

Person-Centered Care and Multi-Morbidity: Listen to Me, Share with Me, Support My Goals and Communicate



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Abstract

Person-centered care is popular across the western world and with the increasing age of the population, multi-morbidity is common. Specialization and the variety of settings where care is delivered have opened many avenues where the needs of the patient can be overlooked or ignored. Different understandings of person-centered care can result in conflicts and sub-optimal management of complex care. My personal and professional experiences inform this opinion piece on issues and improvement opportunities. Recognizing and realizing opportunities requires leadership, communication, interdisciplinary engagement and zero egos.

Keywords: Multi-morbidity; Person-centered care; Complex care needs; Leadership; Communication interdisciplinary.

Introduction

There is no need for references to convince the reader that populations across the world are ageing. Similarly, any reader of this journal would know that ageing is associated with more chronic illness, complex care issues and multi-morbidity. I do not plan to re-hash the literature to support well known facts. I will look briefly at person-centered care (PCC) and the definition/principles pertinent to my opinion. Thereafter I will be using my own lived experience of chronic/complex health issues and fifty odd years of variously practicing, teaching and researching health/ aged, dementia and person-centered care to illuminate issues and inform my opinion.

Essentially, I am using auto-phenomenology (I used this approach to discuss pain and dementia [1] and it was well received) to bring to the surface the essence of PCC when a person lives with multi morbidity and complex care. Let me be clear, I had the good the bad and very bloody ugly. I will use critical experiences rather than drag you through a long and tedious timeline.

Shock

It was 1999 when I really started to feel all was not right. My Dad died that year and initially I thought it was just losing my

'rock' and the consequent bereavement that was the problem; then maybe menopause. I put to work my coping strategies: denial, 'be a man', suck it up, relaxation strategies, positive thinking, more exercise, and more water. All of this helped to some extent but still I was having trouble concentrating, my eyes were very blurry, and I had a couple of corneal ulcers. This resulted in several days of being totally unable to see. I learned a level of patience I did not know was possible. Driving long distances was an issue because of back pain and the killer fatigue. When my partner hugged me it really hurt my ribs. Weeding the garden sent my thumbs into painful rebellion. My impatience in meetings increased, especially those long drawn out affairs where people speak just to hear their own voice provoked intense irritation and my efforts to hide it became less successful. It is almost impossible for people to understand what you are experiencing when on the outside you look hale and hearty. I remember a psychologist friend saying to me: 'Do not complain about never getting empathy when you have spent your whole life portraying how tough and independent you are! Damn - he was so right. I really did not want pity, I guess just some recognition that it took a big effort to do all that I was doing and just sometimes...anyway plenty worse off Ma always said so get on with it I did. Investigations for Gastrointestinal issues showed general inflammation; Sjogren's emerged from my routine eye tests - I had never heard of it so that put me on a learning

curve. Raynaud's I had had for as long as I could remember. On January 8, 2000, my specialist rheumatologist phoned (it was Sunday, so I was most impressed) and confirmed I had Lupus and Sjogren's. A busy specialist taking the time to phone a patient on a Sunday night is PCC.

What to do? First thought is making sure people do not know. I – that is the ME I became and now AM – is not sick! I could have been one of the first female vice chancellors in Australia; I am retiring at 95 and dying at 105. This is my plan. Nothing has changed...a few words made up by doctors will not define me. I armed myself with artificial tears, artificial saliva, back brace, tiger balm, orthotics, smaller and smaller bags and cases and with encouragement and lots of support carried on. 'I'm excellent' I emphasized whenever my health was queried, or I received the usual 'How are you' with increasing curiosity. Then the big crunch came... I am sitting in a staff meeting and as I stand up the pain drops me to the floor; expletives roll freely from my tongue. My beautiful administrative staff know this is not how I want to be seen, exit quickly and close the door. An ice-pack, analgesia, teeth gritted, a good friend with a car and I am home. I am crawling, screaming, crying and laughing all at the same time as I try to negotiate the path up to the door. Poor Susan, she has never seen me like this either.

Confusion

This ME it was diagnosed had a 'crap spine'. Being the researcher, I am I decided that if the Sjogren's could dry out every orifice of my body and anywhere connective tissue thought it had moisture than of course it could dry out my spinal discs and cause desiccation. More water, more exercise, more physiotherapy and off we go.

I had two weeks in a totally person-centered acute hospital. From the moment of admission to Emergency I felt I was acknowledged as a person, not a condition. My views were asked for and respected. The staff all presented as welcoming, happy in their work and at least gave the impression of having time for me. The environment supported my recovery with equipment and staff assistance when required to enable maximum independence. I was able to adjust the bed with sufficient room to get myself in and out of bed. Meals were always within my reach and were presented as appetizing and nutritious. The environment was hygienic but homely and allowed for flowers and cards. A chapel and garden areas spoke to a valuing of spirituality. Then came the experience nightmares are made of. I was transferred to a rehabilitation hospital. It was scary! The staff might have been refugees from 'Deliverance'. Everything about the place repudiated therapeutic healing. The room was so small you could hardly turn around; the bathroom permitted one person in it and the door opened the wrong way so if a person fell in there, I think the only way to retrieve them would be by removing the door. The bed was too high and not adjustable. The only way to eat I found was to stand. The doctor arrived and announced he was looking after me. I replied as politely as possible: 'No – I came here

because my specialist referred me to Dr X, because he considered him the best.' It was as if I had not spoken, he continued to say he would be my doctor and began telling the nurse he would change my medications. The whiteboard said I was only to 'ambulate with two people'. I repeated that if the doctor to whom I was referred was not available then I would be leaving. Again, it was as if I had not spoken. The television would not work and when the nurse brought me in some flowers, just as I commenced reading the card, she turned the light off. Limited space meant I had to put the flowers on the eating table. In retrospect it was very funny but at the time it was anything but. I called my partner early next morning and escaped. Right here was an example of no understanding of PCC. The Management, doctors, nurses, environment all screamed YOU do not matter; we know what is best for you and you will comply.

Suspect kidney tests see me visiting the nephrologist, problems with the hiatus hernia, colon polyps and inflamed gut generally and I am friends with the gastroenterologist, unbalanced (in walking) and I meet the neurologist. . An ovarian cyst and bleeding uterine polyps resulted in further surgery. My poor GP, he must be so sick of me. I did have a criterion when I selected him for my GP: attended conferences, good sense of humor, gave me advice not orders and in the end let me decide. He has continually met the selection criteria and applied it to the specialists to which he sends me. This is PCC in action from the GP. He listened, respected and acted on MY wishes while also providing the expertise I needed to share in my care. The next major obstacle was the functioning of my brain; I was having great difficulty following conversations, calling people I knew really well by name, focusing for any time was impossible, and then:

I was driving to work ...where the hell am I and how did I get here? Panic rises. I recognize a shopping centre that is nowhere near the road to work. I should park and try to think. My God, a half hour has passed, and I have no idea how I got here. After all these years teaching and researching dementia I have it!! MRI reveals nothing. Neuropsychological tests suggest I am 'slow' but probably just tired, or depressed. Everyone wanted to diagnose me with depression – I am not depressed, I am frustrated, tired, in constant pain and want some answers. Sleep apnea is diagnosed next; I go through the jaw braces and CPAP which give me pressure sores on my nose, pain in my mandibular joints but no reduction in symptoms. More tests and 'idiopathic hypersomnia' is diagnosed. Roughly translated that meant I had four times the daily sleepiness of the average person and it was probably due to the autoimmune diseases affecting the sleep centre. If I complied with very restricted conditions –driving no more than 10 to 15 minutes – my license would not be taken. While the specialist was PCC in my appointments with him his failure occurred when I arrived for my next meeting with him only to discover I had been allocated (without consultation) another doctor who sat staring at the computer and repeating 'Ummmm, I don't know'. I may as well not have been in the room.

Some Answers

Finally, CNS Lupus is added to my medical file. Now that seems to make sense and explain much of my symptomatology. I do not like it but at least it gives me some answers. I love Stephen, my rheumatologist, he has a terrible sense of humor and he is so brilliant and person-centered. He gives me the option of pulse steroids. Three days of high dose steroids every six months and see how we go. Oh my God! The first three days of this treatment I swear nearly killed me. My head and heart were banging against their enclosures and I was insanelly on fire. My body was burning and itching so intensely I silently begged for death and the coolness of the mortuary. Clearly, I had not suffered enough to wipe out the sins of my youth as death was denied! Over time I must have adjusted and the side effects although still awful were never as bad as the first time. Getting back to my brain, next I was off for four hours of very formal neuropsychological tests.

This is silly; I know many of the tests and what answers to give. I know you are dropping papers and making too much noise to see how I cope with distraction. This is useless. In fact, the tests were very informative, if further distressing. They demonstrated what I knew but did not want to admit. I had significant cognitive impairment especially in terms of executive functioning. Good news, however, was that this improved (had to go through it all again) after the pulse steroids. The treatment effect of the steroids was that I was useless for a week or two, pretty good for a while and then rapidly down-hill again. The trips to hospital increased from every six months to five, four and then three. The after effects of 3G over three days and the peaks and troughs were killing me. I suggested we move to one day of steroids every month instead of three consecutive days every three months. Soon I figure I will just carry the bag around with me all the time! My Rheumatologist was the perfect example of PCC. He consulted me at every turn, took my concerns and suggestions seriously, communicated promptly and openly with my other health professionals and copied me in on any correspondence.

I found it harder and harder to recognize this person I was becoming. I used to wear smart suits, high heels and have a bob haircut. Increasingly I had to swap the suits for soft stretch clothing because I found the muscle weakness prevented me from moving against any resistant fabric and caused further pain; high heels were impossible to walk in without causing acute back pain – so flats replaced heels; I could not hold the dryer above my shoulders to do my hair so off went the bob; jeans went out the window as the pressure of the zip and button hurt my abdomen; thank God for roll over tops. I spent a fortune trying to find bras that did not hurt my ribs, even chains or collars around my neck are too heavy. I went from steadfastly refusing medications and assuming I would beat this with positive thinking, more water and exercise but the walking made it worse and the swimming caused frozen shoulder! Now I have reached a point of just saying 'If it will keep me functioning, I will take anything'. The love of my life

is now my beautiful bed. Except after pulse steroids I sometimes lie there and pray I will not wake up. My head and heart thump and my body burns and itches like a million little ants are biting me. I feel like I am in hell. I see the bright light and Ma and Dad at the end of the tunnel (hallucinating) and soon I will find coolness in the morgue – but no they say 'you ain't suffered enough yet girl go back and take some more'. How much more can I take? I feel that I am now costing more than I am contributing. The kids have grown up and have their own lives. I am not suicidal I just wish I could feel better, or it would end. The room spins and I try to rush to the toilet to throw up. I cannot walk straight; I am drunk without the pleasure of a drink! I hit the wall on the way through and my hand is bleeding.

More Questions

Eventually I have no choice but to retire. My ever-increasing health issues continue: I am diagnosed with mitral valve regurgitation, hypertension and AF; I take a stroll on the beach only to rupture ligaments and do a full-on job of fracturing my ankle. RA results in finger surgery, gall attacks require cholecystectomy and Bowen's sees me with cancer removal and skin grafts. Unremitting fatigue sees me referred to see another sleep specialist closer to where I am now living. Immediately following this appointment, I receive a letter instructing me to have a medical assessment to keep my license! I accept that he may have felt required to report me to the Motor Transport Authority BUT PCC would have had him discuss this with me first! The potential impact of possibly losing my license apparently never crossed his mind. Further he did not communicate his intentions with my GP. Every month I continue to have 1G methylprednisolone infusion at an oncology unit. It is perfectly delivering PCC. From the receptionist who always makes me feel like I'm the highlight of her day through the nurses, specialist and service personnel they make what could be an awful experience pleasant and supported. Efficient, effective, knowledgeable and connected to me as a person. I feel respected, in control and in partnership. On a less positive note, my experiences of communication across hospitals and health professionals are frustrating. Despite technological advances it appears patients must constantly repeat information because it is insufficiently shared and available to all who need it.

Multi morbidity and PCC?

So, yes multi-morbidity is my constant. I have had a plethora of health professionals digging into various bits of me: GPs, nurses, physiotherapists, OTs, nephrologists, hematologists, rheumatologists, neurologists, neuropsychologist, gynecologists, gastroenterologists, cardiologist, ophthalmologist, sleep specialists and orthopedic surgeon. My regular list is 7. What have I learned about PCC through these years of making health professionals my regular companions? First, I was luckier than most because of my experience in the health system I knew better how to negotiate it and because many health professionals knew

me no doubt, I sometimes received preferential treatment. BUT being a professor at times also resulted in rudeness from health professionals.

Naturally, my years of researching and teaching PCC focused my attention on PCC in my own health care. In my review of PCC and Consumer Directed Care definitions [2], it can be seen that there are common principles all of which aim for organizational and individual wellbeing: My trip so far through multi-morbidity and PCC has reinforced the research but with real life experience the nuances become technicolor.

Having complex health issues challenges every aspect of a person's life. PCC can make the experience less daunting. From my experiences I draw the following principles of PCC in a situation of multi morbidity:

- i. See, respect and listen to ME – the person;
- ii. Support MY goals, values, independence and control;
- iii. Be honest with me;
- iv. Have no professional ego and territorial behavior - be truly interdisciplinary;
- v. Have the best evidence based knowledge to inform my

decision making;

- vi. Ensure constant and open communication across systems, practitioners and especially with me;
- vii. Pay close and informed attention to ensure a therapeutic, enabling environment of care ;
- viii. Create a supportive, cheerful environment for staff and families and they are more likely to create that for me;
- ix. Develop and constantly improve systems and leadership to ensure the above principles can be auctioned.

The challenges of multi morbidity can be exacerbated by health practitioners and systems that privilege disease and tasks and lack smooth communication systems. Finally, for me at least, the experience is less hazardous when humor greases the wheels. Laughter really is good medicine.

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