

People, purpose and passion. Be extraordinary

Illumination: Practice up close and personal. The battle of the bowel

Abstract

People, purpose and passion in disability nursing have always been about supporting individuals to fulfil their potential and goals in order to lead full lives. Optimal health outcomes have necessarily been essential to this pursuit, and a major focus of the work. This paper reviews, in general terms, the nature of the giving and receiving of support, in a health context, for people who have intellectual disabilities, and the nurses who provide that support. A personal health experience is examined, as another useful body of evidence.

Illumination: finding creation in that space, the tension between the real and the imagined (Cadwallader, 2018)

At the PANDDA conference in 2012, I presented a paper called *In the first person: A body of evidence*; a reflection on stories of a body of evidence taken from moments over time. A telling of lives lived and of extraordinary relationships that may be needed for the telling, that belong to ordinary people and nursing work. I said then that I would not dwell on the health/illness aspects of the evidence that people give. I want to reflect on that now; a sort of companion piece.

In reflecting on these relationships, I used you/your; and I/me/we (nurses); it gets us past words that we don't really need (people who have intellectual disabilities), because they are a functional necessity only, and in no way define you. I will do the same here. We are a functional necessity too, of course, in these extraordinary relationships, but so much more surely, in our striving to keep things ordinary for you.

For *In the first person: A body of clinical evidence*, I looked at the evidence through a series of vignettes; moments that contain your stories. In *Palliative care: A shared experience* (2017), Robyn Buller and I chose the composition of Beethoven's *Moonlight Sonata*, with its shifts in intensity, as an underlying structure. Here I am inspired by Robyn Cadwallader's brilliant new novel *Book of Colours*, especially the details from *The Art of Illumination*, the creative vein that leads the chapters. This is a book about the making of an illuminated manuscript; about creativity and the importance of connection for the making of something wonderful (Cadwallader, 2018). Sounds a bit like us?

The notion of health is the same for you as for any of us, make no mistake about that. Our meanings of health are at once universal, similar and unique. They are determined by how our bodies work for us, body as the whole being: mind soul and physical container of our life force. Health, for you, encompasses comfort, minute by minute (comfort is an essential health ingredient, something that I still have to explore in detail), chronic health issues, being able to do what you want to do; when you don't have control over that, being able to enjoy what you want to enjoy. Feeling ordinary. Having the support that you need to manage all this. What we do for you, and how we do it. We both have investment and a determination of purpose in this.

Embodiment: being and having a body. Living in and through a body (Draper, 2014)

We have to do this with what we've been dealt, to experience our living. The extent to which this impinges upon your ability to fulfil your potential and goals, necessarily determines the level of support that you require from us. And so this special relationship is built.

We, in our role of giver of support, have to look directly at and process the dominance of mechanistic physiology (Draper, 2014) because how your body makes – lets – you experience your living, is determined in part or more by your chronic health issues and/or mechanical challenges. This is the functional you, no getting away from that. For some of you, breathing, eating is close to all.

The limner brings the light of understanding and awareness...he illuminates the world he decorates (Cadwallader, 2018)

At the same time, though, we look past this; we embrace and work through a different descriptive discourse and look for different understandings of lived experience (Draper, 2014), because this is what we must do. We all have to make the most of what we've got. The support that we give you, moment by moment, the intimacy negotiated with care, so that it is and isn't perceived as real, so as to make it wholly yours.

The object body, the subjective self (Mackey, 2009). You are always a full participant in your supported activities, not merely a recipient, never fear.

SPATIAL RELATIONS

I have introduced the body, that fine, strong, fragile, infinitely complex thing. What it may take for you to carry on your living, in and through your body. I want now to consider what happens when you experience bodily disruptions (Draper, 2014) in the context of the spaces which you negotiate as you go about your living.

The body no longer passes by in silence (Draper, 2014)

You are familiar with the body's workings; it is what you have come to expect. It is yours. You are familiar with the spaces you live in; you feel secure there, You have your routines. You are used to us; you take from us what you need. We know by now what worries, frightens you, what you don't like, so when you go out, we don't take you to those places. When you are unwell, we look after you, reassure you.

But then, the dynamics of your body, the spaces that you inhabit, change.

Suddenly. Just like that, because this is how it can happen.

Narrative

Dramatis Personae

The Beast from the East

You

Catharine (me)

Disruptions

The Beast from the East hits the UK with a vengeance. We knew it was coming, but still...

Something is wrong. Your body is doing things that you don't recognise, don't understand. It has become an alien landscape; betraying you. We don't have what is needed to help you at home.

I wake at 01:30 and am immediately aware of right-sided abdominal pain.

Wind (hopefully)? No, it doesn't shift with position change, and has a different, burning feel. Constant, unfamiliar, concerning. I am alone.

The vast snowfall overnight. It started moments after reaching my cousin's house in Bearsden. It is beautiful, fascinating, of course, but I am no longer a child to revel in snow play. I am a 60 year old adult with osteoporotic hips, trying to negotiate knee deep snow in a blizzard, hoping to God it doesn't turn to ice.

The ambulance ride. Strangers talking to you, touching you, doing things to you. They are kind, competent. You have one of us with you. You arrive at the ED and either wait in the corridor or are transferred to a bed. You may not be

able to sit in a chair.

I'm up. Dressed. The pain stays, keeping me company. It is significant, but tolerable. I think: heart? Bowel obstruction – bet it is. Oh God. I have a large bowel motion, it hurts. No nausea. Just this pain. Surreal. I have to act. I don't want to be alone. But still...car? Ambulance? I don't want tie up an ambulance. It's only 15 minutes. I can always pull over. I know where I am. I have my mobile. By the time I reach the ED, I am doubled over.

Snow is piled up against the front door. Each step is slippery. Getting to the gate has become a treacherous challenge.

The routine starts for you. Your family has been notified. It's nothing that you know. All the bruising you're going to have from failed cannulations. Hard to be still when you don't know what's happening, don't know that you need it. The noises, lights, people, machinery. The bed is not your familiar bed. We have sent a nurse with you who knows you; whom you know. We have sent a thick folder of information about you, to help them help you. We will find out how much we don't know about you, your body, right now. Does it hurt? Where? How can we know?

I eventually get to triage, eventually get to a bed in the ED, am left for a while. If alive, conscious, talking, obs stable, I can be left while they minister to another. The pain is a beast, gnawing away at me. I text my eldest daughter, my NOK. I don't want to alarm her, bother her, but someone needs to know that I am here.

I get to the gate safely and walk to the station with my cousin. The snow plough hasn't come through here yet; too early in the drama for that. I have to be so careful, don't know where the curb is, what may lie under the snow. We wait an hour in sub zero cold for a train that can't come. We eventually find a taxi to take us to the hospital in Glasgow where I will see my beloved uncle for the last time. And still the Beast from the East howls; the snow swirls and falls.

Evidence: signs, indications of something (Ayto, 2001)

What space do you inhabit now: the bed, your body, as it does things that are out of your control. There is evidence of what is likely to happen, but nothing is certain. Those doctors and nurses come and go. They have purpose; they know what to do. They are kind, but they don't know you. As you rely on us to support you through your days, so you need us now, in this alien space. But we have handed you over to their care. We do what we can to support you, your family, your doctors and nurses. It's daunting; a challenge to your comfort and sense of self.

I'm in a chair now. Someone else needs the bed. It doesn't matter. The pain has moved across the top of my abdomen. Its core stays constant, but there is a surge to the left and right, an escalation which is almost unbearable until thankfully it subsides a bit. This is now the pattern. I have a cannula. My 60 year old skin bruises, which comes as a minor shock. I am given IV morphine. My nurse describes what it will feel like. It is as she says: a fizzy, queasy rush as it leaves the line, into my vein. My daughter is with me now. It is difficult to talk. I try to think of the pain as pain, a thing that I can abstract.

No. it consumes me.

We reach the hospital. It's like a re-birth, getting out of the howling wind and swirling snow. Order is restored. My uncle is in a ward on the top floor. The view from the window is amazing. Cars skidding all over the place in the white. White out. More snow. The evidence is there: I'm stuck up here. The only question is how long for.

Knowledge is power. What you don't know. What we don't know of your experience. You, in that body. I use what I know of you. I hunt your doctors down. So busy, but they always respond as soon as they can. I consult, negotiate, plead, sometimes. Evidence: the real and the imagined. We have physical evidence. Your body signs, tests, scans. We can see you inside out. But... I say that we can borrow from what others have described, surely? If others say that pancreatic cancer is painful, then use that for him. Imagine. Don't leave him to face that without help. Don't leave us to face that with him. Imagine. Be creative. I do this, not just because it's my job. I want you not to hurt; to be back in your own bed; doing your own thing.

Knowledge is dead scary. It's bound to be a bowel obstruction. Oh God. The pain is now wrapping itself around my lower back. A spiteful visitor that won't leave. The morphine haze intensifies. Now I have to worry about falls risk as I lurch my way to the toilet. So grateful that my girl is with me. I've drunk the contrast medium for the CT scan. Like that'll stay down.

Nothing like pain to let you know how alone you really are. People all around, helping you, caring about you, but alone. The point of existence.

By the time we leave the hospital, there is a howling blizzard again. There is now no transport operating. So we walk for an hour. In the blizzard. I have snow drifts behind the lenses of my glasses. One careful step after another.

You can't, or won't tolerate all these investigative procedures. You pull tubes out. I can't blame you. They must be painful, irritating. But you need them, so you're going to get them back.

The moment I've been dreading. The NG tube is big, hard. I knew that, but... No. The doctor and nurse regard me with compassion. The pain has subsided. I'm tired, and hazy with morphine. The buscopan helped. I don't know. My girl wants to stay with me for the tube insertion. I send her away, with love. The doctor and nurse I don't mind; they've seen it all before. As have I. But not like this. Happening to me. Happening to you. This young nurse is good, and gentle, but I stuff it up. I've bitten dentists for less. So I say, do it again; whatever I do, push on. So it's done. It's awful. It's necessary. It mustn't come out.

Back at the house in Bearsden. Out of the blizzard. I have survived a day in a blizzard! My body aches. People are stranded at Glasgow airport and train station. Those who ignored the warning to only drive if essential, face a freezing night on the motorway. Those living nearby walk up and down the road all night, with food, drink and offers of toilet usage. The tracks between Scotland and Carlisle are covered in snow drifts. No train track snow removal equipment. Scotland's greatest ever snowfall. I'm in it! Mountain rescue teams and soldiers work to get hospital staff to work. A shared purpose.

Once admitted, you may not be permitted a special, although I always push for one. You get plenty of visitors, familiar faces, to make sure that you are getting the treatment and care that you need. To be with you, bring you things. To let you know that you matter, that you are loved.

Consider the ED, what happens in that space, packed full of activity at once to give you intensive, intimate care, and to process you home or to a ward for further care. Whatever you need. I still wonder how the woman with post miscarriage complications is doing. I only heard her, in the space next to me. Now I'm in the surgical ward. I'm a NG tube, it seems. Let's not consider what's in the attached bag. Swallowing, talking hurts. I have a heavy rod jammed against the back of my oesophagus.

The body laid bare. What we're reduced to. Not reduced in others' eyes. Only our own. Just as well we feel too ill to care most of the time.

I'm warm, safe, with family. I just can't leave. Not a great feeling. I'm booked on the Eurostar to Rotterdam early next week. I check with my cousins there: no snow forecast. More snow falls in Bearsden.

The nausea, discomfort. Eating and drinking. How do you feel? How do you cope? I'm sure that at some point you give up and just endure. What else can you do?

I feel sick. I can't swallow the fluids they give me, can't swallow meds. My head hurts. So much light and noise. I'm in a room with three men. Three groups of visitors all talking at once, in different languages. The NG tube fills my body. I ask for the IV fluids to be re-instated. I'm dehydrated. I can't sleep.

I have many lovely visitors, but I can't talk. The light hurts my eyes. I endure.
What else can I do?

Finally, I get a ticket on a bus from Glasgow to London. An uncomfortable 10 hours, but I am out of the Beast from the East's clutches.

Discharge advice often changes by the minute. We work hard to have you home. You can inhabit your own familiar space again.

I feel much better. The tube can come out. I feel more like me again. Solid food and star of the Bristol Stool Chart, and I can go home, to my own familiar space.

Battle of the bowel: notes

Bowel function: so vital for the body, such a large part of our support practice. As with most things, if the bowel isn't functioning well, it becomes the body space, fills the mind.

Constipation: for some of us, achieving any sort of bowel motion and expelling it, is a Herculean task. No exaggerating here. From one who knows: general malaise, tired, flat, feeling of stones in the gut, headache, lack of appetite, nausea sometimes. It becomes all consuming. For some of us, it is a way of life. Sometimes my bowels suddenly start emptying, not all at once; over hours. Usually accompanied by nausea. Debilitating. No discernable cause.

Tension between the real and the imagined (Cadwallader, 2018): this guides

our practice, it seems to me, because whilst so much is real from the evidence given by the body, there is always imagining, because you can never fully articulate what is happening to you, how it feels. It is informed imagining, on our part.

We devise plans for trying to keep you safe. Nothing new here, a never ending work in progress. We win battles, but not the war.

Bowel care guidelines, bowel management plans, bowel charts: your best friend, or your worst enemy. Ongoing consultations with doctors regarding your treatment plans – can we try something else, to give you a better result? I'm sure I'm not the only one to say in despair 'but what else can we do? We have tried everything. We really have'.

Staff training: one of the last things that I did as a Clinical Nurse Consultant (CNC) for Health at Metro Residences and with colleagues, was the development and presentation of a bowel management package. This included principles of bowel management, bowel motions, factors affecting bowel function, constipation, bowel obstruction, nursing management procedures to maintain health and wellbeing.

Nothing new here. No. but we keep going through it because missing the evidence that we could have, is unacceptable.

I participated in a working group some years ago (in my role as CNC Health at Metro Residences) concerning bowel management, because serious bowel function complications were an increasing health issue. Differences in staff knowledge and experience – nurses and DSWs – were debated. My

contribution: back to basics. Identify what is the norm for the person. Observe, record, report any deviations from that norm.

I called the bowel chart your best friend or worst enemy, because if not filled in, with stool changes and absences noted, essential evidence is missed.

Bowel obstruction

I have supported a number of you through your bowel obstructions. These were usually due to sigmoid volvulus (loop of intestine twists around itself and supporting mesentery) or ileus (failure of peristalsis). Treatment was conservative; one of you had a colostomy.

I always felt so bad for you; what you had to go through. I sometimes thought: one day that might be me. And on 21 June 2018, it was. Most of you had signs: lack of appetite, abdominal distension, vomiting. I didn't. Just sudden right sided abdominal pain. I received conservative treatment: fasting, aspiration via NG tube, build up from clear fluids to soft diet. I eventually produced a perfect stool with the help of a suppository.

The CT scan showed distal ileal loop collapse which could be due to small bowel obstruction from prior adhesions. The surgeon had said to me that this was due to adhesions from my appendectomy – 48 years ago. I said that I thought the endometriosis more recently would have been more likely, but no. 48 years ago? Really? My first thought was: I couldn't have avoided that. It wasn't my fault.

So I had a brief look at the research. One study looked at the incidence of bowel obstruction following appendectomy. The authors looked at a cohort of

2332 Canadian patients between 1999 and 2002. There was no statistical difference in small bowel obstruction rates between open appendectomy and laparoscopic appendectomy (Leung, Dixon, Gill, & Maclean, 2009). Mine of course was open, all those years ago in Prague.

Another study involved patients from 1 January 2006 to 31 December 2008. 11,289 patients had open appendectomies; 11, 289 had laparoscopic appendectomies – the latter were controls. None of these patients had had previous abdominal surgery or small bowel obstructions. Findings indicated that open appendectomy posed a significant risk compared to laparoscopic appendectomy. Being female posed a risk factor (Tseng, Sun, & Chon, 2016).

This was alarmingly interesting; my whole experience was simply alarming. It could have been a one off, or may happen again. Every abdominal twinge or discomfort makes me go cold. Discharge advice was to make sure that I chew food really well. I avoid insoluble high fibre foods that might get stuck in my intestines. If symptoms recur, I must fast and may have to re-present at the hospital. Small comfort, as the only symptom was the pain. As I was asleep at the time, I don't really know if the onset was that severe, or if there was a build up before I awoke.

Whilst I was undergoing all that unpleasantness at the hospital, what I kept thinking was: what if those of you whom I was supporting through your bowel obstructions experienced pain like that? How would we have known? I know that you did get pain relief, we made sure of that, but this ended up being severe pain that the morphine didn't really touch, and that scared me as well.

Did you not get relief from your pain medication? The NG tube thing, well, that's something that has to be endured. If I hadn't been so horrified, I would almost have laughed at the doctor saying: do you think that you can possibly manage this? Guess I did ok! I would have so hated a re-insertion, which would have been for medical reasons, as no way was it going to be dislodged!

Pain, and not knowing your pain, how to gauge it, is something that continues to haunt me. Correct identification of pain for you continues to be a challenge. Pain usually functions as a warning sign (Amor-Salamanca, & Menchon, 2017) and if you can't communicate this so that we can recognise it...I think that we generally do a good job, and demand pain relief for you.

It is a real problem, you not being able to cognitively reflect on your own Pain (de Knecht, Pieper, Lobbezoo, Schuengel, Evenhuis, Passchier, & Scherder, 2013). Is it acute or chronic? Do you display typical behavioural pain indicators in the absence of pain (Ailey, Brown, & Ridge, 2017)?

I think that we will always struggle with this; not wanting you to struggle with this. We keep trying, pushing, advocating for you. This needs to go on forever. The desire to write this paper came directly from my small bowel obstruction experience. I would never say that it was a good thing, but given that it happened, I want to pass on anything learnt from it, however small. The more voices, the better.

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