

“Blossoming in the storm: An illustration of Narrative Therapy with someone drawing on Chinese knowledge as she approaches death”

Sasha McAllum Pilkington & 川 Chuan

In the hospice inpatient unit.

I knocked on the door of 川 Chuan’s¹ room and waited. When I heard a faint murmur in response I stepped inside.

Chuan lay in a large reclining chair by the window. Tufts of black hair framed her face and her smooth golden skin hid the trails of illness. Her eyes stared at the ceiling.

I moved closer. “Ni hao Chuan.”

Only Chuan’s eyes moved as she looked at me.

“Hello Sasha.”

Her voice had lost its musical lightness.

I sat down on the edge of the bed hoping my presence might offer some comfort.

Chuan reached out and grasped my hand. It was the first time we had touched in the two years we had known each other.

I first met Chuan when she requested counselling following an operation. Cancer had caused the bones in her arm to crumble and a pin had been put in to hold her bone together. I visited Chuan at home as is usual for me in my role as a community counsellor working in palliative care. From our first meeting I respected Chuan’s way of living and integrity.

Chuan was married to 山 Shan and they had a son 康 Kang who was 12 years old. They had migrated to New Zealand from China. Mandarin was their first language but Chuan kindly accommodated me by speaking English. There were few counsellors who spoke Mandarin in Auckland and none in palliative care.

When we first met, I got to know Chuan through her love for Shan and Kang and her compassion. She was a preschool teacher and highly respected in the community.

Sometime later we decided to write this story together. Chuan hoped other people might learn from her experience.

Six months earlier: Opening doors of possibility

I could hear voices speaking Mandarin as I climbed up the outside stairs to the second level of the house. When I reached the deck at the top of the stairs I looked down at the mangroves in the estuary

¹ All names and identifying details have been changed.

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below. I imagined it could be a soothing view for someone forced to remain at home. The voices stopped as the TV was turned off.

“Ni hao Chuan!”

“Ni hao Sasha!” Chuan laughed.

From her position on the sofa Chuan groped for a chair for me before falling back from the effort. The large black chair remained in its original place. She smiled, more focused on welcoming me than her own exhaustion. I completed the task and moved the chair around to face Chuan conscious of my relative strength and agility even though I was a decade older than her. I didn't want to bring forward loss for her by emphasizing my capability.

I sat down on the chair and returned Chuan's smile. “It's so good to see you Chuan. How did the visit with your family go?”

“It was great! I was in heaven!” Chuan almost sang.

“You were in heaven?!”

Chuan's reply tumbled out as if she could barely contain herself, “My sister-in-law is very good at massaging... and my sister. My brother and sister did all the cooking.”

I imagined the feel of a good massage and lovingly cooked food. “Did they come and look after you?”

A huge smile engulfed Chuan's face. “Yes!”

I could almost smell the pork buns Chuan loved.

“Was it the cooking and massage that had you in heaven or were there other things as well that were great about their stay?”

Chuan laughed as she spoke. “They just like chatting with me and ask me all the time “How do you feel?” and “What do you want to eat?” Just feel so good.”

I was delighted for her. “Did you feel loved?”

Chuan laughed again. “Very much!”

Chuan shared with me some stories of the time with her family. I encouraged her with questions aware that such experiences of connection could become increasingly important as she contemplated her approaching death.

After a while the conversation turned.

“How do you think your family found staying here and seeing you?”

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Chuan stopped smiling and the pace of our conversation suddenly slowed. She leaned back in the large leather sofa. “They quite worried about me at first but then I get better and it reassuring for them. I felt very bad the week before. My blood cells very low and I had two blood transfusions. My energy level so down and feel depression.”

I murmured an acknowledgement and waited to see if she wished to continue. There are usually few occasions when a person can speak freely of the difficult aspects of their experience (see Willig, 2011).

Chuan continued. “They said when the blood quality is so low people do have depression...it was very bad last week.”

“What a lot you are forced to manage....” I paused while Chuan nodded her head. “Would you mind explaining what the depression was like for you?”

Chuan bowed her head. Her thick black hair fell across her face but she didn’t tuck it back. “I just cried and cried. I couldn’t stop. Feel despair.”

I reflected on the overwhelming feeling of fatigue, so different from tiredness.

“Did the fatigue from the low blood cells take you to a point of despair?”

Chuan looked up. “Yeah. When I went for chemo my red blood cells so low they did a blood transfusion instead. My family came next day but I need time to recover. My heart was so....it didn’t belong to me anymore! I feel exhausted and terrible. I feel like I probably couldn’t survive anymore!” Chuan’s voice rose in what I imagined was disbelief.

“Oh,” I acknowledged, solemn as I responded to the significance of such a declaration. Chuan had withstood so much.

Chuan held her chest as she confided, “Inside it is all blocked here. The chemotherapy you know”. Chuan’s hands remained over her heart (see Chen, Miakowski, Dodd & Pantilat, 2008).

“You said you felt like your heart didn’t belong to you anymore...?”

Chuan was eager to talk and anticipated my question. “Feel nervous and angry. I feel worried about everything....is too much and not settle down. Then one of my friends, she’s a Buddhist, took me to the Chinese temple. I went to a...what you call....a monk and he prayed and talk to me. Then my heart settle down.” Chuan sat back on the sofa and her arms fell down to her sides.

I framed my response to draw to Chuan’s attention her efforts to influence her life. A sense of agency can help people stave off despair at the end of life (see McClain, Rosenfeld & Breitbart, 2003).

“Would you mind telling me a little more about what you did at the temple that allowed you to settle your heart?”

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“...Told him I need help. My heart feel horrible and beating...and then he prayed something and play meditation music. It calmed me. Listen, it very beautiful.” Chuan reached over to the table beside her. The soothing sound of a flutist began playing what I guessed was Eastern music.

I reflected on Chuan’s ability to make such a request for help. “You’ve spoken about talking with the monk and the music. How have you used what the monk shared with you?”

“The music is for meditation and I doing it every day. It calm me down. It is support for the spirit. After seeing the monk I listen to the music, and meditate and pray. I can feel my heart is going back to the right position.” Chimes sounded as the music continued in the background seeming to underline her words.

We talked about the difference Chuan’s new daily routine was making for her. As we talked I listened for how Chuan was responding especially if they were in ways that she valued. I then asked her more about the visit.

“Could you tell me a little bit more of what it was like at the temple?”

Chuan seemed to glow. “It’s like a family and they are so warm. Everybody is caring for each other’s sickness. The monk was very kind and support me. I feel like a reassure... I’ve got someone to help me and I feel more hopeful.”

Hope can mean many things to people especially when someone has an incurable life threatening illness. I wondered what it was to Chuan. “Could you help me understand a little more about this hopefulness and what it means to you?”

Wonder entered Chuan’s voice. “I can feel it when I pray and chant... I feel like the Buddha is touching me. I feel light from inside my body,” Chuan mimed the light flowing from the top of her head down her body, “...and I calm down. I imagine that and just feel better.”

I felt honoured that she could share such an intimate spiritual experience.

“What is it like when you feel the light going down your body?” I asked. I didn’t know what would be significant for Chuan.

Chuan answered readily. “It feel warm and good”.

“How does it affect your ability to calm yourself?” I named calming as an ability and something Chuan was doing. She might want to develop it for the future.

Chuan smiled. “I feel very calm and even though the pain is still there... feel more positive about it”.

“What do you make of that?” I asked.

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Chuan spoke quickly as if reciting a well known fact or the words of someone else. “It feels like I can accept everything and less complain. I accept it as part of my life experience and Buddha will support me. It’s like everybody will have their own problem not just me get sick. It’s just part of life.”

“When the cancer and symptoms feel part of life what difference does that make *to you*?” I asked.

“It’s like it’s going to be part of my experience. People have different life experience. It’s just the way it is but the Buddha will direct and help me to go through that suffering. Not alone.” Chuan smiled as she spoke cueing me that the sense of companionship might be helpful to her. What she had voiced was different from her previous understandings and so I pursued it.

“When you have a sense of not being alone, how does that change the way you experience suffering?”

Chuan’s voice softened. “Feel like company and caring from other people. The feeling of loneliness get better. When I pray I can imagine the Buddha is touching me. Feel the light.”

I noticed Chuan described herself as imagining.

“You said when you pray you can imagine the Buddha is touching you and you feel the light. What kind of imagining do you do to feel the Buddha’s touch?” I was seeking to highlight Chuan’s knowledge in generating such an experience.

“I imagine the lightness will go down and warm my body and the water will wash it clean.” Chuan brushed her hands down her body. “That feeling very good.”

“Mmm,” I murmured in wonder. I was unfamiliar with what Chuan had just shared.

We sat in silence for a moment with the sun streaming in.

Chuan continued. “I was thinking about spiritual help for a long time. You remember I tried a Christian church too? I tried so many things. I think this is the right choice for me because the Buddha is from the tradition of Eastern culture.”

“What are you prioritising that’s important to you when you draw on knowledge from Eastern traditions?” I asked.

Chuan seemed to meditate on the question. “It is a philosophy for the people. It is part of life...it depends, I listen to many ideas.”

I reflected on her skill in doing such listening in a country where she wasn’t born. “How do you go about deciding which ideas you will draw on?”

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Chuan pointed to the Chinese herbs on the table and a steamer that her family had brought from China. “I learn about anything that might help. I’m keep practicing qi gong and steaming. I’ll carry on the chemotherapy. All trying to help. I think it’s positive and it make your body accept and not fighting.”

I noted her comment of not fighting. “Is your body ‘accepting’ rather than ‘fighting’ more useful to you?”

“Yeah.” Chuan looked at me as if waiting for more.

“Could you help me understand a little more of what you mean when you speak of your body accepting?” ‘Acceptance’ could carry so many meanings in the context of illness and dying.

“Even the cancer is part of my body. I meditate and try to get the cancer cell to be neutral not active, make them sleepy... harmonious.”

“Harmonious!” I repeated captivated by the idea.

“Harmony of the body,” Chuan enthused looking as if she was delighted by my interest (see Chen, Miakowski, Dodd & Pantilat, 2008).

“You’ve said the cancer cells are you...and you’re looking to calm them, to put them to sleep, to be harmonious. How does this harmonious state influence your well being?”

Chuan’s face softened and a small smile played around the edges of her mouth. “It’s like....we can survive together.”

“Survive together.” ‘Wow’ I thought to myself. It was so different from Western ideas of how people should live with cancer.

Chuan suddenly grinned. “You now know the new philosophy of the Chinese doctor!” I smiled back warmly. Chuan began sharing with me examples that illustrated what she wanted to convey.

“If someone was watching you day by day what would they notice about you that would tell them that you were surviving together with the cancer?”

Chuan sat back looking thoughtful. She answered slowly as she contemplated. “They probably notice my tempers been better. More happy and my family atmosphere is better. Maybe my temper and the tension influenced everyone and made us argue. This week we are all harmonious. We’re trying to talk to each other in a gentle voice. We’re a lot happier.” Chuan laughed.

“Have you spread the harmony from this ‘surviving together’ relationship you have with the cancer... to the family?” I asked, wishing Shan could join the conversation. He was now the sole income earner and busy at work.

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Surprise was in Chuan’s tone as she answered. “Yeah! ...I’m trying to change my son’s behaviour so I have to change myself first. I’m trying to talk with him in a gentle voice and be more tolerant of his behaviour. Even if he get angry, I won’t argue with him. I will let him calm down first and talk about it later. That’s my new technology!” Chuan finished with a conspiratorial laugh one mother to another. I joined in, appreciative of her wisdom.

I continued to work at strengthening the newly revealed links. “As you’ve learnt these things what difference has it made to your experience of the cancer and the way you live with it?”

Chuan leaned forward on the sofa. “I’m brave now. Still experience lots of pain and bad feeling but I am growing with cancer. I learned a lot from my experience. I have spent the most precious time with my son instead of working. The money’s not always important you know. I listen to my body and respect it. It’s for my family too. You’re not just yourself! My courage is back and I can handle it more with the help of my husband and friends. I can accept it more calmly.”

I appreciated Chuan’s ability to see herself as connected to others. Cancer doesn’t just happen to one person. I also noted the way she cherished time with her son Kang. People often feel pressured to find the good in hard situations but this had come wholly from Chuan with acknowledgement of the hard times. I considered asking her about her courage but instead took another direction. “What is it that you can accept more calmly?”

“Accept the fact I have cancer and still life threatening... but more calmly.”

It was the first conversation where I had heard Chuan touch on her approaching death without panic or fear.

Chuan and I continued to talk. I discovered how she had inspired her friends. I learnt of what she gave to her family by the way she received their gifts. I wondered what might sustain her as she was forced to contemplate the end of her life.

Towards the end of our time together I asked, “How has this conversation gone for you today? Have we talked about what you hoped or have I taken us a bit off track?” I wanted the conversation to be what Chuan had hoped for. Chuan assured me the conversation had been as she had wished.

It was late and I needed to get back to the hospice. As I walked out through the sliding door I turned to say a final good bye. Chuan’s eyes were wide open. “Sasha, I didn’t know I was like that before....I didn’t know I was strong...I didn’t know I knew that! Thank you”. I left wishing I could have asked her more.

Stories through the generations

“My memory getting bad these days. It’s side effect from my new chemo,” Chuan told me when we met a month later. We were sitting in her living room with the sun shining in through the large windows that

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overlooked the hillside. It was just after Chinese New Year. Special sweet treats were on the table and I caught sight of a red envelope that was likely Kang’s.

I murmured an acknowledgement. There were many challenges not just those the illness posed. The cancer that was part of Chuan’s body was progressing and as first line treatments failed she had been prescribed new chemotherapy with significant side effects. “How does that impact on your day to day living?”

I looked at the cap Chuan now wore. As she had predicted, her hair had fallen out.

“I remember good things, the bad things easy to forget. I have to write down all my appointments. Memory’s getting worse. That’s sad aye.” Chuan laughed. I remained solemn.

I was curious about the disparity in what she remembered. “How do you go about remembering the good things that you want to remember?”

Chuan giggled. “Still can remember...it’s quite funny. It’s like the good things give me deep impressions.”

I was drawn to Chuan’s description. I often noticed how her constructions of English led me to richer understandings of what she wanted to convey.

“Like when my son was a baby time, I can remember all the funny things. The funny things he did make me laugh,” Chuan chuckled, her eyes sparkling.

“Would you mind sharing a story of a fun time you had with Kang?” Chuan and I had previously agreed to preserve any stories she wanted to share with Kang. They were to make up part of an ethical will she would leave him.

Chuan talked about Kang when he was a baby. I asked her questions so the stories became fuller versions than those she usually told.

Chuan described how Kang liked to imitate accents especially a New Zealander trying to speak Mandarin when the language was unfamiliar to them. We were both soon laughing.

“How did he do? What was the accent like?” I asked mischievously. I was delighted Chuan felt comfortable to share a joke about the group I belonged to.

Chuan laughed as she replied, “It’s so funny. You probably think it’s good ‘cos you don’t know the way we speak Chinese, but we know what the proper accent should be! Kiwi² people can’t make certain sound you know. Kang making the accent just sounds so funny! Make me laugh.”

² New Zealander’s are often known as “Kiwis”.

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“Well I’ll make sure I learn from you and not Kang!” I joked, following her lead that this was a light hearted moment. Chuan laughed again. I reflected on how much fun we had together in amongst conversations of loss and suffering. Sometimes I thought our conversations reflected both the savouring of life as well as the harshness.

“Who else in the family has a good sense of humour?”

“My husband, his side of the family...Probably me too... I like funny things. Maybe I got it from my father,” Chuan chortled.

“Have you got a story about your father’s humour that you could share?”

Chuan became serious as she explained, “He is actually like a two sided. When he is happy he is so happy. He could be fine and have a sense of humour. But sometime you know he is black with his bad memories, the story of his early age. And he will be just so sad especially when it is Chinese New Year. He remembers his Mum and Dad.”

“Did he mourn his Mum and Dad at Chinese New Year?”

I often asked questions that clarified and summarised to support our communication. I wanted to do all I could especially given Chuan was using valuable energy and concentration by speaking English to accommodate me.

Chuan nodded as she pondered her Dad’s sorrow. “Yeah, sad.”

As respectfully as I could I asked, “How did he go about that mourning? What did he do that told you he was feeling sad?”

“You can see he’s sad ...at that time...very cries. Sometime he will just tell us a story about when he was young and when he had hard time starving. His mum was sick in bed and he got no food. He remember that and tell us about it.”

I tried to absorb what she was telling me. “Would you mind explaining a little more about that?What was his mum sick from?”

“Sick from poverty. He got no food and the people all get very weak and easy to catch all the bugs you know.” Silent tears gathered in the corners of Chuan’s eyes.

Death from starvation and poverty was suddenly personal. I tried to imagine what it was like for Chuan’s Dad as I stuttered, “From poverty and starvation... she was sick... and he was hungry?”

Chuan seemed to respond to my measured congruence. “Yeah...’cos that was the time when Japan invaded China and lots of people they’ve got no home and no food. We live in the North East parts of

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China and then when the war start there is nowhere to go. They have to go to the South...and everywhere people poor. No food and no shelter and I think his mum died from that.”

Again, intentionally letting some of my reaction show I asked, “His mum died from starvation and poverty?” I wanted to respond showing my recognition of the importance of Chuan’s story while still centering her.

Tears rolled down Chuan’s face. “Yeah... and sickness. It’s easy to get sick when you’re very weak and they don’t have money to pay for the doctor. No way!”

“No,” I acknowledged.

Chuan lowered her voice and I leant forward to hear her not wanting to miss a word. “Even for the food... Starving you know.” More tears escaped her eyes.

“And his father?” I almost whispered.

“His father... when Japan was in the North part of China they need people, labour for the coal mine. My father’s father, my grandpa, was cheated by one of the people from the mine. The man said “you can get good money. You go work there.” My Dad’s father and grandpa went together with that man to the mine and they never came back. They died. Nobody know. Just buried in the mine I think.”

We were both fully focused on the story giving Chuan’s family our respect.

“Oh how terrible!”

“Yes, this terrible. So many people killed. They just trick, cheap labour to work for them. They never get good pay and they could not escape from there. They die.”

I tried to imagine what such a history was like for her family. I considered the impact such stories might have on the way Chuan made meaning of her life as she faced the challenges of living with cancer.

“What sort of effect has that background had... on the family, and what you’ve learnt... and come to value and appreciate?”

Chuan remained silent. I realized my question was unclear and decided to break it down into smaller inquiries. While we had often talked about how to manage me not being able to speak Mandarin, Chuan was hesitant when I was unclear and often tried to work out my meaning. I therefore remained alert for questions that could be confusing.

“I’m sorry. That was a jumble of ideas. Would you mind if I reworded the question?” Chuan indicated I should go ahead, her eyes on me. “How has that sorrow affected the family, do you think, going down the generations?”

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She responded immediately. “It’s like we should never forget... that history. And as a nation we should work hard and get a better life. It’s better not to have that happen again. We have education at school ...we need to work hard and be independent ...economically. It’s like a nation’s things pass on to generation after generation. Don’t forget that history.”

“What is it about the history that’s important for *you* not to forget?”

As Chuan spoke I listened for her values. “I would like my son to grow up be a good people and don’t never do bad things to other people and other nation. I want him to be a kind person. That was terrible animal behaviour before. I want that never to happen to him.”

“Is kindness something that is important to you?”

Chuan sat up straight as she stated, “That’s what I think yeah. Be a human being. Be a good people you know. You can’t do bad thing to other nation or other people. That’s just horrible. I would like him to grow up kind. Also I want him to be a useful person, an independent person. Have a happy life.”

I repeated, “Kind, a useful person, an independent person, and have a happy life,” as I checked I had understood her.

Chuan nodded relaxing her posture. “Like he can have his own skill and survive. I want him to grow up like that.” Implicit in our conversation was the knowledge Chuan wouldn’t see Kang grow up, giving added weight to her declaration.

“We’ve spoken in the past of your compassion...I asked you a lot about starting as a preschool teacher...does some of that compassion have its roots in your family history and also in what you want to pass on to your son?” Not only did I want to bring forward for Chuan her legacy but it’s possible history and continuity as she made sense of her life and approaching death.

“I think so. Being my dad grown up like that, want us to be kind people.”

“How do you understand your Dad wanting you to be kind rather than say angry, even though he’d seen his mother die of illness from starvation and his father killed without the family being told what happened?”

Speaking on her father’s behalf Chuan stated, “He had been treated very badly by some people”.

I replied firmly. “Yes”.

My strong affirmative seemed to encourage Chuan to move further into the story. Tears flowed down her face. Her tone became plaintive. “But he think it not fairand people shouldn’t do that to other people.”

“Was he a principled person?” I suggested offering her words to consider.

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Chuan lent forward as she wept, “Yes”.

“...Somebody who believed in justice?”

Chuan nodded seeming unable to speak.

We sat in silence. I thought about what a remarkable man Chuan’s father was. I wondered if he considered himself in such a way.

“Would you say he has passed on that value of justice and... doing the right thing, to you?”

Chuan found her voice. “I can remember when we were young there were still some people who live in very bad condition and very poor. They begging for food. When we have some we always give them some. Share you know...”

“Oh,” I uttered, as I reflected on their generosity.

“My Dad he knew what it was like to starve. He had that experience and he, when he can, always help other people. Yeah...if you can, always help.” Chuan clutched her chest her eyes wet with emotion.

I stuttered, moved with admiration, “Is that something you’re proud of in your family? That you’ve turned the cruelty of war such a terrible experience... into a desire to....be kind?”

I wanted to draw Chuan’s attention to the ways the family had responded to hardship. Such stories could create landscapes of agency for her to draw on as loss wove itself into her day to day life.

“I’m so proud of my father. He was a good person even though he experienced that. He learnt from the good side of life not the bad side. Always been very kind....a good person,” Chuan choked as her tears flowed.

I was moved by her love and respect for her father. “Chuan does it make any difference to you to be connected to your father, to his integrity and kindness as you live with this cancer?”

Chuan furrowed her brow thinking. “I think of my Daddy’s life and I know I am so lucky even though I have cancer. I got lots of people to help and new medicines. I have hope and very grateful. My Daddy’s life far worse than me but still he survived and had a life and a family. I think my father is very powerful in that part. He grew out of it and struggled but still survived. I’m so proud of him.”

I noticed Chuan’s irrepressible ability to see luck in her life, to feel grateful. I decided to return to it later and learn more. I thought of her father’s story and the story tracing the integrity of her mother’s family that I had heard previously.

“What is it like to be part of a family who even when things are terrible turn to goodness rather than anger or hatred?”

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Chuan reflected and then replied firmly, “It’s very powerful and helpful.”

I asked Chuan about how such knowledge was helpful to her.

I remembered Chuan’s Dad had died only a year ago.

We spent the next half an hour talking about how Chuan’s Dad’s legacy showed up in her life. I brought her Mum into the conversation and learnt that Chuan had courage like her Mum. I then turned the conversation to Kang. Like many parents of young children leaving Kang was the most painful thought for Chuan to contemplate. We were gathering stories for a therapeutic document for Kang and now I sought to include him in it.

“How do you think Kang is learning about kindness and justice from you?”

Chuan immediately answered, “It’s from how I love him. We give each other a cuddle when he come back home. He learn how to love people. He learns from daily experience. I think he is observant and he learns every day about love.”

Chuan rested her head on her hand.

“What does he do that tells you he is learning about love?”

Chuan smiled and turned to face me, her eyes crinkling and her voice soft. “He gives me lots of cuddles and when I feel ill he will ask me, “How do you feel mum? Are you OK?”, “Mama I’ll give you a kiss and you’ll feel better”. It’s those sweet things. Make me happy...feel loved.”

I nodded warmly, appreciating Kang. “Is there anything else that springs to mind that shows Kang’s knowledge of loving?” I was keen to bring forward what Kang was giving to his Mum. The gifts of young people can easily be overlooked.

Chuan shared with me many ways that Kang was helping her.

“My son make me laugh. My friend bought me a bag...My son told me “Mum I think this bag is for old woman. Not for you, you are young and pretty”. Chuan laughed heartily.

“Oh!” I exclaimed in delight. “What was it like to be told by your son you are young and pretty?!”

“I was laughing... He was so serious. He try to persuade me. No, no, mum you still young and pretty.”

“And in that moment did you get a look of yourself through his eyes and feel young and pretty?”

“I just laughed.” The joy of her laughter seemed cocooned in love.

“What did your husband think?”

“He was laughing too!”

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I smiled. “What’s it like to know that Kang thinks you are young and pretty?”

“I think he probably does think I’m young and pretty! Very happy and feel quite proud!” Chuan lent back on the sofa with a big grin on her face.

“What do you feel proud of?”

Chuan’s face glowed. “Proud of....how do you say....proud of the way he is and the way he look at me.”

I imagined Kang with his Mum. “What difference does it make to be looked at as young and pretty and be loved by your son as you live with this cancer?”

Chuan considered. “I feel I have more reason to look after myself ...it’s for my son. I have to treat myself good and if I can, live longer.....give me courage as well.”

“ I wonder what it will be like for him when he is older to know that he made you feel happy, gave you purpose in looking after yourself, and inspired your courage?”

“I will tell him if I can. I will tell him how important it is for me to hear his word and know about it and give me hope.”

Chuan seemed to reflect and laughed again.

I responded to her amusement. “I wonder what ideas he has about the kind of handbag you should have?”

Later I gathered my bags and got ready to leave. As I stood up Chuan again said, “I didn’t know that about myself Sasha. I didn’t know that about my family”. There could have been pride in her voice.

Second by Second

“Where do you think would be a good place to start?” I asked having just sat down. I had been away and it was now a month since we had last met. Chuan sat on the sofa. Wisps of barely visible hair covered her head and I could see the effects of steroids lingering in her cheeks.

“I don’t know. I’ve just kind of lost my voice ‘cos I got a cough recently. The doctor say it may be side effect of my new chemo. Just started it. Apologise. On off the cough. It quite annoying sometime.”

I immediately considered the possible impact of our conversation on Chuan. “How is talking going to be for you then?”

“It’s Ok, but not too much maybe.” Chuan cleared her throat.

I lowered my voice aware of my concern for her. “Not too much... How will you know when you’re getting towards the end of what you can comfortably do?”

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“Cough... cough. And I have to stop for a little while,” Chuan explained screwing up her face.

“Ok. Would that be a sign that we should stop our conversation and I go or how would you envisage it?”

Chuan’s face relaxed. “We can see how it goes.”

“OK... I don’t want to over tax your voice alright?” I replied, smiling to remind her that I was on her team and she was who mattered. I suspected it might be hard for her to tell me she wanted to stop.

Chuan’s face seemed to light up. “It’s alright”.

I smiled again and in an easy tone tried to create more space for her to tell me how she was. “...So I’m counting on you letting me know early”. I resolved to watch out for any signs Chuan might be tiring or her voice being taxed.

Chuan nodded smiling back at me. “Yeah I will. I am very happy to meet you all time. Give me lots of help. Like I understand a lot of myself when I feel bad and allow myself to cry. From all the pain, all the suffering you know. Not bad thing. I used to think I am so weak and not a good strong person. I would criticize myself when I cry but you gave me the chance to understand there’s a good side actually.”

I hadn’t expected what Chuan had just shared. I cast my mind back to conversations where we had talked about crying. All I could remember was asking Chuan about what her tears were expressing from time to time. “Would you mind sharing a little more about that?”

“Feel quite negative about when I feel sad ...I feel so weak not strong enough. When I cry I just kind of blame myself. But you helped me to understand it’s OK to be sad and it’s not negative things. Actually give me lots of help about that.”

I hadn’t been aware that Chuan was developing some new beliefs about expressing her sadness. I wondered if the action of inquiring into her distress and the process of respecting and companioning her tears could be powerful without actually talking much about it head on. I reflected that even passing tissues can inadvertently give a message of ‘stop crying’.

“Would it be OK if I asked you a few questions about that?”

Chuan nodded. “Yeah sure.”

“What different understandings do you hold about expressing sadness now, that you didn’t have previously?”

“In my education, in my background , my culture not good to cry... when I cry I always criticized.” Tears spilled onto Chuan’s cheeks. “Told “Stop crying you silly girl” that sort of things.”

“How do you think people developed those ideas?” I inquired.

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Chuan looked out the window briefly before returning to face me. “I think it was from their life. Struggle to survive. The society was very cruel for them. There was a root from that I think. They have to be strong and not show emotion. Not allowed to cry and show weakness. I thought that too but then think about what we talk about....and about time with operation. I didn’t want to think about it before. Very terrible.... make me so scared... hard time.” Chuan clasped her shoulder. I remembered how her bone had been pinned after the cancer had caused it to break. Her recovery had been long and difficult. Tears forged their way down Chuan’s face in spite of her attempts to wipe them away.

Tentatively I checked, “Would you like to talk about what happened in that hard time?”

Chuan replied immediately. Small sobs escaped her as she spoke. “It was the night... I was in so much pain from the operation... The pain was terrible. They numb you but the drugs already gone. I did take some oral pain killer but just not strong enough. The pain was still there... It was horrible.”

Chuan began to cry unreservedly. “So terrible. I didn’t know how I would get through the night.”

My voice was low. “How awful. What did you do? How did you manage to get through that night with such terrible pain?”

Still weeping she explained, “I couldn’t do anything. So bad....I counted second by second by second for that night.”

I tried to imagine such an experience. I noted that Chuan felt she hadn’t done anything and reflected that feeling powerless was usually unhelpful and especially when approaching death. I started to search for how Chuan responded reminding myself that counting was doing something “What did counting second by second do?”

“It just tell me time passing. Only way I could know. ...so bad.” Chuan wrapped her arms around herself and drew her knees up to her chin.

“Could you help me understand what was important about knowing that the time was passing?”

“Only way to survive...knowing it must end sometime. Thought if I get through one second then I move onto the next second. All I could do.”

“Can I check that I’ve understood you properly? To survive the agonising pain you kept hold of the knowledge that it might end sometime... and got through the night by counting each second?”

“Yeah I did that.” Chuan looked up at me unfolding her body from its semi cocooned position.

“What did you draw on that allowed you to do that?”

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“Need my courage. I need it all, so terrible the pain.” I reflected on our recent explorations of Chuan’s courage and her comment that she had not known she had courage before. I wondered if re-connecting her to such courage had helped make this conversation possible.

Chuan’s eyebrows drew together as she explained further, “I had to keep calling the nurses. I thought maybe if they change my position for me it might help but just not work. But I feel sorry for them so busy.”

I was struck by her ability to feel for another person at such a moment. “Did you feel sorry for the nurses even though you were in terrible pain?!”

Chuan lent forward sounding indignant. “Other patients yelling at them. They were trying their best but some people very rude.”

“When you called the nurses do you think they noticed that you were feeling for them?”

“They say I’m sweet and they try to help me. They say I’m not like the other people who were shouting at them. One nurse tried many time to fix my pillows and make me comfortable. They tell me to call them and say they will come straight away.” I wasn’t surprised to hear this. Chuan’s kindness and humility stood out to me.

“What do you think they noticed about you that led them to think you were sweet and someone they wanted to reassure they would help immediately?”

“They know I have pain and don’t want to bother them. They can tell that I feel for them. I use soft voice and polite. They trying their best. Doing everything they can for all the people. They very good to me actually. Even if they can’t help they still tryingfeel support.”

I reflected on how much I enjoyed time with Chuan. “What do you make of your ability to form this kind of relationship with the nurses?”

Chuan considered and then in a soft tone replied, “I think I might be like my Dad. We always think of other people...” She paused a moment, then sat up as if gathering herself and stated,

“...And courage maybe like my Mum...she is brave.”

Chuan and I went on to research other stories that showed her capacity to respond compassionately even in hard times. We linked these to the legacy of her family. It wasn’t long before I discovered that her family and friends were drawing inspiration from her.

As we talked I checked in with her regularly as to how she was managing the conversation. Each time Chuan firmly assured me she wanted to talk. Nevertheless I was careful to leave on time. Fatigue can catch up on a person.

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Flowering in the storm

Six weeks later Chuan sent me a text requesting that we postpone our meeting. She had been admitted into hospital.

At the end of the week I learnt that Chuan had stopped taking all Western medicines and discharged herself from hospital against medical advice. The reason for her departure was unknown.

I wondered what had happened. I knew Chuan would have considered reasons for her decisions. I also thought it likely there were obstacles to Chuan speaking openly about her experience in hospital. She was an immigrant and guided by knowledge that may have been unfamiliar to those looking after her.

The hospice team was worried for Chuan. She was very unwell and suddenly stopping her steroid medication was dangerous, even life threatening. After consulting with my colleagues I telephoned Chuan and Shan and asked if they would like me to visit them that day. They both responded enthusiastically.

Clouds shrouded the hillside above the estuary as I climbed up the stairs of Chuan and Shan’s home. Shan greeted me at the door and led me into the bedroom. Chuan was resting on top of the bed. Her eyes were open but her focus seemed inward. A sick bowl lay beside the bed.

Chuan turned her attention to me. “Thank you for coming Sasha.” Relief layered her tone.

“It’s good to see you Chuan. Thank you for seeing me when you’re feeling so unwell.”

Shan hovered in the doorway. He indicated I should sit down and I pulled a chair around so Chuan could see me without any effort.

Chuan sighed but then with more energy than I anticipated said, “I am very happy to meet you all time. Give me lots of help. Sasha I had terrible time in hospital! Thought I was going to go crazy! No sleep for 3 days. An old person keep our room awake every night. Asked for another room but there is none. Was going crazy!”

I tried to imagine having no sleep for 3 nights when very sick with advanced cancer. I couldn’t.

“No sleep for three days! I imagine you’re exhausted! No wonder you felt like you were going crazy.”

“Yes going crazy. No choice, had to leave. Couldn’t stay!”

Chuan had good reasons for leaving hospital. “Did you leave to get some much needed rest?”

Panic seemed to edge its way into Chuan’s voice as she spoke. “Yes. Feel very terrible. Pain in head and can’t remember things. Been falling over for no reason. No one know why. Shan had to carry me up the stairs.”

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“You fell over for no reason?Did it happen out of the blue?”

“Just happen. No warning. My legs suddenly not holding me up. Lucky I not hurt.” She moved restlessly on the bed.

“Thank goodness you weren’t hurt....Were you scared?”

Chuan and I began to go over a little of what had been happening to her.

She then raised the topic of her medication. “I stopped all Western medicine. Just doing acupuncture now...”

Tentatively I inquired further. “Would you mind me asking, what led to your decision?”

“Worried about side effects... On too many pills....”

I reflected on some of the challenges that came with medication. Weighing up possible benefits versus the disadvantages could be a murky task. It wasn’t always the straightforward process people expected.

As respectfully as I could I asked, “Did you have any particular concerns about the steroid?”

Chuan explained she believed it wasn’t helping.

Tentatively I asked, “Our doctor wanted me to check with you....I imagine it may not have been explained or it could have slipped your mind since you are managing so much... but did you know that stopping the steroid suddenly is dangerous?”

Chuan immediately looked concerned and indicated she hadn’t known this. I continued, “...If you want to stop it our doctor could help you do so safely. Would you consider talking about it with her?”

Usually I am rigorous in taking a position of not knowing about medical matters. A position of naïve inquirer allows me to be alongside people and hear their concerns from a unique vantage point. I want people to have the space to explore what is right *for them*. However, working in a multi disciplinary team can be helpful to achieve this. Chuan had been distressed in hospital and understandably unable to hear what the doctors had said about suddenly stopping the powerful steroid she had been prescribed. The hospice team wanted her to have the best chance of making an informed choice and had requested that I raise this safety issue with her inside the comfort of our relationship. Our doctors would then follow up.

I knew Chuan to be a thoughtful person who took care of her wellbeing. Our conversation flowed easily.

Shan joined us and together we discussed what they might do next should Chuan continue to experience the unexplained symptoms.

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A week later, Chuan decided to come into the hospice inpatient unit however first she was scheduled to have a scan of her brain in hospital.

Full Circle

I sat on Chuan’s bed in the hospice.

Chuan held my hand. Her fingers seemed to reach into the familiarity of our relationship for comfort.

The results of the scan had arrived. The cancer was throughout Chuan’s brain. She was dying.

Chuan, Shan and I were reflecting on her life.

“What sort of life would you say you’ve had Chuan?”

“I’ve had a good life but now it is my time.”

“Can I ask you Chuan...what is a good life to you?”

“A good life for me isI really admire people even when they having a hard time they are showing their beauty to other people like a flower even though the weather is bad it still blossom. I think that is a good life.”

In awe I repeated, “... A flower....that shows its beauty...”

Chuan smiled slightly, “Even in very bad weather....in very bad situation....they still blossom. It is so great.”

I paused soaking up the image.

“If your family and friends were here, how do you think they might describe *you*?”

Chuan considered. “Maybe my story will give inspiration to someone...”

A few days later I sat by Chuan. It was lunchtime and Shan was on the telephone in the next room organizing support for Kang. Chuan lay unmoving in the bed. I listened to the sound of her breathing and offered what companionship I could.

I left not long after Shan returned.

It was time for my team meeting. Health and safety, cars, staffing, and then it was over. By habit I looked down towards the inpatient unit as I left the meeting room.

My head jerked. The candle was lit.

Chuan had died.

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References

Chen, L., Miakowski, C., Dodd, M. & Pantilat, S. (2008). Concepts within Chinese culture that influence the cancer pain experience. *Cancer Nursing*, vol 31, 2, p103-108.

Hsu, C., O'Connor, M. & Lee, S. (2009). Understandings of death and dying for People of Chinese Origin, *Death Studies*, 33:2, 153-174.

McClain, C., Rosenfeld, B. & Breitbart, W. (2003). Effect of spiritual well-being on end-of-life despair in terminally ill cancer patients. *Lancet*, 361, p1603–1607.

Willing, C. (2011). Cancer diagnosis as discursive capture: Phenomenological repercussions of being positioned within dominant constructions of cancer. *Social Science & Medicine*, 73, 897-903.

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