2000; Nistala & Wedderburn, 2013; Ramanan & Feldman, 2002). Weakness often begins insidiously, with children and young people struggling to get up from sitting and not being able to climb stairs, quickly advancing without treatment; to render the child bed bound, unable to sit up or roll over, requiring to be tube fed and receive support with breathing (Batthish & Feldman, 2011; Ernste & Reed, 2014; Gowdie, Allen, Kornberg, & Akikusa, 2013).

As a senior nurse with years of experience caring for children with JDM, I have noticed that they frequently have difficulty expressing their feelings, holding eye contact, with low mood and difficulties joining in everyday conversation; more so than their peers with other comparable rheumatological conditions. Conversations with parents and other nursing colleagues around the United Kingdom (UK) also supported this observation, and provided real evidence of how these children, or those they looked after were struggling. However, there is no research asking young people with JDM how they cope with their disease and the psychosocial effects and unmet needs they experience. Therefore, with a need and a lack of current research, a study which actually asks the young people what their experience is and what their needs are, was required.

What better way to do this, than to use the methodology of Phenomenology, which is concerned with the 'lived world' (Fochtman, 2008). Interpretive phenomenology aims to describe, understand and interpret phenomenology, predominantly described by the

philosopher, Martin Heidegger, (Cooney, Dowling, Murphy, & An, 2013; Flood, 2010; McConnell-Henry, Chapman, & Francis, 2009), often referred to as Hermeneutics, which can be further defined as the science of interpretation. In interpretive hermeneutic phenomenology (as it will be called from this point forward), the researcher seeks to understand the human experience (Crist & Tanner, 2003). In this study I asked young people to tell their story of how they experienced JDM, and then through hermeneutics, I interpreted those stories, in order to bring the phenomenon into the open.

Fifteen children and young people between the ages of eight and nineteen years of age with JDM were recruited through clinics at one hospital in London. Interviews were audio-recorded and were either in the traditional interview format, or aided by creative methods such as drawing whilst talking (Horstman, Aldiss, Richardson, & Gibson, 2008). Interviews ranged from 18-130 minutes long and three occurred at home whilst the rest were carried out in the clinic or on the ward. Audio-recordings were transcribed verbatim as soon after the interviews as possible, which yielded between 31 pages for the shortest to 130 for the longest interview.

At this point, I began to develop a sense of growing alarm to know how to start working with the increasing amount of data. However, staying true to the interpretive hermeneutic phenomenology methodology; reading, and re-reading through the 'Hermeneutic Circle' (Snelgrove, 2014), data analysis began. As the literature is intertwined throughout the analysis, adding the interpretive hermeneutic phenomenology lens is equally important and as Smythe (2011) recommends wider reading of novels, media sources, letters or poems can all add too and open up a wider horizon of thinking (Smythe, 2011). Interestingly that Smythe (2011) should highlight poetry reading as an important consideration at this point, as here, quite by accident, I found the young people's words from their transcripts, taking shape into poems.

One young adolescent's interview had been particularly moving. After the interview, unable to stop replaying it in my head, or reliving the words spoken, they turned into a repetitive poem whilst walking through the streets of London. Without even the need to read them, the emotion behind the words, the depth of feeling and the gratitude that they had shared them with me, was amazing. Here is that first poem:

Tomato Face

“Tomato face” they called me,
Come on guys, can't you see,
My face looks more like a “baboons bum”,
Bright red, swollen, horrible, really not fun,
You can't hide your face, can you?
If your arms get fat, you cover them up, that's what you do,
“Don't worry” the doctors say,
“We're not worried that you're a little redder today”,
But the fear is that after a little, comes a lot,
And that my JDM just won't stop.

This poem clearly illustrates the battle these young people have with their altered body image. One of the treatments for when the disease flares-up, comprises a corticosteroid which is well known for causing weight gain and a ‘cushingoid’ appearance, both of which can be devastating to an adolescent. It also reflects the longer conversation about how the medical professionals can be less concerned, “more blasé”, than the actual individual who is suffering with the condition, because, put simply, “it’s not them!”

Crafting further poems

It was at this early stage in the data collection and analysis that I could see the power behind the adolescents words crafted in this way. This led me to look at the other transcripts in a different light and wonder if words and sentences were moved around, would I also achieve a similar outcome. It was important to only use the young people’s words, as this was core to the telling of their story. Each line of the poems was checked, to ensure the message had not been taken out of context due to the deletion of any text.

A further poem was created from the transcripts from one older adolescent about the frustration at getting diagnosed, a common theme highlighted by the participants in the study:

What is it?

Is it psoriasis? Is it eczema? Is it scarlet fever?

Why are you such non-believers?

Is it Lupus? Is it growing pains?

Please help me, use your brains?

Shall we google it?

There’s got to be something that fits?

We’re made to feel we’re wasting their time,

The examining couch too high, I can’t even climb,

My face bright red,

The weight too heavy to lift my head,

I now am very weak,

An answer I seek,

Help me get a name,

Please help me, stop the pain.

The young people often talked about the fact that, because it is so rare most General Practitioners (GP) have not heard of JDM. These young people recounted many visits to their GP, prior to referral to their local hospitals, where often they were still left in the dark, and did not know what was wrong with them. This is a very anxious scenario for the child, young

person and their family, who often admitted to turning to the internet to try and find out what it was. This ‘uncertainty’ which many young people clearly described, later became one of the main themes emerging from the data analysis.

Again, when looking at an individual’s transcript, there are certain words or phrases that may naturally be separated in the normal flow of conversation. Each interview was pages of data, but within the pages, there would be the same concerns; hinted at, mentioned or discussed at length. One of these was the perception from the young people that JDM can appear invisible as time goes on. As the interviews were phenomenological, opening with “Tell me what it is like to have JDM?” the majority of young people talked about the positives and negatives of having an invisible disease. One young person in particular, was incredibly eloquent throughout their interview and this poem created from the transcript talks about so many of the shared issues, such as feeling different; the invisibility and the potential long term implications of the disease:

Invisibility

Not allowed to do PE as they were cautious of me,
No wall climbing, or strenuous activity,
I can’t do the stuff I want to do,
They don’t understand, they have no clue,
I don’t want them to judge me on my illness,
Leave me behind, in the wilderness,
The same thing 24/7 I have to explain,
Tell them what it is, again and again,
In the beginning, red food colouring spilt all over me,
Red on knuckles, elbows and my knee,
They could see I was different,
My limitations were apparent,
Now as times gone on, not visible on the outside,
But hidden away on the inside,
A disease that could kill, that’s secret power is invisibility,
A disease with no cure, but long standing emotional disability.

Poetry dissemination

Using poetry in dissemination can be a powerful means of sharing the findings to a non-specialist audience and places the listener in the moment, illustrating meanings and transmitting key messages quickly and with impact (Macdonald, 2017). This impact could be clearly seen recently at a Healthcare Professionals meeting. I was anxious about presenting

“qualitative data” to a room full of predominantly medical professionals, but even more so, to be adding in the “creative” element of poetry. I therefore decide to start with a poem at the opening of the presentation, and the same one again, delivered slower, after the findings had been discussed. The rationale behind this was that if I was going to showcase some poetry, then I was going to be bold with it. During the presentation, some members in the audience were clearly moved to tears and afterwards others wanted to come and share their reflections on the presentation. One registrar commented that she had “got goose bumps” during the poem, and another medical professional who had been previously sceptical about the study, had come to share that he would now be talking to all children and young people about their psychosocial needs in each clinic appointment. The poem that was shared was:

Worry

You give me a name that I can't say,
But I have to explain what it is every day,
I am ten now, but I worry about how I will be,
What is my JDM doing to me?
It's not easy to see,
But I know it's there inside me.

Tying it together – the poems aiding the bigger picture

In this study, I did not take the poems any further through the analysis process, but instead the transcripts were crafted into individual stories and then examined to reveal the overarching phenomena and themes within, in a process described by Caelli (2001) as how to ‘craft’ or ‘derive’ narratives from transcripts (Caelli, 2001). I found the reshaping of the transcripts into poems definitely made the next stage; moving into the complicated task of data analysis, easier due to the familiarity of the transcripts I already had which ultimately led to myself having an enhanced, deeper understanding of the lived experience of JDM.

Phenomenology aims to uncover the subconscious phenomenon at the heart of the experience under study, a means of interpreting participant’s experiences (Ajjawi & Higgs, 2007). As I repeatedly went back to the transcripts and the created narratives, I could see all the different voices of the effect JDM has on the equilibrium of the child and young person. For those that could remember life ‘before JDM’ they clearly described to me how JDM had just suddenly happened and knocked them down, almost physically as they were often soon unable to climb stairs, attend school and in some cases – even scratch their own noses. However, there were moments when they felt better, physically and emotionally; such as being allowed home from hospital, or feeling the medications start to work. This visual up and down journey captured all fifteen stories, and so the metaphor of a ‘rollercoaster’ emerged (Livermore et al., 2019). This was a turning point as the metaphor not only represented all the accounts from children and young people but was easily explainable to children. It had a positive message, for example, there will be an up bit of track coming and you should feel better and so many have ridden this before, you are not alone. Thus the overarching phenomenon of ‘Being-on-the-JDM Rollercoaster’ was finalised, and although there are not poems set out clearly along the track, the poems provided the lens through which to view the experience of JDM.

Discussion

There are many different ways of using poetry to express research, as Faulkner (2009) cites through her 'Poetry as Method' textbook, with the main three ways being; poetry used in research asking individuals to critique it; poetry used to illustrate research transcripts; or poems to present the themes the researcher notices (Faulkner, 2009). For this study, poetry as a form of data presentation; of young people's words taken from their individual transcripts was crafted, however, this comes under a myriad of names in the literature.

Glesne (1997), now over ten years ago described this as '*poetic transcriptions*', which is transformation of interview transcripts into poetry. She further went on to present three rules she created when undertaking her poetic transcriptions, these include; the words had to come from the individual's transcript; they could be from anywhere and juxtaposed; and finally, enough of the words had to be kept together to re-present the speaking rhythm (Glesne, 1997). Langer and Furman (2004) use the term '*research poem*' which utilises the exact language of the client taken directly from the narrative, with no words altered, although deletion can be used to give a greater sense of compression, allowing the reader to focus on the essence of the work (Langer & Furman, 2004). Koelsch (2015) agrees with the terminology a 'research poem' and highlights how the primary purpose is to evoke an emotional response from the reader (Koelsch, 2015). Shinebourne (2012) use the term '*poetic representation*' as poetry derived from the account of one participant; introducing the reader to one person in a more intuitive, expanded, holistic sense than the actual interview (Shinebourne, 2012). Gabriel, Lee and Taylor (2018) however, more recently calls them '*found poems*'; poetic condensation of data using only direct quotes from transcripts to create 'found poetry'. Whatever term is used, the one key element is that they must remain grounded in the data with the focus on the poem, rather than the literary form, with the participants voice loud and clear (Koelsch, 2015).

It was never intended to use poetry within this study. In fact I have never written poetry before and only read poetry at school over two decades ago. Nonetheless, putting these poems together was, I found, relatively easy, whether due to the quantity or quality of data, but also a desire to ensure the young person's words were captured, to do each young person justice in each poem that was crafted. Now I can see that there are many more advantages of creating research poems in this way which were not fully appreciated at the outset. The first benefit, is as Langer and Furman (2004) share from their creation of research poems, which was the surprise of the emotional intensity for the reader compared to the narrative. As they go on to say, the clarity and conciseness of the poem was like blowing away the husks on wheat to leave the kernel (Langer & Furman, 2004). Through poetry the text has already been condensed to its smallest element, due to reduction in physical words but with emphasis on emotion (Roberts, Brasel, & Crawford, 2014). Research poems whilst still using the language of the participant, unlike a lengthy narrative, due to its concise poignant form it encourages the reader to see him or herself within the experience (Koelsch, 2015). Other advantages include those research findings which may otherwise go unnoticed become visible and the researcher can often gain a new perspective (Brown, Candace, 2019).

Presenting the poem as a final offering is an effective way to reconstruct and confirm the lived experience of others (Glesne, 1997), and can capture a unique and fresh aspect about the experience under study (Langer and Furman, 2004). There is no doubt that use of poetry, contemplating and reflection can complement phenomenological studies, and in fact Heidegger himself was interested in poetry, as this quote highlights:

“Poetry, creative literature, is nothing but the elementary emergence into words, the becoming-uncovered, of existence as being-in-the-world. For the others before it were blind, the world first became visible by what is thus spoken” pg. 171 (Heidegger, 1975).

An area of debate in the literature is whether the poems should be taken back to the participant to ‘member check’ (Macdonald, 2017). Throughout the construction of the poems, I have been mindful that these young people had been very open and honest about how they felt; ‘brave’ in many ways to share their experiences. Although the study received ethical approval and the young people signed assent or consent forms (as appropriate) for their anonymised words to be shared in the process of dissemination, I was concerned about causing any undue upset through reading the poems. Presented as poems, the context of the interview has been stripped away with the words now not buffered by other words. I was concerned that reading their words after time has moved on could be upsetting. However at the time of writing, with support and face to face discussions, two older adolescents have viewed their poems and shared their ‘relief’ that “someone understands”. In the future, we are hoping these poems, or similar poems from the next stages of the research study can be used to create a resource for future patients with JDM to share an insider’s view on ‘Living with JDM’.

Whilst discussed so far as a positive impact or even the primary purpose of research poems (Koelsch, 2015) is to spark emotion in an audience, I believe it is only ethical to also consider the upset which may be caused through reading and hearing powerful texts such as these. As seen in the Healthcare Professional’s meeting some of the audience were moved to tears, and in fact any one could potentially see ourselves or other family members or friends within the experiences shared as poetry. Thus in the future, I will warn audiences in advance that some could find the content upsetting.

Limitations

Phenomenology is often criticized for its inherent interviewer bias, however, the findings presented are always simply the impressions gained, an offering of thinking to engage others in their own thinking (Smythe et al., 2008). However, it is true that when writing poetry, given the same data, different individuals will create different versions (Prendergast, 2006), and as researcher in this instance I was in charge of deciding what goes into the poem and what stays out, which ultimately could alter perceptions of the data (Glesne, 1997). In response to this, one could argue that interpretive phenomenology as its name implies, always has one interpretation at the heart of the process, the data leads, not tells, after all, life is only ever lived as ‘my experience’ (Smythe, 2011).

Conclusion

The phenomena of the rollercoaster captures all twelve poems created so far; from poems explaining difficulties in getting diagnosed, right through to living with JDM day to day. The visual representation of a roller-coaster and the powerful images conjured up through the poems, work together to provide a creative, pictorial, emotive and eloquent representation of the experience of JDM. From the beginning, it was important for the results to have an impact and inform practice, importantly with the outputs to reach a wide audience, beyond the nursing or psychology professions. From presenting the poems to a predominantly medical conference and seeing the power the words have had and hearing

clinicians say it will change their practice, then I believe that in itself is a positive outcome for the study. Through the use of poetry, made from the young people's words themselves, the lived experience of JDM has been presented in a succinct and powerful expressive way. Interpretive hermeneutic phenomenology aims to resonate with the reader, and there is no better way to present this than from the words of the children and young people themselves in poetic and powerful form.

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