

Failing health. Exploring tensions.

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Abstract

Recently I was invited to write a short paper (Salter, 2023) for *Context* magazine, a magazine for Family Therapy and Systemic Practice in the UK. It is a themed edition, edited by Joanne Hipplewith who generated the theme of “Failing, to do better”. For me the title speaks to the idea that there is a tension to explore within failure; the tension of present pain and future opportunity that the inclusion of the comma brings into view.

I wrote about experiencing the theme as a writing prompt and used the opportunity to reflect on times I have experienced failure in academic contexts and to reflect on the process of writing for publication. For many this can invite anxiety around failure and provoke fear of “getting it wrong”. I explored also the tension between the pain of failure and the hope of learning something useful from the experience.

A sub-theme emerged in my writing linked to current health status and the recent loss of my father who died from cancer in September 2022. I suppose I was reminded of the invitation to see ill health and end of life as a failure of some kind, that I had been *failing* in terms of my own health and that my father ultimately had *failed* to survive cancer. But there were opportunities, even here. My father and I found a way to live with (and for me, live through and beyond) the health challenges we faced and we were able to create space in our relationship to honour each other’s challenges. This was new territory. A new tension.

Presence

In the last six months of his life, I viscerally experienced my father as more present to me than he had been before. It was in the way he looked at me, held eye contact for longer than he has previously, and in the way my body felt more relaxed in his company than it ever had before. I think he might have experienced me in the same way, though I did not ask him and it

would have been difficult for him to articulate this, for many reasons. Most notably this is because he was unable to talk following throat surgery. However, he seemed to be more relaxed in my company, when we were able to meet in person. We did not live close to each other, he could not travel, and often my health precluded my travelling also. When he was in hospital, for prolonged periods, he was not allowed visitors due to COVID 19 restrictions. So physical contact was limited. We communicated via text messages most frequently and when together he would write things down on paper. This might have been experienced as a barrier but, in reality, we “spoke” in ways that were far more open than we otherwise would have been or ever have been before. It reminded me of times when, as a therapist, I have sat with people in silence and they have communicated so much in that so-called “silence”. I was reminded, also, of how people have often asked to communicate through pictures, letters, creative writing or poetry or sometimes communicating through writing on a tablet or phone. I can sometimes experience these moments as times of tension. What am I being invited into and why? Am I enabling someone to communicate with me/ have their story witnessed by their family or am I entering into a complex power struggle between parents and children in ways that miss nuance and complexity? Or both? A *simple* “yes that’s ok” to a teenager, for example, could communicate all sorts of undermining messages to parents struggling to set boundaries or have their own presence acknowledged.

I offer an example from text communication with my father, share some reflections and then introduce an example from practice, as a counter position.

Space between

Dad: You brought tears to [my] eyes when you told us the story of you swimming after your surgery and feeling alive. Wonderful. Thank you!!

Me: Thank you for sharing that. That means a lot. I really feel your aliveness lately and I’m so pleased to see it. It makes me feel close to you x

Dad: More tears... xxx

My father adding kisses to messages and suggesting he might be moved to tears is so far removed from the man I had known in my childhood and for much of my adulthood that it brings tears to my own eyes even now, revisiting these messages. Of course, time has passed and we were both older than we had been earlier in our relationship. This is part of the story. So too is our shared experiences of ill health, that has entered our relationship and so too is the fact that my father (at the time of the communication) knows he is at the end of his life. The tension that had existed in the relationship before is perhaps being replaced by a new tension. The tension of life and death. It is a tension that speaks to loss. A loss of what has been, and even more a loss of what *might have been*. I experience this loss as both backward looking and forward looking. The loss of what I missed from my father when he left the family home, when he physically moved some distance away, when he emotionally kept his distance. And then there is the loss I feel now that he will no longer be in my life (in a physical sense) just as we were getting somewhere in terms of narrowing that distance. This is an ongoing tension.

An example from practice, in the context of family therapy that also centralises tensions and

technology as a means of communication offers a different reflection on the use of technology within family communication.

K: Can I use my phone?

Me: Does that make it easier for you to communicate the things you want to share today?

K: Yes

Me: Ok, if that works for you, we can try it.

K: Mum, give me your phone.

K's mum sighs as he grabs her phone from her. She says "no", snatches it back, then pivots and gives it to him, giving him her pin, sighing again.

The experience with K and his mum reminds me of the importance of paying attention to all the relational contexts within differing modes of communication and how the *medium* and *materiality* of the communication, just like the content, is never neutral. It reminds me also of the challenge many parents face in staying present in the lives of their children amidst multiple other presences, including technological ones. Often (though not always) families experience technology as something that comes *between* them and prevents closeness in the relationship. It can readily speak to power and powerlessness as I think is present in the case of K and his mum. The tension here, I think, speaks to a different kind of loss within the parent-child dynamic. A loss of parental presence (Omer, 2004). I have had so many conversations with parents who are desperate to encourage their children to exist (as they often see it) in 'reality', rather than exist in a 'virtual' world. They often express a concern that their children do not have 'real' relationships. Of course, there are generational differences and often younger parents feel this tension less acutely, in my experience. Because I work in adult mental health services though many conversations I have are with parents of adult children who are living at home so I can sometimes represent (by my own age and stage of life) a different kind of *space between*. I am 'young' enough to have a pretty immersive relationship with technology but also 'old enough' to have known life before mobile phones, smart phones, social media and the internet. I often inhabit an ambivalence that probably speaks to this *in between* relationship.

Reflections

For my relationship with my father the use of technology enabled us to communicate in ways that I don't think would have been replicated if we were talking in a more spontaneous, live way. It offered a bridge within the *space between* our experiences of our relationship in the past (loaded with guilt, shame and hurt) and our current position (imbued by compassion and care). Communicating via text seemed to help us bypass the blockages that being physically present to each other, looking at each other, talking to each other would previously have evoked in both of us. It supported us to communicate more freely and that, in turn, helped us when we came together, in person. We were able to connect more freely with experiences that bound us rather than separated us. We were, as far as I can tell and as far as I am able to speak for us both, more comfortable in the tension. Of course, I cannot know for sure what my father was feeling at the time of our shared experiences of ill health or what he would make of me writing about this now, but I think he would be touched that

I am moved to write about our relationship and I think he would appreciate the care I have taken/ am taking to not centralise aspects of his life and our relationship that would evoke blame or shame for him. I think he might also be intrigued by the idea of technology featuring in this writing as part of our relational story. My father certainly did not find it easy to move towards using technology. It took quite a few lessons from others to help him use a mobile phone and 'get to grips' with texting. I think he would agree though that, without it, he would have been far more isolated in hospital and would have found it significantly more difficult to connect with his family. A tension with technology is another experience we had in common though. I continue to experience this tension in my work and personal life; and I continue to resist certain aspects of technology. I do not use social media, for example, and privilege being outdoors over being with my laptop even though we are bound together more and more each year and seem to be unable to exist without each other. We go on holidays together nowadays and certainly spend more time together late into the evenings and on weekends than we used to!

Beyond human relating

Many scholars are exploring the tensions within the posthuman, techno-human era we are living through (Braidotti, 2013; Allenby and Sarewitz, 2013 as examples) and it is important to explore this within the context of therapy and systemic practice; acknowledging the materiality of the medium and an understanding of what it means to engage in more-than-human ways of relating (for example, Helps and Le Coyte Grinney, 2021; Hertlein et al., 2014; Simon and Salter, 2019).

It would be easy for me to convey the negative aspects of our growing intra-dependence with technology. But there are advantageous aspects that my relationship with my father at the end stage of his life have shown me. My father rarely directly verbalised love towards me but, at this stage in his life at least, he expressed it over text messaging with (seemingly) far more ease, and fluidity, occasionally using the "L" word and prolifically using "X's" as kisses after most messages, something I did not experience from him in a physical sense. We would have both felt uncomfortable. He did kiss me on the cheek on the last occasion I saw him, before he died. He held my gaze in a way that spoke to a kind of knowing that this was our last encounter that we had run out of time to try and get this right. The look said, "Thank God we got to this point". There was hopefulness within the sadness.

The shared experience of us *both* coming close to the end of our lives (at times) and feeling *both* more alive in the world *and* more present to each other has given me multiple opportunities to reflect. I have reflected deeply on the sadness that we did not reach this point earlier in our relationship and I have reflected on the extreme sense of gratitude I feel that we did, at least, get to that point. This loops me back to the tension, within failure, of pain and opportunity. I cannot say if the moments of closeness we experienced would have been possible had I not been able to connect with the pain he felt, his fatigue, his frustration at his body not working like it used to... all of the things that I was experiencing concurrently. I cannot say if we would have got there without the aid of technology supporting our communication either. Maybe we would have found other ways, I do not know. I think I can say with reasonable certainty though that without the advanced technology involved in the treatments we had both had that year, we might not have been alive to have those moments together. It was a life *changing* time.

Looking back

The year Dad died, I had five different hospital procedures, two non-surgical but requiring of a hospital stay and three surgical procedures that required the same, with a longer period of recovery. Two of the three seemed to blend into one and I *failed* to notice the 'recovery' in between, it was just one long period of feeling dreadful. Ultimately all five procedures *failed*. They did not work. My condition and long term health has not been improved by any of the interventions. I spent a long time experiencing that as somehow my responsibility/ my fault, like I could and should have done better somehow. I tried, and try, to counter this by telling myself that I look after myself- I exercise, eat healthily, follow medical guidance etc. The counter narrative keeps losing its footing though and the former keeps returning, elastic-like, even now. So this story of failure, of pain, of not having done/not doing a 'good enough' job keeps showing its presence. The story, I am sure, has multiple personal, relational and cultural connotations that are perhaps beyond the scope of this paper, but I certainly hear and recognise a relationally framed life-script of 'must do better'. For me, the opposing tension within failure (the hope and opportunity) is often less visible/ harder to hold onto. I imagine this feeling is one that is shared by many of us, across differing family and cultural backgrounds, those of us who identify as systemic practitioners *and* those who come to talk with us. It has the potential to be a unifying tension once it is recognised and honoured.

Writing through the tension

A few weeks after I had submitted the piece of writing for "Context", I was sorting out a drawer full of papers and books and I found a notepad I had taken into hospital with me at the time of the second surgery. This surgery, like the others, had not done what was intended/ hoped for and, on this occasion, I became very unwell a few days later, needing an urgent readmission and another procedure. My bag was still packed and I had to take myself back off to hospital, in some distress. Breathing was difficult, heart rate rapid, shaky, dizzy, disorientated. I knew, from experience, what they would offer me as an intervention and I knew from experience (and from instinct) that it was unlikely to work. I did not want a further hospital stay, but I also knew I had little choice. I was feeling battered and bruised, beaten up by the people and procedures that were meant to be helping me to get better. I had, in this period, lost touch with what it meant to feel well, to feel myself, to feel present and alive. I was also TIRED, tired of being a patient, tired of being examined and assessed, tired even further by the interventions and medications. I was tired too of managing other people's expectations of what these might do. Tired of trying to hold a balance between the hope that it might work and my gut instinct telling me it would not, and trying to convey some kind of positivity outwards. Tired of the tension.

In the notebook I found these words that I had completely forgotten I had written. They were written in the post-anaesthetic haze period, capturing some of what the surgeon had advised me and some of my personal responses. They are raw, immediate and honest and reflect a sense of urgency, incredulity and turmoil that later subsided, to some extent.

failed procedure

failed to restore rhythm

failed to isolate the vein

failed to respond to treatment

failing heart

failing eyesight

failing energy

failing hope

I've never failed so many ****ing things in my life.

I'm not used to failing. I don't fail exams, assignments, interviews etc.

I pass.

I get things done.

I find solutions.

Who is this person they are talking about?

Is this what I've become?

I don't recognise myself. I'm not me any more.

Beaten up. Beating widely. Barely breathing.

When I read this back it sounds a little dramatic to my ears. Well, I am feeling quite a bit better now, even though the procedures did not work. I am not in the same fragile, raw place. I have found a way to be with/ go on with the presence of multiple long term health conditions. It is getting easier. I feel more hopeful. But the writing reflects my feelings at the time. It is not a reflection of the care I received by the surgeon, the consultant or the nursing staff. They showed as much care as they could but they also looked beaten and tired. They, too, had a look of anaesthetic haze.

Failing health care

Another point of reflection for me. At the time of publication for this paper the world is in multiple crises, what Gail Simon has termed "panmorphic" (Simon, 2021). Health crises, social justice crises, economic crises, environmental crises and so on. The state of our health service in the UK and the state of health of its employees illustrates this *panmorphic* quality all too well. During my last stay in hospital, a few days before Christmas and a few days after a large-scale organised strike by health care unions in the UK, I overheard nursing staff talking about how they have budgeted so that they could eat Christmas dinner. Another said they were looking forward to a dinner provided by a local charity. I heard others talk about struggling to pay their mortgage, another saying they had downsized their home, another fearing they would never leave the parental home. A health care worker told me that they wanted to work over the Christmas period but could not afford to as a taxi would cost more than they would make for their shift. A nurse, holding back tears, talked with me about their daughter's mental health. I felt devastated for them. Here they were, helping me, and yet seemed to feel helpless in their own situations. It felt all too resonant with my own experience; holding things together in work, listening to other's problems, whilst wondering how I would get through the day with growing levels of physical and emotional fatigue.

I want to reiterate that these people showed me great care. I am sure they were fit to practice and, for my part, as soon as I felt too tired to be effective in my job, I took time out. But when I looked at the nurses doing their jobs when I was in hospital, they looked as tired as I felt. I wondered who was caring for them so that they could care for me. Who *has their back*? And who is invested in *holding them back*? This raises huge questions about how we *do* collective care, how we live it and breathe it, honour it and promote it. Care is limited and undermined by uni-directional definitions (for ourselves OR for others) when it is seen as a commodity, is marketable and yet continues to be devalued by advanced capitalist agendas. Vikki Reynolds (2019) and Cathy Richardson/Kinewesquao (2023) amongst other therapist-activists bolster me up when I am depleted and remind me that when I am down and out, someone else is staying in, or joining in, the struggle. I am never alone.

Ethical tensions

I feel ethically compromised sharing these snippets from my time in hospital. I am sure the people cannot be identified, but I did not seek consent. I was not undertaking research after all. I was a patient, stuck in a bed with little to do other than listen and notice. But I also feel these stories should be told and heard. I feel the same about the relational stories I share about my family. I have taken care to talk about my relationship with my father without attempting to talk for him or about him in ways that are disrespectful but I do not have explicit consent from him as I had no idea, whilst he was alive, that I would be moved to write about this. But I feel these stories are important to share also.

I am reminded of my doctoral research where I spoke with women who had experienced sexual abuse and-or other forms of oppression and abuse. Many of the women in the inquiry wanted their names to be used and for important descriptors of their identity to be used, so that they were visible in the story. The ethics committee prevented this. My own ethics were troubled by it. I went with the priority to “keep them safe by keeping them anonymous” but what about the damage done by silencing people when they have important things to say and important injustices to speak into and out of? Because someone is deemed to be “vulnerable” does that mean they are to stay unheard? Does that not continue the story of vulnerability? I have previously written about my own experiences connected to abuse (Salter, 2017). Who decides if I am competent enough to name those experiences as abuse and call them out using my own name? And who decides others are not? These are complex dilemmas and there is no one-size-fits-all answer. The same could be said for those of us with significant health conditions. I have had dilemmas about what to share and not share in this short paper out of respect for my father and other family members. I have worked with that tension by staying close to the relationship and not attempting to speak out of things I do not know. I have also struggled with the tension about telling my own stories of ill health because I might then be defined by “patienthood” rather than by my professional identity. As if these two things cannot co-exist. But they do. This is one of the biggest tensions I have experienced during this last year or so- how to hold onto the multiple, ever evolving definitions of self that can be obscured or even obliterated by consuming experiences of ill health. I have attempted to work with this tension by staying within it. I am a competent professional with multiple strengths *and* multiple vulnerabilities. I imagine my surgeon is too. And my consultant. And the nurses. And the health care assistants. What troubles me is that some of us are more resourced, more valued, more cared for, more enabled to voice our vulnerabilities and our concerns and take action accordingly. That is a tension that I am not comfortable staying within, without calling it out.

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