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Combining creative writing and narrative analysis to deliver new insights into the impact of pulmonary hypertension

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ABSTRACT

Introduction Pulmonary hypertension is life limiting. Delays in diagnosis are common, and even after treatment has been initiated, pulmonary hypertension has marked effects on many aspects of social and physical function. We believed that a new approach to examining disease impact could be achieved through a combination of narrative research and creative writing.

Methods Detailed unstructured narrative interviews with people with pulmonary hypertension were analysed thematically. Individual moments were also summarised and studied using creative writing, in which the interviewer created microstories from narrative and interview data. Stories were shared with their subjects, and with other patients, clinicians, researchers and the wider public. The study was carried out in hospital and in patients' homes.

Results Narrative analysis generated a rich data set which highlighted profound effects of pulmonary hypertension on identity, and demonstrated how the disease results in very marked personal change with ongoing and unpredictable requirement for adaptation. The novel methodology of microstory development proved to be an effective tool to summarise, communicate and explore the consequences of pulmonary hypertension and the clinical challenges of caring for patients with this illness.

Conclusions A holistic approach to treatment of chronic respiratory diseases such as pulmonary hypertension requires and benefits from explicit exploration of the full impacts of the illness. Narrative analysis and the novel approach of targeted microstory development can form a valuable component of the repertoire of approaches to effectively comprehend chronic disease and can also facilitate patient-focused discussion and interventions.

INTRODUCTION

Pulmonary arterial hypertension (PAH) is a rare condition in which increased pulmonary arterial resistance results in progressive right ventricular failure. Median survival in untreated idiopathic disease is <3 years and, although specific therapies are now available,

it is still associated with reduced life expectancy. Sufferers may appear well at rest, even when cardiac output is critically limited, leading to diagnostic delay and a substantial associated medical and psychological morbidity.¹

High-impact medical research has become dominated by fundamental science or the development of new interventions. However, the delivery of good clinical care is often centred in profoundly personal interactions that change outcomes for individuals very powerfully.² Quality of life can be assessed by clinically relevant and applicable scoring systems^{3–5} and correlates with outcomes.⁶ Study of these qualitative aspects of health-care, though central to clinical practice, is rarely accorded high impact, perhaps both because of its perceived immediate failure to generate a new therapeutic target, and also in the difficulty there is in precisely quantifying the impact that it has. Qualitative studies in pulmonary hypertension have nonetheless highlighted the challenges for patients of developing an understanding of their illness and of coping with its progression,⁷ and holistic care includes close attention to qualitative factors.⁸

Narrative analysis is a qualitative research discipline developing deeper understanding of (in the medical case) illness from unstructured subject-derived data. Narrative approaches have roles in developing key clinical skills in clinical practitioners,⁹ and narrative research and practice have an important place in clinical medicine.^{10–12} Clinical practice operates in a narrative environment in which evidence-based medicine is applied within the context of individual patient stories. However, applying results of narrative studies to clinical practice is more

challenging; the impact can be felt by highlighting paradigms or assumptions that are made, often without conscious thought. The length of narratives and their examination by techniques such as thematic analysis do not lend themselves to linking of narratives to changes in management within an individual, and communicating key findings in a concise form is challenging.

We believed that a narrative approach would yield specific and valuable insights into the challenges and management of PAH. We took a new approach using interpretative observer-dependent creative writing to summarise narratives and present them as microstories. We believed creating microstories would generate a new way to analyse these narratives, and simultaneously make the narratives more accessible to others. These stories have revealed themselves to be remarkable for their ability to reveal and communicate experiences of illness that are fundamental to a deeper understanding of an individual's changing circumstances. These stories were received well by the participants who inspired them and have proved to be a powerful initiator of conversation and the reflective sharing of meaningful experience in other patients, family members and clinical care teams.

METHODS

Unstructured interviews were conducted by one author (JCG) in a variety of locations (hospital ward, hospital canteen/café, patient's home). Conversations were initiated with open-ended questions but with an aim to initiate discussions about the patient's illness. Data were recorded and transcribed, and subjected to narrative and thematic analysis using subjective qualitative evaluation to identify key themes arising from the interviews. The study was approved by NRES Yorkshire and The Humber Ref 14/YH/1016.

Microstories were defined arbitrarily as short stories of approximately 200–300 words. Topics were identified by transcript review by JCG as being reflective of important or pivotal moments for the participant at that point in time, and stories were written by JCG. Where names or initials are used in attributed comments or stories, these were randomly selected from a predetermined list and are therefore deidentified. Where random anonymised initials are used to identify speakers of individual comments, the same initials are used for the same individual throughout. Evaluation of microstories was undertaken through (1) by showing them to the participants who inspired them and, if they chose, to their families (2) a focus group made up of patients with pulmonary hypertension and their partners, independent to the narrative collection, recruited through the Pulmonary Hypertension Association UK and under the same ethically approved main study protocol, and (3) a public 1-day exhibition of microstories developed and supported by a local arts charity, Ignite Imaginations.

RESULTS

Interviews were conducted with 12 patients from the Sheffield Pulmonary Vascular Disease Unit. Two patients were in the 20–29 year age group, four in the 30–39 year group, two in the 50–59 year group, three in the 60–69 year group and one in the 70–79 year group. Where possible, multiple interviews were conducted with the same person to allow for new themes to emerge and participants to reflect upon previous conversations. Six male and six female patients were recruited. Three patients were interviewed once, six were interviewed twice, one interviewed three times and one interviewed four times. Twenty-three interviews of average length 70 min were undertaken, transcribed and analysed. Prominent themes were identified, which included the prolonged delays in diagnosis experienced between symptom onset and specialist centre referral, impact of diagnosis, complexity of therapy, frequency of hospital admissions, access to information and the reassurance of care delivered by an expert unit in a supportive 'family' environment. Impact of the diagnosis showed up in discussions of life expectancy, holiday planning, effect of illness on children, other family members and friends, and effects on ability to work, undertake exercise and perform routine tasks.

Narratives revealed PAH to have marked effects on individuals that changed sometimes rapidly with time. Many subjects showed evidence of a frequent reappraisal of their illness and its impacts, and the fluctuating priorities and issues displayed in the narratives highlight a need for healthcare workers to be very sensitive to changing patient concerns. Specific themes are discussed here. Narrative analysis seeks to consider the individual as a whole, rather than only one element of their story. Therefore, microstories have been used to illustrate specific themes to present the change within the context of an individual, rather than an abstract concept.

In this manuscript, we explore issues around *diagnosis, perceptions of liaison between local and specialist services, symptoms and their impact, impact on family and young children, coping*, and how narratives change.

Diagnosis

The microstory 'A Diagnosis' (box 1) was inspired by one of the younger participants and reflects the relief she felt after being diagnosed with pulmonary hypertension (PH).

It takes on average 2½ years from onset of symptoms to diagnosis in PH and consequently many participants spoke of their diagnosis and the process leading up to it. Despite having such a poor prognosis, many found the diagnosis a relief; it bought with it an understanding of why they were experiencing symptoms, and also provided an opportunity for appropriate treatment. The quotes below show participants' attitudes towards getting a diagnosis, and comments from being misdiagnosed. All quotations are taken as spoken from transcribed audio.

Box 1 A diagnosis

To finally get a diagnosis! Amanda has been waiting for it for months, for years even. She has been feeling ill, feeling exhausted, feeling unlike herself and not knowing why. The doctors told her there was nothing wrong, that she was fine, that had she thought about visiting a therapist?

But now she has the answer! The answer may bring up more questions than it answers but it explains the fatigue. It explains why she wasn't able to play with her kids, why she couldn't take them to school, why she couldn't help with their homework.

The diagnosis doesn't provide a cure, it doesn't mean all her problems are solved. But it helps many of them. They say the medications may just be for the symptoms but this is what she has been looking for. She feels normal again.

She no longer has to go out in a wheelchair, feeling like an old woman. She can walk up and down stairs unaided. She can drive again. She has got her independence back.

The diagnosis is not an easy one and there are still many more challenges to face but at least now she knows what she is facing. At least now she has some help. At least now she has a reason for it.

"And I thought, 'Well, I'm just unfit'." JB (male)

"And she said, 'I think you've got angina'." TL (male)

"Got misdiagnosed as asthma for a long time." BW (male)

"Then when [the doctor] told me that I'd got it. It were like a weight had been lifted. It's scarier not knowing, than knowing." EJ (female)

"It's nice to actually have a diagnosis... the medicine to help you carry on and remain stable." SW (female)

Perceptions of liaison between local and specialist services

Many patients commented on the extent to which they relied upon the specialist unit for support and management. Several narrated experiences where care in other hospitals had left them unconfident. In particular, patients were concerned and anxious when other care teams either gave the impression of not listening to the patient, or being reluctant to contact the specialist centre for advice. The following microstory (**box 2**) proved consistently popular when read by other patients and was highlighted in a focus group as being highly representative of experience of others.

Symptoms and their impact

Participants spoke about their symptoms and the impact they had on their lives in different ways and this is reflected in the microstory 'Changing Plans' (**box 3**).

Other participants spoke of their physical symptoms. Tiredness and shortness of breath featured heavily, as did sensations of palpitations. Professor Havi Carel, a philosopher who has reported on her own lung disease, observed 'Our attention is drawn to the malfunctioning body part... it becomes the focus of our attention, rather

Box 2 Insider's knowledge

Andy smiles to himself as he sees the confused look on the doctor's face. He knows full well that this doctor, and probably most of the people on the ward, haven't heard of his disease, most people haven't. And Andy knows roughly what's about to happen next as well. There's a few ways that it can go, but it tends to follow a certain pattern.

The doctor may try and bluff his way through it. Entertaining, but obvious. They may look it up on their phone. Wikipedia has a lot to answer for. The preferred option is, however, that they ask.

After living with the disease for half a decade now Andy has a range of explanations at his fingertips. He has the one for younger children. He has one for when he's in a rush. He has one for his grandma's friends who are being polite and enquiring after his health. And, of course, he has one for doctors who admit to knowing little about this rare condition.

It can become a little awkward if they don't ask. If they demand that he listen to them, that they are the doctor and they know more, that they understand what the ECG means. Andy may not know what each of the little squiggles on the page mean but he knows his ECG isn't going to look normal, isn't going to look like everyone else's. He could have told them this at the beginning as well, if only they had asked.

than the invisible background for our activities.'¹³ So it was for the patients in our study:

"It's not a tired. It's like you've been hit by a bus three times. And I want to feel what it's like to just be tired." EJ (female)

"My heart's fluttering about so much, I think I'm going to pass out." BP (female)

"Sometimes I'll go to bed and I'll feel that bad, I think I won't wake up in the morning." EJ (female)

"What does me head in most is how random it is." SJ (male)

Patients have commented additionally how the disease is hidden from those around them, since at rest patients are usually not breathless, and do not usually experience overt stigmatising of their illness.

"Outwardly... I look fine, and I do to everybody else, so loads of people think I'm putting it on or I pick and choose when my illness affects me." CE (female)

Microstories were produced to reflect on this dominant component to narratives, illustrated in the online supplement story, 'Well, this don't seem right!'

Impact on family and young children

Many participants spoke about the impact PH had on their family life and this is reflected in the microstories in the online of supplement of 'Water Baby', 'Reactions' and 'Getting On With It', and below in 'Children' (**box 4**) and 'Separate Elements' (**box 5**).

Participants with young children often spoke about how if affected the way they were able to act as parent, and respond to societal and family expectations. This was

**Box 3** Changing plans

A lot of people make plans leading up to retirement and these can be plans about anything and everything. Harry and his wife, Barbara, looked forward to his retirement because it meant more time spent enjoying each other's company and enjoying their old age. Harry had always worked a demanding job with long hours and they were looking forward to relaxing and travelling more, taking up new hobbies and spending more time on their old ones. It was a retirement that was well deserved.

But health is difficult to plan for. Harry's breathing is gradually getting worse and tiredness is starting to creep in. And with great sadness, he has had to give up his motorbike. It was a heavy, 'long-legged' bike and the worry was that the weight of it would be too much for Harry. It was a huge wrench for him, and one that isn't forgotten easily; each time he is sitting in traffic watching the motorcyclists weave their way through cars.

Not all is lost though. He has been a petrol-head for years and still drives the circuits he loves in the newest cars. Only now he adjusts the time he spends driving—a little less is better than nothing.

It might not be the retirement they planned for, but Harry and Barbara will carry on. After all, the road between home and the hospital alone is a delight to drive, especially in the early morning when it is free of traffic. Arriving early, there is time for a coffee and breakfast before facing whatever clinic has in store for them.

especially apparent if they viewed themselves as 'failing' at something they feel they should be doing. Some patients also made specific comments on their preparedness for death and their own funerals, and expressed concern about the future impact on their partners and children.

"I still wanted to be a mum, I still wanted to be a wife... it's not fair on my son, it's not fair on my husband." CE (female)

Box 4 Children

It is natural and normal to worry about your children and it is something that any parent will know well. But as Maggie watches her son her worries run much deeper than the normal concerns of whether they have nice friends, how they're doing at school, if they're happy. She is watching him for signs of the same illness she has—the illness that she carries in her genes and that she thinks about every day. It is something she turns over in her mind each time she looks at her son.

She describes the guilt she feels, a powerful emotion. One even more powerful because it is not her fault, there was nothing she did wrong—fate rolled the wrong dice for her and only time will tell if it rolled the wrong dice for her son. Watching and waiting is a difficult prescription to carry out but Maggie hopes to wait for a long time, hopes that she will always be watching and waiting.

Because she will. She will always be watching her son and this is what will protect her children from whatever the future holds. There is nothing more powerful than a parent's love.

Box 5 Separate elements

Old Sophia. That's what she wants back, Old Sophia. The person she used to be, before all this. The more relaxed one, the one that had less to worry about, the one whose days passed easily.

If it's Old Sophia does that make now New Sophia? I don't think so. I'm not sure but I think now is Now Sophia.

Now Sophia is battling through each day, battling through the thoughts that fill her mind. There's so much there, there's so much to accumulate and process, there's so much emotion, so much energy there.

It's like there's different people, people she has separated in her mind. There is the memory of Old Sophia, there is Now Sophia and there is always Show Sophia.

Show Sophia is the one that people see when Now Sophia is feeling low, when not everything's going well. But that doesn't mean Show Sophia is miserable, it's the opposite, Show Sophia is bubbly, happy and lively. She's the one that's always there with a smile and a wave, always asking how you are, always feeling fabulous, if you ask her.

Show Sophia hides the pain, the difficulties, the struggles. Hides the strain that can be getting through each day.

All these Sophias are all there in one—in Sophia. All these Sophias are needed sometimes to understand what is going on, to deal with it and to carry on each day, to keep getting through. Each of these different parts of her combine, they're all her, even if one is stronger on one day and another on another, each of these elements are what has made her, her.

Made her Sophia. The one who will continue to fight.

"I try not to let it affect them. I mean, it's going to affect them, I'm in here [hospital] and they're, they're out there." EJ (female)

"I knew I couldn't go home [from hospital for Christmas]. That would have been very disruptive... I didn't want to be an imposition on the family." JB (male)

"You feel a bit lazy if you can't do what everyone else does; run a house, look after your kids." SW (female)

"Planned me funeral, I've wrote everything down." EJ (female)

"I've made a list of my will or what I want to happen at my funeral and things like that." CE (female)

Coping

Many patients spontaneously discussed how they coped with illness, and in this context humour was a powerful coping mechanism, illustrated in the next microstory (box 6).

Other microstories such as 'And I'll do it' (below, box 7) and 'Getting on with it' (online) illustrate other aspects of coping. Each of these microstories contains, however subtly, the impact of other people. Each time a person speaks about events with those around them, the questions asked, and elements of their story focused on, influence how a person thinks about, and consequently reforms, their narrative.

Box 6 Humour

Betty pulls out the tissues, this is the second time I've made her cry and this time she's prepared. She's even got tissues for the friend sitting next to her whose eyes are also watering. I tell them that soon I'm going to be banned from speaking to any of the patients or their friends.

But she starts laughing again soon. Betty always laughs. Betty normally laughs at herself. Something she's done or something she's thought. But this is something I've often found when talking to people. Humour is a way of coping with things.

Dark humour, dry humour, self-humour. Anything to make light of it. Anything that undermines the issues, mocks it. It will be controlled, not the other way round. Humour is a way of making the disease your own, not you the disease's.

Betty just takes it a step further. She laughs at everything and anything. Our conversations always make me smile. Life is not there to be taken too seriously, life is there to have fun.

Specific illustrations of the use of humour and irony as part of a coping process are also illustrated in these individual quotations:

"And that is, that's one of the hardest things, is not being able to know how long. Because nobody can say, but do I get my patio windows? Am I going to be able to live in the house for a length of time?" BP (female)

"They're making jokes about how fat my tummy is and stuff." CE (female)

"It's best to laugh at it because [you] take control of it then. It's yours to take the mick out of. My condition has me, I don't have my condition." BW (male)

Changing narratives

A narrative is not simply just written, or spoken, but is built up out of a person's previous experiences and their expectations of the future. The microstories often provided a better representation of a narrative and an individual, providing greater information than individual quotes.

Box 7 'And I'll do it!'

'And I'll do it!'

Four words. Four words that can mean different things depending on how they're said. Katy says them with such confidence, such surety that you can't help believe her. Said by her, when she's convinced, would persuade anyone that the impossible is possible.

She will prove people wrong, other's expectations are there to be broken. There's nothing that'll motivate her to do something like being told that she can't. Can't is not a word that Katy knows or uses—can't is something for those much less stubborn. Katy knows how to beat the odds, she's not here to play someone else's game. She's here to play her own game under her own rules—to try and try again.

And she will. She will do it.

Box 8 Beneath the surface

I sit and listen to what this gentleman is talking about. The things that worry him are little things, they're not big worries, they only seem to highlight the privileged life that he's led. His concerns reflect on things that most people don't worry about. Not being able to organise fixing up the house doesn't bother many people, for some paying the rent is enough.

But then I read through his transcript, then I look through it again. There's not much there. It's why the little things stood out. Because they're the only things that are really there. Where's everything else? At one point he thought he wasn't leaving hospital. He thought he would die on the ward. He hasn't said much about that.

How much hasn't he said? What's going on beneath the surface? What are his thoughts during the night when it's dark and quiet on the ward? How much is this really hurting him?

The following two microstories (box 8 and box 9) were written about the same participant. They were written only 2 weeks apart but show a marked change in the participant's perspective on his illness. In the 2 weeks between the microstories the participant was in a hospital and he was heavily influenced by having people around him on the ward with the same illness; notably, some of the patients died.

Bruner, an American psychologist, also speaks about this, noting 'When somebody tells you his life... it is always a cognitive achievement rather than a through-the-clear-crystal recital of something univocally given.'¹⁴

Box 9 Working things through

It's so difficult knowing what's going on in someone's head. Often people don't know themselves what's going on, what they are working through subconsciously, what's about to show its face. How can you always know?

Sometimes I think I understand where a person is coming from. Other times I feel totally lost. Sometimes I know exactly what I want to ask next. Other times I have no idea. No idea how to better understand what's going on.

What people say can change quickly, anything can happen; the situation or the understanding of it. Sometimes it takes a little longer to process things through. Sometimes it can be the accumulation of things, building up. Everything together combined to be too much.

That's what happened with Richard. All those little things one after the other. The last not finishing before the next began. It's so difficult to keep that positive attitude with so much pressure.

He's working on it though, he's talking about it. Trying to understand it all, trying to get his head around it. Sometimes it takes that bit of extra time, a bit of time and the right words in the right places. Someone attentive to listen to him. He knows now that he's struggling a little but he's working on it. Working things through.



Summarising and communicating patient experience through microstories

Most stories were shown to the individuals described. Responses included:

‘That is so good and accurate. You really summed it up well.’

‘[laughs] Really, really nice!’

‘I can easily recognise me even though I know I'm supposed to. I have actually been quite flattered reading them.’

‘That's really good... I love it, I do... my mother would like [the microstory].’

Microstories were shown to a focus group of subjects with PH and their partners. ‘Insider's Knowledge’ was considered strongly representative of others' experience. Rather than reflecting on the content of specific stories, the sharing of these proved a strong invitation to others to share their own stories. A workshop with people experiencing other life challenges was conducted, and works of art produced based on the microstories by these participants and shown at a public exhibition. Again, these proved to be a powerful invitation to visitors to the exhibition to tell their own stories.

CONCLUSION

We used narrative analysis to explore the impact of PAH. Our patients particularly spontaneously discussed delays to diagnosis and the impact of their disease on their identity and lives, and on their families. The value of narrative to illuminate the experience of receiving life-changing diagnoses has also recently been shown in a study of Parkinson's disease.¹⁵ The narratives of pulmonary hypertension additionally reflected a continual requirement to adapt to changing circumstances, in an illness associated with nearly inevitable decline and punctuated by episodes of acute care and changes to therapy.

In our analysis, we began by summarising the personal experience of individuals in headings such as ‘adaptation to change’ which helped to group data, but lost its immediacy and resulted in outputs that were unwieldy to use in the communication of the experience of illness. In contrast, the generation of microstories created a resource that caused clinical practitioners, patients, family members and the public to pause, reflect and respond with their own stories. Each of these has highlighted points of patient experience that have the potential to change care delivery by clinicians. The stories also indicate powerfully how the landscape and impact of disease is not static, and how patient and family concerns change over time. They offer insights into the family and personal impacts that will shape the decision making and illness perception of patients.

Strikingly, the act of engaging with narrative research generated a reflective series of discussions

that revealed much more of the individual hopes, fears and goals of individual patients than is normally accessed during routine clinical service delivery. While engaging every patient in narrative interviews is challenging in resource-limited environments, experience from a focus group undertaken during our project showed that sharing microstories provided a rapid way of initiating the sharing of stories that were often deeply personal.

Close attention to qualitative aspects of illness has been identified as of significant importance in the management of pulmonary hypertension.⁸ Future questions for further study will need to explore the optimal way of producing stories, and whether coproduction with the subjects of the stories changes the nature of the stories explored. It is likely that different observers would pick different moments of interviews to base stories upon, and it is also possible that the conduction of interviews specifically to identify points for story development could change the way interviews progress. Nonetheless, we believe that these stories have significant potential clinical use. We hypothesise that sharing a bank of microstories with patients will allow them to identify and highlight specific areas of personal concern that can form the basis for targeted discussions in clinical consultations. Their success will be possible to evaluate in studies assessing the extent to which patients feel listened to and understood, which may be reflected in improved quality of life scores. We believe further studies can develop a larger panel of stories and evaluate their use in a variety of settings, in the education of clinicians, the initiation of conversations around difficult subjects with patients, and in wider communication regarding the impact of respiratory disease.

Contributors JCG conducted the interviews, analysed the data and wrote the microstories. IJA, BJS and IS developed the protocol, supervised the research, guided the analysis, and supported the development of the microstories. DGK, AC, IJA, RC, IS and CAE together managed patient identification and recruitment, and discussion and exploration of the narrative content. The manuscript itself was principally written by JCG and IS, with contributions from all authors.

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Ethics approval NRES Yorkshire and The Humber.

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Data sharing statement Additional microstories are uploaded as a supplemental document.

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