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# 15 Accounting for Dystonia: Personalising Illness Through Narrative

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## **Abstract**

This paper explores how people living with dystonia, a chronic neurological condition involving involuntary muscle spasms in multiple body parts, use narrative to make sense of illness by linking past, present and future, and giving their condition personal meaning (what Early calls the “customisation” of illness) (Early, 1984). It draws on a life-history interview with Sarah, a woman in her thirties living with generalised dystonia to show how people integrate their condition into their lives, and looks more generally at how narratives of causation are used to make sense of illness.

Little research has been done on the causes of dystonia; even if the ultimate cause is genetic, there is usually a reason why a genetic predisposition “expresses” itself at a particular time. Discovering what Hunt called the “provoking factor”, in her research with people with diabetes, can enable the person to integrate it in their biography, experiment with alternative treatments, or reinforce their sense of themselves as knowledgeable actors (Hunt, 1998). “Provoking factors” link biomedical and personal understandings and enable the attribution of responsibility so people can “bring meaning to the arbitrariness of illness” by “weaving” its cause into their life history and “making it part of the fabric of their life”.

The interest in causation shown by people living with dystonia is reflected in the full responses to questions about causation in the Dystonia Society’s 2001 membership survey and a pilot study for a questionnaire exploring the quality of life of people living with dystonia. In the survey, 55% of respondents thought their dystonia was triggered by an external factor and 14% mentioned more than one factor. The main factors mentioned were stress (41%), injury (26%), medication (19%) and surgery (9%). Others included viruses, repetitive strain, and exposure to chemicals; all reflecting contemporary preoccupations with stress and environmental and medical risk. The predominance of stress is interesting because for many years people living with dystonia have struggled against popular and medical perceptions that their condition is psychosomatic; presumably once its organic nature has been

acknowledged by a diagnosis they feel more able to acknowledge the complexity of its causation.

Even where only one factor was specified, it was possible to read others beneath it; for example, where “medication” was taken after the death of the respondent’s husband, or “accident” occurred after a lapse in concentration due to the repetitive nature of the respondent’s job. Despite the space restrictions respondents produced powerful and complex narratives that embedded dystonia in their life histories. In fact, much of their power derived from their terseness and omissions which let the events speak for themselves, something Skultans observed of her narratives from Latvia (Skultans, 1998). For example, one respondent simply recorded “blue baby/fractured skull/ bombed out/injured spine” and another noted the “year of stress and no laughter” that followed her parents’ death aged 16. The accounts used medical vocabulary (“retinal blood clot to the r eye”, “myoclonal from sunstroke as a baby”) but wove in personal elements, often including a critique of the treating doctor. The onset was usually attributed to external factors (stress, illness, family or work problems, or childhood events) rather than personal weakness.

The majority of respondents to the pilot study for the questionnaire also identified external triggers and had sufficient space to produce detailed and dense narratives that functioned as moral accounts, as they argued persuasively that the respondent had a right to have dystonia and that if you had been through those experiences, you would have it too. For example, one man recalled the death of his sister (aged 20), redundancy after “26 years of being in continuous service”, two car accidents, the lengthy illness and death of his father, and, almost as an afterthought “repossession of my house in 1991”. Another attributed his condition to his persecution by his colleagues after he “broke ranks to report a senior police officer for malpractice and an unhealthy association with a millionaire businessman”, culminating in early retirement “due to stress and injury” when he was “tripped deliberately in a running race”.

According to Frank, this is an example of how “in the absence of a comprehensive medical explanation, individuals weave together disparate strands from personal experience to give coherence and meaning to their condition” and “claim the capacity for living uniquely - seizing the point of one’s life - with illness” (Frank, 1998).

Many illness stories from people living with dystonia use ideas about causation to account for and master dystonia. For example, Sarah, whose story I explore in greater detail in the second part of the paper, attributed it to a back injury while working as a nurse for exploitative employers. The biomedical explanation of “a chemical imbalance in the basal ganglia” may not provide satisfaction or resolution as it ignores the “Why me?” “Why now?” questions that are an important part of making sense of illness.

Having outlined the importance of theories of causation in the narratives of people living with dystonia, I will now look at the process of integration in

more detail using extracts from a life-history interview with Sarah, an ex-geriatric nurse in her thirties who was diagnosed with generalised dystonia in 1997. Sarah has a flat in sheltered accommodation, which has been adapted to her wheelchair, and receives the top rate of Disability Living Allowance to employ four carers. The story she told me during the interview explored her fear of deterioration and its effect on self-preserving activities like her craftwork, and how her relationships with doctors and the social services were characterised by mutual distrust. She linked her dystonia to her childhood and working life and attempted to capture and control it through vivid and precise description (n.b. dystonia, in addition to being fairly rare and under diagnosed, is a very diverse and variable condition).

Sarah told me that during the last two months she had noticed a change in her dystonia as the spasms in her hand have now spread to the whole of her right side and her hand “balls”, “spreads”, and “claws”.

How can I think of a sensible way of putting it without sounding really strange?  
It's like something in a film where someone is trying to cling on to something while being frozen in a block of ice. It's like someone getting an electric shock as my fingers stiffen in different directions.

She showed me how her right foot rotates and inverts and left leg “spasms” up to the knee, “it pulls up and down, a bit like I was rowing”. Before she began using Baclofen (a common antispasmodic) her spasms were very violent, “I was like an American jumping bean”. She describes her oromandibular dystonia, which affects her mouth and jaw as “a yawn” or “a tic”, accompanied by blinking. Last night she “tossed and turned” until 2 am as the grinding of her jaw caused her other muscles to go into spasm, “I tried to glue my jaw with a carrot rather than chomping at my cheeks”.

She told me she has been prescribed a gum shield but doesn't want to wear it as she doesn't like things in her mouth or near her face, recalling how during an asthma attack her ex-husband put a pillow over her face for a “joke”. Her jaw sometimes locks when she speaks which she said made her sound “like a scratched record”; “I have to wait until the needle has jumped over the scratch before I can continue the sentence”.

Sarah explains her dystonia by situating it in a history of personal and work-related stress, for example, having dreadful migraines as a child (“I would come home from school, throw my bag in a corner, flop out on the kitchen floor and my mother would put a blanket over me and leave me there to sleep it off”). She also attributes her early clumsiness to her dystonia (“different pockets of things happen and fit into place and I think ‘I've been here before’”), which she uses as an explanatory device to make a coherent narrative from diverse and traumatic memories. Sarah finds not being believed particularly painful as “when I was a child, no-one would believe me”. This sense of predestination is shared by people with Temporomandibular joint

syndrome (a similarly borderline condition); in Garro's study one person described herself as 'a walking time bomb for TMJ' (Garro, 1994).

Despite her blurred vision (a side-effect of another anti-spasmodic) she can still read but finds writing difficult as it involves hand-to-eye coordination, which often brings on a spasm, "I can only write a shopping list three lines at a time, taking regular breaks". She worries about future deterioration in case it means the end of her "craftwork", which is a "life saver" - this is reminiscent of Cassell's definition of "suffering" which occurs when a person can no longer participate in self-defining activities (Cassell, 1982).

My *normal* spasms are familiar and I can accept them. I've never been a person to sit and do nothing, even when watching the television I would be crocheting. I don't sit back and dwell on it - I'm a pushy person to myself. I try to be too independent - I say, 'sod it body, I want to this and I'm doing it'. I haven't got the time to be bitter. I've been dealt that hand.

Sarah believes her dystonia was triggered by an injury to her back while working as a nurse for elderly people with mental health problems.

The home was on four levels and there were no hoists, so if someone wanted to go down for dinner, three people would carry them up and down the stairs in an ambulance chair. People often wanted to return after the first course and they could be obese or have psychological problems that made them struggle as they moved. We were always short staffed. It all adds up, eventually your body says 'enough, I'm going to rebel'.

Sarah experiences her dystonia as directly produced by the conditions of her life - the cumulative effect of years of stress and exploitation. Her interpretation has persisted, even though many fade into the background once a diagnosis is obtained, particularly if the person obtains relief from conventional medicine. For example, Thomas, a man with dystonia of the neck writing in the Dystonia Society newsletter, advises "selectivity in choosing help" as "it is of little help spending a fortune rummaging around with such notions as the Oedipus complex to explain one's condition when true causation lies in a chemical imbalance in the basal ganglia". Other theories remain to organise the experience of illness and guide action. Beatrice's allergic response to 55 of the 58 common substances she was tested with prompted her to create a "controlled [home] environment" with "no carpet, no wall paper, filtered air and water and no cleaning chemicals". Regretfully, this ideal of purity and control is occasionally disrupted by visitors "because of the chemicals that are still hanging around their persons from the environment outside".

This interest in causation has been observed in other chronic conditions (for example, multiple sclerosis) where medical uncertainty about cause or aetiology provides space for alternative explanations. According to Robinson,

“the problematic initial search for a diagnosis through the formal health care system, the often contentious and transient relationships with medical staff, and the frequently continuous experimentation with a wide range of medically unorthodox therapies are a corollary of personal attempts to create or maintain a progressive narrative of life in the face of the disease” (Robinson, 1990). For example, Paula makes discovering why she has dystonia central to a review of the effects of her life on her body, deciding “if only I could discover why I had this disease I would be able to put it right”. She attributes her condition to three “sets of reasons”: “physical defects or damage I have collected in the course of my life” (for example, “a nervous tick in my right hand when I was young” and “lower back pain after a pregnancy”), “mental, centring around stress”, and “age”. Paula likens her body to “an aging house with a lot of weaknesses in its fabric” which has experienced “collapse and major damage” after “a sudden shock or continuous stress”.

According to Williams, a similar process occurs among people with rheumatoid arthritis who reconstruct the past through narrative to create an impression of continuity and purpose (Williams, 1984). Hunt has also observed this among people with cancer and their doctors who “deny the arbitrariness of suffering by associating it with antecedent events and thereby sustain the idea that the world is essentially orderly and controllable” (Hunt, 1999).

These are examples of an illness narrative functioning as a new “map” (or “guide to living”) that counters the “biographical disruption” of illness, which may have turned the person into a “narrative wreck”. By constructing a narrative they become the editor of their life and assume responsibility for it; which can be an almost political act if the alternatives are to write or be written upon. Although Frank fears that encouraging “confessions” of illness may be “panopticism in benign disguise” or what the Foucauldian medical sociologist Armstrong would call “pastoral power” I believe that the problem for most people living with dystonia is not that their stories are recorded and used against them, but that (aside from the Dystonia Society newsletter) there is no discursive space in which those stories could be heard (Frank, 1998; Armstrong, 1995). Frank later notes the irony that “first-person stories are told to express what cannot be expressed in the clinic where people ostensibly go to talk about illness” as “the point of medical history taking is not to provide the person with a hearing of his or her suffering”. Stories can become what Foucault calls a “technology of the self” where power operates by convincing people to transform themselves using practices like diet and therapy. According to Crossley (1999), relating the stories then becomes a “moral imperative” and “involves a profound assumption of personal responsibility”, including a willingness to “re-shape that self story if the wrong self is being shaped”. Crossley’s analyses of “healing” stories from sexual abuse survivors and HIV-positive men question whether they are “empowering” as they could lead to “narcissistic withdrawal”. But these stories can also be “care of the self”

if they involve “reclaiming a voice that bodily trauma and institutional treatment have caused to be silenced”. Self-actualisation thus becomes a balance between opportunity (care of self) and risk (truth games and power).

I believe that a narrative approach to illness is worthwhile because stories are a valuable source of information and understanding, if handled carefully (for example, acknowledging that they are creative interpretations rather than transcriptions of experience and are highly context dependent) and because telling stories can be therapeutic and enhance doctor-patient relationships. I concur with Frank that illness stories offer more than other forms of representation because they “claim a unique way of being ill” against the “standardisation of disease”, refer to and develop “we” relationships, and depend on and extend a “shared horizon of moral significance” (Frank, 1998).

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