A living theory of care-giving

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Abstract

In this paper I explore how my values based practice has helped me develop my authenticity as a leader of a care-givers' centre. I use the American term care-giver as this is based on a presentation I gave at the inaugural conference of the Action Research Network of the Americas in San Francisco 1-2 May 2013. In the UK we are called a carers' centre and our aim is to support unpaid carers who care for a family member or friend who could not manage without their help due to illness or disability. I explore how my story from child in care to chief executive of a carers' centre and carer of my mum has developed my living theory of care-giving.

Keywords: Care-giving; Carer; Authentic; Leadership; Living Theory; Values.

Introduction

This paper is based on a presentation I gave at the Inaugural Conference of the Action Research Network of the Americas in San Francisco 1-2 May 2013 (video 1).

Video 1: Sonia Hutchison at ARNA on the 1st May 2013 (Whitehead, 2013b)

Video 1 gives my living explanation of my influence as the Chief Executive of a Care-Givers' Centre in the UK and how my lived experience as a child in care and then care-giver to my mum has shaped my values which I seek to live by as an authentic leader. The paper has evolved as I have worked with the responses from Jerry Allender and Jane Spiro, who both reviewed my paper on the EJOLTs open reviewer page, and what emerged in SKYPE conversation with Jack Whitehead and Marie Huxtable we recorded and can be accessed at http://youtu.be/hkgXD262wPg (Whitehead, 2013c).

Staging and Sequencing

I begin my paper with a description of how I came to research my living theory of care-giving, which includes the background to my context. I introduce what a care-giver is and bring this to life by using two examples of care-givers I work with. I then explore what it means to be a leader and look at what it means to be an authentic leader.

I then go through several concepts that have helped me think about what my values are and how I can live these fully to develop my own living theory of authentic leadership. I will explain my decision for choosing the methodology and methods I use in this paper. I explain why I use Living Theory as a methodology and how I am answering my question by collecting video data, reflecting on my teenage diaries and using action reflection cycles to improve my practice.

I then share my findings as I use the video of me talking with my family to identify where my values come from, and analyse video of me working with staff, carers and trustees to identify whether people can see me being authentic and living my values in practice.

My Study of a Living Theory of Care-Giving

I'm researching into my authentic leadership. I am a chief executive of a carers' charity. I work with care-givers which is the American term for carers as they are called in the UK and my context is leading a carers' charity. The Centre's website (www.banescarerscentre.org.uk) explains that, 'One in every eight of us is a carer, giving time and energy, without pay, to care for friends or family who can't manage on their own.' This is a significant percentage of the population who are playing an important role caring for a family member or friend who could have an illness, frailty, disability or problems with drugs or alcohol.

It can be difficult to understand who carers are so I am going to give a real case study to clarify my meaning. Surrinder cares for her daughter Nina who has autism. So Surrinder is both Nina's mother, which is the same relationship every mother and daughter has, but on top of her role as mother she has to deal with the special needs her daughter has. Surrinder takes on this extra role, which includes being an advocate for her daughter to have the schooling her daughter chooses and advocating for equity of access to education provided for other children. Surrinder has this extra role where she has had to fight for her daughter to have the same experience in education that other children get. Surrinder also has had to fight for other services, such as social services, to get good social workers involved in Nina's care. Surrinder has had to fight to get Nina a statement which means her special educational needs are recognised and accommodated in a school environment. Surrinder experiences a tension between wanting a special education for Nina because she has autism and the desire Nina has to be a normal teenager. So Surrinder is not just a mum she is also a carer. That's what it means to be a carer in a parental role or to be a parent carer, as they are known in the UK.

Another form of carer is a young carer who are carers aged from 5-18 caring for someone in their family. A real life case study is Mitch who cares for his mother, Yvonne, who has a crumbling spine due to Ehlers–Danlos syndrome. Mitch has to wake up in the morning, make the breakfast, make sure his mum's ok and she's got out of bed because he knows once he goes to school she won't be able to get up without him. He also makes sure his sister is ok and is up and out of bed as she has similar problems. Mitch then goes off to school and is being bullied, has problems from the teachers because he isn't getting his work done on time. He isn't getting his homework completed on time because when he gets back home from school, he has to make sure his mum and sister are ok, he has to cook the dinner, do the cleaning and do all of the household work and then it starts all over again, except he's tired because he hasn't had much sleep, because his mum's had a bad night.

There is a huge range of literature on carers (Carers UK, 2004; 2007; 2011; 2013; Clarke and Riley, 2006; Clifford et al 2011) and young carers (Becker et al, 2000; Becker & Becker, 2008; Fives et al, 2013). Whilst I use these research papers as an excellent resource for funding bids and find the stories described in them interesting and useful illustrations, the third person nature of the research means I feel there is a gap between the researcher and the carers in the research. My original contribution to the carers' literature is to research from the perspective of a carer for my mum with mental health issues and drug addiction, leading a carers' centre and encouraging the carers I support to tell their own stories and to be involved as participators in the research.

The literature on leadership is diverse (Bolden et al, 2003); I have engaged with literature on Authentic Leadership (Chan et al, 2005; Avolio & Gardiner 2005; Gardiner,

2011; Walumbwa et al, 2008; Shamir and Eilam, 2005; Sparrowe, 2005) as it seems to be concerned with leaders developing their practice while being true to their values. However I feel the literature, even on Authentic Leadership, lacks authenticity as it is talking about leader's authenticity from a third person perspective lacking the authenticity of the voice of the leader researching their own leadership in the research. In my research I am interested in how I am leading my own learning the learning of others and the learning of social formations, which necessitates starting from the first person (Hutchison, 2011a; Hutchison, 2012a; Hutchison, 2013a; Walton et al, 2013).

I'm a leader in my organisation and I want to be an authentic leader and that, I believe, requires vulnerability to be self-aware and be transparent in relationships with those you lead (Gardiner, 2011). I don't want to be this type of leader or that type of leader. I really want to be me as a leader and that's taken time and courage to get to the root of what my values are to be able to develop my leadership authentically. I'm going to go through how that process has worked now.

Concepts that have helped me think about what my values are

In my research for this paper I thought through several different concepts, which have helped me identify which values I hold and try to live fully as an authentic leader. I will briefly explore some of these concepts in this section. I am not going to go into depth as I only want to introduce them as concepts that have been helpful rather than as the focus of the paper. One concept is mindfulness. "Mindfulness means paying attention in a particular way, on purpose in the present moment and non-judgementally" (Kabat Zinn, 1994, p. 4). If we're not fully present for many of these moments because we're rushing all the time which I am often guilty of. This is why mindfulness is a great concept for me because if we are rushing all the time we miss what is most valuable in our lives and we fail to realise the richness and the depth of our possibilities for growth and transformation (Kabat Zinn, 1994). I love this concept because it is so hard. I want to rush, rush, rush and get to the next thing.

Video 2.   Ubuntu told by Nelson Mandela (Canonical, Ltd., 2006)

Next I have been introduced to the concept of Ubuntu which can be translated as "a person is a person through other people." Nelson Mandela talks about his understanding of Ubuntu in the video below (Video 2), which includes values of respect, helpfulness, sharing, community, caring, trust, unselfishness.

Video 3.   Camilo Manchola's greeting for the Action Research Network of the Americas (Whitehead, 2013a)

I was looking through the video clips people posted in response to an invitation to the inaugural conference of Action Research Network of the Americas to work to the values freedom, love and hope. This video (Video 3) posted by Camilo Manchola, who is a Master's of Education student, at Universidad Militar Neuva Granada in Bogota, Columbia, South America, really spoke to me because it highlights how so many different communities are coming together and talking about what is important to us. Camilio is saying what he is excited about the contribution of the inaugural conference as a starting point for Action Research Network of the Americas to make a contribution to enhancing freedom, love and peace throughout the world.

Love is a difficult thing to bring into research and practice, however I am trying to bring the concept of love into my research and practice. It has been a tricky thing for me to do because I am aware of the boundaries in work. I feel bringing the concept of love into research and practice is something we're not meant to do. I feel we are meant to keep those we work with separate and yet I love what I do but I find it is difficult to talk about. I think it is difficult because in English there is only one word for love which covers everything from I love my partner to I love my phone. What does love mean? It has this huge range of meanings. In other languages there are lots of words for love some of which I have found helpful and I explore them below.

Agape means an intentional response to promote well-being when responding to that which has generated ill-being (Oord, 2005). With that meaning of love I don't feel strange about saying about the people I work for that I love them in this way, of course I want to promote their well-being and to make better the things that are ill-being. This meaning feels much more appropriate to talk about love in the context of love if it is taken with this meaning.

I have also looked at Buddhist ideas. Karuṇā (in both Sanskrit and Pali) means "compassion is that which makes the heart of the good move at the pain of others" (The Buddha Vacana).This also feels ok to talk about love in respect of being moved at the pain of others. I want to make something better in the other.

At the 2012 AERA (American Educational Research Association) annual conference there was a presentation (Whitehead, 2012), which introduced love according to Peck (1978) which is, "the will to extend one's self for the purpose of one's own or another's spiritual growth" (p. 85) I use the term spiritual according to the definition Hooks (2001) as quoted by Campbell (Campbell et. al. 2013, p.19) provides, "one who seeks to know and live according to values that promote universal well-being."

I feel these definitions of love aren't so scary to talk about in terms of research and of the people we work to support.

Methods and Methodology

I have used living theory action research (Whitehead & McNiff, 2006) as a methodology to develop unique knowledge and understanding in how being a leader in a carers' charity can fully live values of love and participation. Living theory methodology (Whitehead, 2008) enables a use of methodological inventiveness (Dadds & Hart, 2001) to develop my values based research.

I have used ethno-autobiography (Kremer, 2004) as a method to tell my own story grounded in socio-cultural factors that have affected me and enable carers to tell their stories through the research. I have use multimodal methods (Crotty, 2012) including multimedia approaches (Whitehead & Huxtable, 2009) as it enables the embodiment of the expressions of the stories which hold evidence of the pooling of energy within the values of the relational dynamics as they emerge in practice. I use a narrative method where those involved in the research use stories and reflection (Clandinin & Connelly, 1991).

I have also tried to use participatory research (Cornwall & Jewkes, 1995) methods to empower others involved in my research to tell their own story. I bring myself into the research to show how my own story and those of others influence me to improve the organisation I am leading and the social formations I live and work in.

Living theory is about improving practice; this involves constant learning and change. Reflection is important to improve my practice, however participation of those involved in the organisation enables my personal improvement of practice but also moves it beyond continual professional development into research. As I am researching how the changes I make in the organisation to improve things for the carers I support and how this improves their social context.

I was keen to use a narrative method and use some video of the stories in my research. It has worked well videoing myself but has not always worked well videoing others telling their stories as people don't always like being videoed. What it has helped me to do is to develop my use of video. Instead of just recording and videoing my current research I went back and started checking if my memories of my childhood were "right" and validating what I thought had been true. I went back to my family and asked them questions of the kind "Do I remember correctly or do I have an idealised memory of me as a child?" Through

this questioning I have been able to validate whether where I thought my values came from were right. Videoing conversations with my family also enabled me to take another perspective of what I was like as a child by seeing it through my parents eyes which was really great and helped me to avoid only telling a "smooth story of self" (MacLure, 1996, p. 238).

I also have data from videos talking with my staff, volunteers, trustees and other people involved in the organisation to see if others can see me as an authentic leader and see me living my values in practice. It is really important to me to get the voices of as many people as possible in my research because that is my value of participation and I want to improve the situation that they are in, to improve the organisation I run. I feel that if I am being an authentic leader, how can I know if I'm being an authentic leader unless I go back and ask? The cycle of going back to different people in the organisation and asking if they see me living my values fully as an authentic leader is on-going in my research and having video conversations, where people are happy to be videoed. This opens up opportunities to do different pieces of research not only asking, "how do I improve my practice and the practice at the centre?" but also, "how do we improve the practice of other professionals?"

Finally I have the video data of my presentation and video and written data of my peers critiquing my paper to help me improve my paper. This has helped me to make my paper more valid in terms of Habermas's (1976) criteria so my writing is more comprehensible, truthful, authentic and right. The critique I faced was that my written paper was not my authentic voice and that in my presentation I communicated more authentically. In order to get closer to my authentic voice I have transcribed my presentation and used a mixture of my transcribed presentation, my original paper, my Ph.D. proposal and new writing to be authentic and provide a better structure to my writing.

My Findings

Video 4. Talking with my mum (Hutchison, 2013b).

This is a still picture of me and my foster mum, Jo, taken from Video 4. I was fostered when I was three and a half; my parents both had schizophrenia and drug and alcohol addiction. My biological mum is still alive, sadly my biological father died when I was 25. I love this still picture which is when we have finished talking and we look up at my foster dad who is videoing and my mum and I both agreed we could see a real love, we're both looking at my dad and we're really pleased with our conversation and there is love in the room. I am blessed because I have always been loved in every respect. I was and am loved by my foster family, I was loved by my real family, even though they didn't have the capacity to love me in a way that they could bring me up but they continued to love me even though they weren't able to bring me up. So I've had a lot of love in my life.

When mum and I talked through the video (Video 3) my mum affirmed some things for me. Mum has her own values and Mum talks about these coming from her mum being respectful by listening, paying attention and valuing children's views. My mum had her mum as this great role model that gave her strong values, which Mum then reflected back to me. My mum lived these values which meant I was listened to, I was paid attention to and my views were valued and respected as a child. Mum also said that I was lucky as most of my social workers were, "always careful to listen to and seek your views" (1:12). So I had this other experience of lots of professionals coming into my life all the time but that they actually sought out my views and they listened to me. So I had this experience that adults should listen to me as a child, I expected that and I told them my views. Mum confirmed that I had many opinions about things as a child (3:36) and that I was confident to articulate these. So this validated that my memories were correct.

At the end of the video with my mum you can see the embodied love for each other as we finish talking. We look at each other and then we look at my dad. I find this piece of video beautiful. Mum's final words are that she hopes I find something's in the video conversation are helpful. I did as I was able to describe our love for each other and affirm my childhood memories.

Below is a picture (Image 1) of my real mum or biological mum. This is a picture from a trip we took together to Spain. My mum loves to feed the birds. I think you can see a bit more sadness in this picture due to Mum's illness and difficulties. However we had a lovely time as the trip to Spain was a time when Mum was well and we were able to have an amazing time in Seville seeing my brother. Even though it's harder with my real mum and I haven't been able to have a video conversation with my real mum because of her illness I wanted to still bring her into my research because in my mum's own way she values and loves me. She listens to me and she supports me in the way she can in her own capacity.

Image 1.   My biological mum on a trip with me to Spain.

Image 2.   Conscious Conversations

What I have found is that as I have been researching I have found that I bring the love that the definitions are referring to into my research. I have found a pooling of energy with those I work with that makes us want to research together and bring energy to each other as we work in a collaborative group. The energy I feel is like the drawing below (Image 2) called Conscious Conversations, which I drew when I was 18. It shows people coming together with a pooling of energy in the middle depicted by bright dynamic colours. I felt the picture below (Image 2) represents action research with people coming together in a collaborative group.

What I have found as I have brought video into my research that, "watching the video changes the nature of knowledge itself and allows its development" (Laidlaw, 2008, p. 17). This is because I have been able to go back, review and see what's happening in the video so it's not just a tool to record what's happening it also captures the embodied expressions that are happening. You are able to look at the videos on so many different levels and keep learning and keep going back which makes video a great tool.

Video 5.   [Sonia in conversation with Rosie](). (Hutchison, 2011b)

This still image above is taken from a video with Rosie and I (Video 5). Rosie is a carer and she cares for her husband who has dementia. I would describe Rosie as having lost her husband before he has died. He can't really remember her; he can't look after his own appearance even though he once was a very proud man and would not have wanted to be in that scenario. Rosie is in a really tough time and Rosie talks about her caring role as being completely 24/7. Rosie doesn't know if her husband is going to wander off, if they are going to leave, whether they know what they are doing. Rosie had an awful time when her husband did wander and Rosie didn't know if he was dead or alive. This has meant Rosie always has to be on her guard. Rosie comes from this awful scenario of caring but you would not know that from the picture. We're having this great conversation where Rosie is talking about me as a leader at the Carers' Centre. I wanted to give the back story because it shows that when we bring out people's stories it gives them so many more dimensions.

When Rosie was with her husband and he was well they had a wonderful life, Rosie has her own business and is very successful and an incredible lady. It's been great to work with her and for her to be part of the organisation as we support her but also as she supports the organisation as a trustee. Rosie is very challenging as a trustee but also really supportive so I've been able to have that input. In this conversation that we videoed I have been able to use it as data for my research as to whether she sees me as an authentic leader and how she describes that.

Rosie says that, "because you're a carer yourself the empathy is naturally there." I am a carer for my mum. It took me a long time to realise that because I don't live with my mum she lives a two hour drive away and when I'm caring for her the most it feels the most uncaring time because it means she's ill and she says things that are unrepeatable to me and gets very angry and is very quick to tell me the things she doesn't like about me and that she doesn't want me to be part of her life and things like that. Luckily Mum has a great professional team and we've overcome some of the issues such as confidentiality within the caring role because when mum is well she sees me as a very fundamental part of her life and she wants me to be involved. So when Mum's unwell and she's saying she doesn't want me around, the team still talk to me and we still work together because that's a really important time. It means I really understand those tensions of being a carer. Carer can be a difficult title because when you're doing the most it doesn't always feel like your caring. What I want to explore is what does it mean to be a carer? How does that feel? Part of our research group has been a very supportive group where we can bring issues of caring as well as what we are researching about authentic leadership, moving things on for carers making differences for people in their lives also what does it mean to be a carer and our stories. That really gives me that authenticity that I'm able to empathise because I'm a carer myself. I don't think that means that to be a really great authentic leader you have to walk in the shoes of the people you work with but it has certainly given me an extra dimension in my authentic leadership.

Rosie picked out that I "empower carers to become spokes people … you can see their confidence grow." That's really affirming because Rosie was seeing one of my values in practice of participation so that Rosie is able to pull out from my work with carers that I am enabling people to get involved and to have their own voice. I was really able to look at my lived experience of being a leader as actually living my values in practice.

Rosie says that she feels, "I am very inclusive of everybody," which again validates that Rosie is seeing me live my values of love and participation that I am being an inclusive leader and not leaving people out. That's a really challenging standard of judgement and we all would like that to be true but it's very difficult to do so I'm glad she could see it.

Below are pictures from videos with of me with staff, volunteers and carers at moments where I feel a love and energy are being shared.

Video 6.   Conversation with Jill Tovey (Hutchison, 2011c)

Conversation with Jill Tovey (Video 6) also helped me to improve my practice by enabling spaces for the staff to have time to know each other on a personal as well as professional level. I feel since I have gained this feedback the team is now a much stronger and loving team as they have got to know each other better and that they welcome new team members into the organisation by getting to know them both personally and professionally. Staff now bring their skills at organising social events which brings the team closer and I make sure we have more opportunities for social time by bringing coffee, cakes, and lunch to encourage this social time.

Video 7. Conversation with Jill Tremellen (Hutchison, 2011d, 2011e)

As the video plays (Video 7) and I see this picture I feel the warmth and love between my Chair of the trustees who is my supervisor and has overall accountability for the organisation and also the energy flowing between us. Jill also talks about this, Jill has gone on to show this love in her actions and I remember feeling truly valued and supported at a critical time in writing a bid that would keep the Centre running by being brought soup by Jill. Jill has improved my practice through this and other conversations by reminding me to keep true to my values of participation and ensuring carers are central to everything we do at the Centre and helping me to make difficult decisions by remembering to keep carers central to my decision making.

Video 8.   [Conversation with Lydia Clark](#) (Hutchison, 2011f)

As I see this picture from Video 8 it evokes in me the warmth, love and energy in our conversation. Lydia's words also helped me to improve my practice by ensuring staff have time to be creative and have their specialisms which they can develop, having a holistic approach to maintain staff's well-being by making time to talk and support each other. Remembering to show my appreciation which I try to do through team meetings and giving time to listen to people through team meetings and Forums. I have also continued to open myself up to critique and being willing to change.

Living contradictions (Whitehead, 1989; Barry, 2012) is a great concept and provides a real release because it's about wanting to live our values but recognising that sometimes we don't live them fully. I always want to live my values but often find I am contradicting my own values so I'm not really living them as fully as I'd like. As I recognise where I am a living contradiction I can learn where I'm not living my values as fully as I'd like, analyse what is happening in that situation, and develop ways of improving my practice. I always learn so much when I can see where I am not doing it the best way. When I get feedback, criticism and complaints from people that I'm working with or my staff, volunteers or trustees I feel I learn the most. It's the hardest thing because I come up against the fact that I'm not living my values fully and I want everyone to be included, I want everyone's voice to be heard, I

want everyone to feel loved as I have defined love in this paper and I want to improve things for people, but sometimes I just don't achieve it.

The best way I have found to learn is to ask people I work with or when people come with a complaint and then not to feel defensive but to open up and realise that I am clearly not living my values fully, and ask, "how can I improve my practice from what you're saying?" and "let's work together to improve what we're doing and to take things forward."

Conclusion

This paper has looked at what I mean to be an authentic leader, to lead a Carers' Centre in a way that is true to my values of love, participation and mindfulness. I have found in the data, both in the words and the embodiment seen through the video, support that I do live these values but have also found that I am a living contradiction at times. Understanding that I am not always living my values fully enables me to develop as a leader and by making my work public I am aiming to have an influence beyond my own practice.

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