

It Sounds Like A Drama

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ABSTRACT

A poetic voice develops in different ways and from different sources. In this paper, a poetic voice is brought to the experiences of patients and family members as recounted in the first phase of a UK National Health Service funded Q-methodological study, the key outcomes of which are summarized. Their stories are presented as a single poetic performance text crafted from the analysis of combined transcripts of three focus group discussions. The performance bears witness to the sadness, frustration, and resolve of those living with chronic low back pain, and offers an additional hearing to that provided by the main study.

KEY WORDS

Chronic illness, low back pain, poetic representation, narrative, reflexivity, Q-methodology

Introduction

In their continuing endeavor to provide effective care and support, health and social care practitioners have drawn on the personal narratives of patients to enhance their understanding of what it is like to live with chronic pain and disability.^{1,2} At the same time, they struggle to respond to managerial demands for metric performance, measurable outcomes, and 'value

for money' in the delivery of care.^{3,4} Researchers select differing definitions of personal narrative, depending on disciplinary context and research purpose, for example: expansive life stories within anthropology; episodic, topically specific stories in response to single interview questions; or extended accounts built up over multiple encounters. The poem presented in this paper is based on stories and anecdotes recounted during three focus group discussions in which patients and family members shared their experiences of chronic low back pain. The focus groups were part of a UK National Health Service funded Q-methodological investigation into self-management in chronic low back pain.⁵

The Q-study

The primary intent of the initial focus group transcript analysis was to look for recurrent accounts from patients of what seemed to be critical to their self-management of chronic low back pain. These would be set alongside the viewpoints of healthcare providers (including representatives from physiotherapy, clinical psychology, pain consultancy, general practice, orthopaedics, rheumatology, occupational health, and practice management in primary, secondary and third sector care services). Subsequently, these combined accounts were organized into ten descriptive themes across the texts. By filtering the categories within them (key experiences) and sub-categories (what characterized them), a set of sixty propositional statements was derived (a Q-set). A further cohort of research participants rated these statements (Q-sorting) along an agree/disagree continuum according to a defined scale and matrix specific to the Q-methodology

process.⁶ The completed Q-sorts underwent statistical analysis using principal component analysis and varimax rotation with Kaiser normalisation. A four factor solution was accepted because each factor: a) had at least two 'factor exemplar' Q sorts loading significantly on it alone; b) satisfied the Kaiser–Guttman criterion, which states that all extracted factors should have an eigenvalue greater than unity ($\lambda > 1$) [4.23]; c) offered a clear, distinct and theoretically meaningful viewpoint on self-management. These four viewpoints are summarised in Box 1.

BOX 1

Four perspectives on self-management in chronic low back pain⁵

"Changing myself." A strongly psychological approach, needing a lifestyle/mind-set change, expressed mainly by health professionals but also shared by patients. A cure is unlikely, so patients should be willing to make lifestyle changes to cope with it. Being positive is key to gaining a good understanding of the problem and overcoming any fear or uncertainty that might prevent the important business of staying physically active. The process is all about patients regaining control of their lives by changing their lives to cope better with the pain.

"Changing what I do." A strongly pragmatic approach guided by accurate information and practical strategies, shared mostly by patients and some professionals. Psychology and relationships are different life issues best kept separate from chronic low back pain problems and their solutions. By carefully observing what works and what doesn't, life can be organised to maximise their capabilities and minimise future flare-ups. Patients want to plan and

organise their lives in accordance to their pain tolerance so that they can get on with their lives.

"Not sure what to change." Mostly patients and few practitioners voiced this perspective. The main focus was on the uncertainty of how to manage the complex characteristics of chronic low back pain. Managing pain is not a simple affair and cannot be successfully managed without help. Because chronic low back pain is so complex, a strong, trusting relationship with healthcare practitioners is important, so that help can be accessed as and when needed. However, practitioners' advice must be easily transferable to everyday life.

"The others must change." Only patients voiced this perspective. They felt very reliant upon practitioners to manage their pain effectively. At the same time, there is uncertainty about the extent to which they can be relied upon. This perspective is concerned with how patients are portrayed in society. Since pain is invisible, others do not necessarily take it seriously or believe them. They want to challenge the perception that they might be avoiding work or playing the system. Their wish is for mutual understanding between practitioners, other patients, friends and families.

(Adapted from Stenner and Cross et. al 2015)

For more details on criteria for factor solutions in Q methodology see Watts & Stenner (2012).

Repositioning ourselves

The Q analysis fulfilled the primary purpose of the project brief. However, it became clear during the

focus group interviews with patients that they were caught up in stories that were "too lively and too wild"⁷ p¹ to simply be tied to the strategic post of rateable statements. Their stories demanded more from us. Taking our cue from one of the patients, who described her life as sounding "like a drama", we repositioned ourselves to try and achieve a more reflexive engagement with the participants. We interwove stories across all three focus group transcripts, and VC crafted these into a single poetic performance text, based on the strategies described by Richardson.⁸ The potential of poetic inquiry as a way of knowing through poetic language and devices, and as an expression of affective experience, is increasingly celebrated, and the scope of its application is wide (see Prendergast for a comprehensive account⁹). Poetic inquiry may be categorized in terms of the voice engaged, for example, researcher-voiced poems may be derived from field notes, reflective journals, or auto-ethnographical writing in a research context. Participant-voiced poems may be created from interview transcripts, or created de novo by participants. Such poems may be written in collaboration with researchers, or reflect singular or multiple voices. We reworked or (re)presented the transcribed data, in the way described below, to create the 'found poem'¹⁰ that follows, although in doing so we were mindful that we were only "moving in the direction of poetry"¹¹ p²¹³ in terms of structure, not composing in the way of those steeped in the traditions of poetry as a creative art form.

Found poetry is constrained by a predetermined text that is reconfigured to approximate poetry through the concentrated language of the interviewee shaped by the researcher. However, found poems derived from data

...are not just transcriptions of interviews or observations with random line breaks – they must be spare, economical, rich and resonant...An effective data poem is no different from an effective poem – each word...Each line break matters; each space matters.^{12 p 42}

To create “It sounds like a drama” the already thematically coded transcripts were treated as one document, which was re-read several times. Phrases were cut and pasted under new thematic headings (which we used to divide the poem into ‘dramatic acts’) then played with poetically to create rhythm and resonance with an economy of words. This process involved making choices to craft an evocative collective response, which is linguistically faithful to the transcripts. Pelias uses the metaphor of a camera, which captures the most compelling pictures.¹³ Then each frame is carefully studied, so that each shot is significant and many are left on the cutting room floor. In so doing we hoped to “...weave a stronger fabric” than was possible with separate stories.^{14 p798} By trying to show as much as tell these stories, we sought to go beyond the confines of the factor solution.

It Sounds Like A Drama

PROLOGUE

*And it sounds like a drama,
but when you're actually in that bed,
and you cannot get up
without help from your kids,
it's not a place I want to be.*

ACT 1 – THE BLOW FALLS

I haven't suffered with back pain all my life,
I've had sciatica a few times, but you know,
it came as a bit of a blow when,
all of a sudden I couldn't walk properly
because of the numbness and things
I've fallen downstairs, broke my tailbone,
no-one came for two weeks.
My back went when I sneezed,
and I thought that was it - for life!
Mobile phone across the room,
couldn't get to that,
couldn't get to the door,
couldn't call for help...
and two Dobermans wandering round!
Mine all started with a lump on my leg,
back operation eight weeks ago.
And I'm not allowed, for another six weeks,
to push, carry, stretch or bend.
And that's been a nightmare, you know.

ACT 2 – GETTING DOWN TO PAIN

The pain can get you down,
sometimes I get very down.
I actually contemplated at some point,
the amount of painkillers I had,
to actually take my life,
because I just thought
“This is no way for anybody to live!”
Well I manage quite well because
I'm on a very high dose,
morphine patches and Tramadol.
I find I'm managing my pain, not too bad.
I could do without it,
but then everybody can.

ACT 3 – TAKING CONTROL TO DO WHAT YOU DO

I live on my own,
there's nobody, you know,
to shout and to help you,
stuff like that.

But you just get on,
because you need to adapt,
there's no ways, you know,
no other ways, no.
when you don't have no-one
no-one to rely on,
you know?

It is hard in the mornings to
get up from bed,
go to the toilet,
simple things like that,
But you just have to learn,
use your common sense,
find different ways of getting round things.

There's things you can't do,
make a bed, stuff like that, and
I wouldn't be without the grabber!

I take it easy, but still
I do what I do.

It's not just like I'm phoning off sick.

You need to move,
if you're just going to stay in bed
it's not going to help you at all.

I'm lucky, part time working
I can afford to get cabs,
but stuck in your home,
is an isolating thing.

You've got to have the willpower
I laid on the floor, for six months.
I done exercises, and after six months

I was walking again
all strapped up

with corsets and metal bars,
Running my own business,
I had to be on site.

Some days you can't get up,
get in the car or the van,
but with willpower,
I succeeded.

I've come to terms with the fact that
I'm going to be in pain
for the rest of my life.

Some days it's manageable,
some days it's not.

Once I come to realise that,
I've taken control.

I'm doing stuff within my own body,
the weight's coming off,
I'll get up and move.

Don't care where I am,
instead of sitting there

If I'm uncomfortable
I'll get up and move.

ACT 4 – GUILT MEETS REGRET

I have a lot of guilt about my back;
can't do what I want with my children.
going to theme parks and stuff like that.

I'm independent, like to do things myself
and now I'm having to say all the time,

“Can you help me because
I can't...”

It's stopped me from doing a lot really.

It takes your dignity away as well.
I've lost the closeness of friendships I think.

I can go out for a bit, but I can't
stand around for too long,

and I feel like I'm
slowing them down.

With my partner,

whenever we go out and about,
we're always the first ones to leave.

It's the feeling that
everyone's looking at you, thinking,
"Why are they going,
it's New Year's Eve?"

People don't always understand
how you feel. Not sympathetic,
they tend to forget,
you're in pain. You can see them
roll their eyes, and it's,
"Oh yeah she's got back pain!"

ACT 5 - TOUGHING IT OUT

Doctors get it wrong.
If you're curtailed by what you're told,
you're not managing your life,
you're not managing the pain,
Basically you know, you don't even think,
you just do what comes straight in your mind.
It just gets so bad you feel you can't cope
but you do, you get through the day.
It's got a lot better,
but it's still ten steps ahead, then
something happens and
you're back where you started.
Got to build yourself back up,
I'll tough it out, not giving in,
won't let it beat me,
But it has completely
changed
my life

EPILOGUE

Well unless you've had it, I don't know,
don't see how you could understand
I want my normal life back!

I don't want to care
about my back!
Back pain,
it just rules
your life!

CURTAIN

Conclusion

We have referred to our representation variously as a poem, performance text, and by its title as drama. These last two may be thought to carry some assumption of live performance that goes beyond a mere narrative.¹⁵ However, in striving for an evocative impact, the criteria for judging it may be considered performative in the way that Galvin and Todres describe.¹⁶ That is: does it tell us something that connects with universal qualities to which an audience can relate personally; does it help an audience to see more clearly by increasing the sense of contact with the experience, without fully possessing it? In other words, to what extent does the poem succeed in making the participants' voices present, not through any presupposition of 'truthfulness' but through a constructed, authentic, composite testimony based on the lived experiences of real people rendered poetically?

Our Q-factor solution played its part in conceptualizing the experience of chronic low back pain. In concert with the four factors (Box 1) "It sounds like a drama" bears evocative and critical witness to the sadness, frustration, and resolve of living with chronic low back pain. Each factor is embedded in the performance to some extent. For example, '**changing myself**' by wresting control

from the pain - “I find I’m managing my pain, not too bad, I could do without it, but then everybody can”. “I’ve come to terms with the fact that I’m going to be in pain for the rest of my life”; **‘changing what I do’** by working out what works – “But you just have to learn, use your common sense, find different ways of getting round things”; **‘not sure what to change’** without help and trust - “Doctors get it wrong. If you’re curtailed by what you’re told, you’re not managing your life.” “Can you help me because I can’t...”; **‘the others must change’** through challenge to perceptions and mutual understanding – “It’s the feeling that everyone’s looking at you.” “Not sympathetic, they tend to forget, you’re in pain. You can see them roll their eyes.”

For practitioners engaged in judgement-based practice, they should not only pay close attention to the particularities of the overtly ‘known’, but they should also strive to relate to the greater whole of the, as yet, unknown; to gain some embodied sense of what the experience feels like.¹⁶ As narrators of their chronic pain stories, patients confront us with alarming, seemingly unanswerable questions and expectations that often fly in the face of prevailing health care discourses. As seasoned listeners, we may fall prey to the assumption (fear?) that these stories (played out in the drama above) of ‘heroes and villains,’ ‘revolt and subjugation,’ ‘responsibility and blame,’ approval and disapproval,’ ‘acceptance and denial,’ harbour “expectations that need restraint.”¹⁷ ^{p9,18} Not least because they may seem impossible to fulfill. Thus, even as we strive to be “attuned to the patient through engagement, on the side of the patient through compassion, and available to the patient through reflection”¹⁹ ^{p1899} it is easy to become disengaged and blasé; to simply go through the motions, foreclose on the possibility of other hearings, and render ourselves unavailable. But for the patients and their families, the drama

continues. Approaches such as that offered here can act as “enabling fictions”, which in their performance, evoke empathic responses to human experience, and create spaces where others might see themselves.¹³ ^{p9-}¹⁰ In so doing, they invite further multiple interpretations and enliven the possibilities for dialogue and relational understanding.

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Vinette and Janet represent a team of clinicians, researchers, and service users who worked together on the project, heard the participants' stories, and brought their voices to these pages.



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