

Grant Campbell: Dementia

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Announcer 2: Okay, let's get on it.

Interviewer: Hello, I'm Alex Mayhew from the Faculty of Information and Media Studies here at the University of Western Ontario. Today I'm talking with Dr. Grant Campbell, also from the Faculty of Information and Media Studies here at UWO. Would you like to introduce yourself?

Respondent: Thanks, Alex. I'm Grant Campbell and I come from a background in English literature and information studies. My primary teaching area is in information organization, cataloguing and classification and metadata. I also teach big data and information systems for the undergraduate courses. And my research is a mixture of research on the Semantic Web and big data and also, and primarily what I'll be talking to you about today, is my research on information aspects of dementia.

Interviewer: I mean that sounds really fascinating. Can you tell me about dementia and what you're looking at?

Respondent: Well, I'm looking at the information aspects of it. And by that I mean, partly, what can information services do to enhance the support of people who are living with dementia, both the people who actually have dementia and also the caregivers, the personal caregivers who are caring for these people in close quarters and are dealing with so many of the challenges.

I'm looking at it however also in another direction. I want to see how information services can help people with dementia, but I also want to see what people who live with dementia can teach us in the information professions and in the study of information. What do the challenges they face and the way they face them teach us about what we should be doing in terms of information delivery, and helping us understand more about ourselves and what we do?

Interviewer: What's your process? What do you go through in order to learn more in the situation?

Respondent: Watch. It's on a number of fronts. First of all, I'm going on the experience I had caring for both my parents who suffered from dementia. And I

volunteer with the Alzheimer's Society's intergenerational choir which gives me a chance to observe. The study that I'm doing involves qualitative interviews with a number of personal caregivers who have been caring for people with dementia. And I've been talking to them and trying to understand their challenges.

On top of that, I have been looking at published memoirs written by people who went through the caregiving process and have written about it after the person has passed away. And on another level, which is further down the road, I'll be looking at reflections of dementia in literary works, how certain residences with dementia pop up, even in novels which are not talking about dementia directly.

Interviewer: Are there any particular authors that we might know of?

Respondent: Well, George Eliot's *Middlemarch*, for instance, is one which doesn't mention dementia and is in many ways all about the agonies of caregiving. I gave a paper at the Virginia Woolf Society awhile ago on Virginia Woolf's *Jacob's Room*, talking about the difficulties of knowing another person and the barriers that exist between people, even those living in close quarters with each other.

The problems that are faced by people with dementia and their caregivers are problems that face us all in one form or another. The theoretical framework that I'm using is one that I took from Paul Grice's work about implicatures and the idea that when we interact with each other, we are obeying certain unspoken contractual rules.

One of the things that I noticed in talking with people about the caregiving experience is that there's all kinds of challenges on a practical level which they have to deal with. They have to deal with caregiving services. They have to deal with finance. They have to deal with medical issues and all these things. But underlying these is a much deeper problem of interacting with the person that they've known and loved for many years who is changing. And underneath that is a grieving for the loss of simple conversation, the fact that it becomes harder and harder to sustain an ordinary conversational interaction.

Starting with Grice's notion of implicatures, I looked at the ways in which conversation is disrupted when you are conversing with somebody with dementia. And using that as a basis, I've been classifying the kinds of phenomena that the caregivers relate to me and trying to relate that to other metaphors that I think might be helpful.

Interviewer: Changing gears for a moment, how does this interact with your other research on cataloguing the Semantic Web? Does it impact it at all?

Respondent: Surprisingly, it does, but it does in a rather roundabout way. And to do that, I have to take a bit of a detour. I found that, like many people, I found that music is enormously powerful with people who are suffering from

dementia. And music can be an enormously powerful bond between people with dementia and their caregivers.

We've seen movies like "Alive Inside" which talk about the ways in which music can revive memories. And I was fascinated by that as an amateur musician who volunteers with doing music programs. And what struck me about it was not so much the power that music has as a phenomenon in itself, but its power as a metaphor for how communication works in general. And I'm using music as a metaphor, and particularly the acoustics of music as a metaphor.

If you look at music acoustically, music is a vibration which repeats, where the pattern of vibration repeats itself. That's what makes a note different from simply the sound of a slamming door for instance. And that sustained repeated pattern is what creates a musical note. In that vibration you have what they call harmonics, which are variations of vibration within the larger vibration. So if you have a note with very few overtones it means you're getting just the basic vibration. You can also have that same note played on a different instrument or sung in a different way, in which you've got vibrations which are subsets of the larger vibration which appear overlapping, and that's what gives a note a different timbre.

What fascinated me about this is that that is very similar to the way in which good conversation and communication works between a caregiver and the person that they're caring for. There are times when the caregiver is with the person with dementia where essentially a stable anchoring position has been established. Very often it's through some sort of ritual, a ritual of some procedure such as making tea where they've done it many, many times before, it's familiar, and there's a comfort that's been established because of that. And that I equate to the establishment of a sustained vibration.

There are times in the interaction where the person with dementia seems to see the person as many different people at once. There were times when I was with my mother where I sensed that she sort of knew that I was her son, I looked a little bit like her husband and, because I played the violin, I seemed a little bit like her own father, and that all of these different personas sort of interacted with each other in much the same way that harmonics interact with each other to create a sustained timbre of conversation.

At other times I felt that there were no overtones whatsoever. All she knew was that I was someone who was friendly, and that in the interaction between the caregiver and the person being cared for there is an endlessly shifting combination of overtones, and that the key to successful interaction is establishing those two stable anchoring points and allowing the vibrations to take place on whatever level seems to work at that particular moment.

Now how that relates to classification and information organization is that traditionally we have seen classification as a hierarchical structure. And

starting back with Ranganathan in the 1930s, there was a fascination with facet analysis and finding ways of codifying the ways in which one concept links to another. And Ranganathan pioneered the concept of establishing how one piece of information links to another piece of information.

This got picked up in the years of the World Wide Web with the concept of hyperlinks, in the sense that you have an anchor text and you have a destination page, and you have a hyperlink that goes between them. Now traditionally, in web development we've seen that as a doorway or a passage which goes from one place to another. But if we take it from Ranganathan's point of view, it's more a stable portal that represents some kind of meaningful resonance between two concepts.

And it struck me – and this is a bit of a leap – that when we are talking about information and classification of information, rather than speaking about traditional hierarchies we should be identifying resonant linkages, however odd they may be, between different kinds of information. That building on Ranganathan's concept of analytical faceted classification and the concept of hyperlinking, we should be finding ways in which one piece of information links to another piece of information in a way which is stable and which is resonant.

And so I'm developing an idea of classification as a form of resonance rather than as a hierarchical structure, which is something that I got from looking at people with dementia and their caregivers. So that's how it all comes back to information organization.

Interviewer: Well tied together. You've already mentioned a bit about your personal experience, so I wanted to ask you about why this topic is of particular importance to you.

Respondent: First of all, I had an opportunity to witness it at close quarters. And I also had an opportunity to witness the pain and the difficulty, but also the unexpected pleasures that came when I was – because both my parents suffered from dementia. And although it was a very difficult and stressful time, there were moments, I remember moments where everything sort of came together. And I wouldn't trade those moments for anything.

Another reason why it matters to me is that I noticed that throughout the whole 10 or 12 years that both my parents were alive, I almost never went to the library. I got almost no information from either the public library or the academic library. And other researchers of dementia that I've talked to have noticed the same thing in their studies, that caregivers do not tend to use information sources, the kind of information sources that I'm teaching people to maintain.

And I thought to myself, 'Well what are we doing wrong if this situation where people are probably feeling horribly helpless most of the time, and yet for some reason they don't feel that the library is a place that they can go. What are we doing wrong?'

And it struck me that the way libraries are set up, they're set up for contemplative and reflective work, which is the kind of thing you do after the person you've cared for has passed away. It is much more difficult to absorb large amounts of information in any meaningful way when you are under the stress of caregiving all the time, and particularly – I had it easy because I wasn't living with my parents all the time. But if you talk to spouses whose loved ones are living with them, they don't have two minutes to rub together let alone hours on end to sit and reflectively ponder on things.

And so I thought to myself, 'Well, I'd really like to be able to find some way to help people who are in the middle of this rather than helping them to process it afterwards.' I think there's lots of resources for processing it afterwards. But when you're in the thick of it you need something different, and we're not providing it yet.

Interviewer: Sounds like a very noble endeavour.

Respondent: Well.

Interviewer: What has your reception been so far?

Respondent: The reception has been interesting. Well for one thing, I am inches close to canonization. The moment I tell people that I work on dementia and that I play the violin for people who have dementia, Ghandi didn't get this much feedback. "Gosh, what a wonderful thing you're doing."

Interviewer: Got it from me a moment ago.

Respondent: Yeah, I did indeed, I did indeed. People have responded very positively. There seems to be a lot of interest in it, although I'm not sure that the real thrust of what I'm doing has really hit critical mass yet. I think people tend to assume that what I'm talking about is just how much people with dementia like music. And that's perfectly true, but that's not what I'm using the music for.

Interestingly enough, at conferences I have found that people who respond most positively are people who have survived other illnesses. I had somebody come up to me at a conference after I'd delivered a paper saying that, as a survivor of breast cancer, she found what I was doing very, very meaningful, not for the research itself but for the underlying recognition that there are experiences, particularly health experiences that radically change our point of view and our attitudes to life. And that she had undergone a transformation of that with her health challenge, and that knowing that my work resonated with her, not because she cared particularly about dementia but because she liked the idea that we were looking at how information can support that kind of radical change in a life view which comes.

I got a lot of appreciation from caregivers when I've spoken to audiences of caregivers. They tend to be very wary of anything that glamorizes the

whole process. The more matter-of-fact I am I think the more they tend to like it. They get tired of hearing people say “Oh my gosh what a noble enterprise.” Sorry, but they want us to understand how hard they’re working and how difficult it is and how lost they feel. I don’t think so far my work has actually given them what they’re looking for, but they are responding to my hunt and my search, and that is what I find promising and keeps me going.

Interviewer: On that score, I would ask you what are two or three things that you wish were more commonly known about your research.

Respondent: About my research?

Interviewer: Or the topic area in general.

Respondent: About the topic area in general, I would like it to be understood that libraries and information services are not simply for the idly curious. I think that’s something that’s been nagging at me like a fly buzzing around my head is this realization that for many people, and I’ve caught myself in this as well, we tend to see the public library particularly as a place where you go to satisfy an abstract curiosity as opposed to something that can actually intervene and help you with things.

And it’s not necessarily the fault of the library. I think it tends to be the way in which libraries are culturally recognized. But I would really like to see public libraries in particular playing a more active role in supporting people who are caring for people with dementia. That’s one thing I would like to see.

I would like people to understand that dementia does not mean that the story is over. I think we have a tendency to talk about dementia in terms of loss, and that is natural and it is unavoidable, but it is not the only part of the story. We tend to talk about dementia as a process of emptying out. People tend to talk of it as the person is going away, the person is leaving, the person is empty. That does not harmonize with what I see when I play music in dementia wards. I see tremendous reserves of life, tremendous reserves of humour. And in particular I see a tremendous resourcefulness and a wiliness, if you will, that isn’t always apparent from their expressions.

When your brain is interfering with what you want to do and what you want to say, you have to find other routes and you have to improvise. And people who have dementia who are still engaging with the world around them are endlessly improvising. And you may not always see it from their face, but if you listen closely you can realize that they are working really, really hard. And they are being inventive and they’re reaching out. And I think we have an obligation to reach out to them as well. And so that’s the second thing.

I think the third thing I would want to point out is that music is not a cure-all. I was playing in a dementia ward one day, and there was a woman

who was sitting in a wheelchair crying “I’m all alone. I’m all alone. I’m all alone.” And I started my music program and she woke up to the music, and she was singing and she was interacting and she looked 20 years younger.

And I thought to myself ‘I am a magician. I have just changed this woman’s life forever.’ As I was packing up and leaving I heard behind me, “I’m all alone. I’m all alone.” And I realized that what I had done had alleviated things for a very short time but it didn’t solve things. And it didn’t change what was happening.

And I think we sometimes glamorize the caregiving process, that the people who do it do it because they’re born to it and because they love it and because they have a special relationship. I don’t think so. Many of them do it because that’s where they ended up. And there are unexpected joys in caring for dementia and there are many, many griefs and pains.

But, I think a last thing I think I wish people knew is that people with dementia and their caregivers have much to teach us, that it’s not a one-way street of giving care in one direction. I think they have much, much to teach us about our lives and about our profession. And I’m trying to bring their perspectives into information science as best I can.

Interviewer: Well thank you very much for sharing that.

Respondent: Okay, my pleasure.

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Announcer 2: So What? is created and produced by students at the faculty of information and media studies at Western University in London, Ontario.

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