An Aboriginal perspective of learning to manage diabetes

Monica Johnson
Craig Johnson
Bernie Kemp
Valerie Smith
Emma Webster
Billie Townsend
Dubbo Aboriginal Research Team
Our approach to the research is collaborative

- “Who else do we need to be talking to?”
- Co-production of design, implementation and analysis with research team and community
- Qualitative study
- Focus groups
Recruitment of participants

- Aboriginal people who have diabetes
- Visited community groups popular with Aboriginal people
- Provided transport where required
Focus groups

- Social feel
- Reciprocal benefit for participants and researchers
Focus group
Conversation map
Focus group
Conversation cards

Card 3
Who changed for you since you were diagnosed with diabetes?

Card 6
Who is it that helps you with your diabetes?

Card 5
What do you see as long-term changes to your diabetes?

Card 7
Most of the health people you see about your diabetes are non-Aboriginal. Is there anything you would like us to share with them?
Focus group
BBQ lunch with Johnny cakes
Focus group
Feltman diabetes education session
Participants

- Five focus groups (n=25 people)
- Average age was 67 years
- 22 have a family history of diabetes
- 17 used tablets
- 14 used diet
- 12 used insulin to control their diabetes (5 people used all three)
Analysing the data

• We audio recorded the focus groups and typed them up (data)
• Five of us coded the first transcript together
• We built a model that linked codes together
• This approach is called Grounded Theory
Learning to manage diabetes

- Learning to manage their diabetes was difficult:
  - Acute- hypoglycaemia
  - Chronic- lifestyle change, managing medications, measuring BSL, routine tests
  - Complications- renal disease, ulcers
- All had goals relating to diabetes and many were extremely motivated
Effects of colonisation

FG1 1271-1275 Well I walked around here on the riverbank and I can’t find the tree I was looking for. Yeah, I’d drink it and I’d bathe in it and I used to bathe my kids in it in the winter time, they never got a cold. It was good stuff... None growing down here ‘cause I looked and looked and looked and looked and I couldn’t find any. Pete

FG1 920-929 The government bloke was there trying to tell us that if we wanted to go out and shoot a roo and eat it, we had to apply to Canberra first, and one old fella said to him, “Hey, how long does it take for you to answer me if I put an application in to go and get a roo for the kids?” … He said, “Oh, I don’t know, maybe two weeks.” He said, “My kids want it tonight not next week or the week after.” Travis
Effects of colonisation

FG1 637-640  ...as we get older and we get more richer, we start buying things like cars and that, and that replaces the walking. I jump in the car, drive down to the shop and I watch my kids today if they want to go to the shop - straight in the car. They don’t walk. Bob

FG4 643 – 645  Because you white fellas come here to this land, cooked lovely food and we ate it. That’s why it’s (diabetes) rampant in us now ‘cause we went off our bush tucker. True. Vanessa
Seeing family members with diabetes

FG4 88-92 – I saw my mother go through hell … My mother died and my grandmother, her mother. She was totally blind by the time she was 60 and now it’s all reflecting on me because I’m partially blind and you know how bad my health is because of my sugar. Bianca
Model of care experienced

FG5 1843 – 1844 The only thing that makes it hard, because I can’t read or write, see. (Aboriginal Health Worker) understands that, and that’s why he explains it to me. Curtis

FG2 2243 – 2245 Aboriginal people they know how – what they have to say to them and then they feel comfortable if there was an Aboriginal person sitting the other side of the table to ask them questions, they feel comfortable… Page

FG4 1422-1433 I went up there sick one morning and she came in to talk to me and when she opened her mouth, I thought, oh my God she’s got to be black… I couldn’t help myself. Where are your people from? Bianca
Model of care experienced

FG1 182 – 185 Doctors – sorry, not doctors, nobody educates you about your diabetes. All they do is tell you you’ve got it, wear it and good luck to you. Bob

FG 4 223-226 Really, really nice… I go every three months and I have a long appointment because first of all I go to the nurse then I go to Doctor (GP) and the nurse weighs you and does all your sugars tells you everything and that and then from there I go to Doctor (GP). Felicity
Interactions with health services

FG1 1064-1067 One of the worst things I come across is because I’m dark skinned, they think I drink and smoke, I never drank or smoked in my life. And the first thing they say is, they don’t even ask the question of me “You will have to give up the grog and smokes”, and I said, “Mate I’ve never tried it in my life.” Ross

FG2 2481 – 2484 I just – I don’t like going up to some specialist and stuff because I feel like it’s all scare tactics and they’re just trying to shame me and I feel real bad about myself and get the guilts when I leave, so it’s easier – not easier not to go, but I prefer not to go because I don’t want to feel that way. Kaye
Interactions with health services

FG1 1165 – 1175  they’re (white people) the ones who run the diabetic programs, they’re the ones who come up with all these you beaut things to do for black people with diabetes, and they’re the ones who will develop and implement programs for the blacks…. The trouble with that philosophy is ‘cause a white fella, he’ll do that and then he’ll blame you. Bob
Learning to understand and manage diabetes. At the level of the individual each circle may have more or less influence on the way the individual comes to understand and manage their diabetes.

- Colonisation
- Intergenerational learning from seeing family members with diabetes
- Interactions with health services
- Model of care experienced
Conclusions

- GP led models of care for diabetes management are acceptable to Aboriginal people
- Some clinicians and services already provide this model of care
- Intergenerational learning is not often considered
- People do experience racism when receiving care
- But we need to think more broadly about how we improve care
Recommendations
Deliver a holistic model of care

– Get to know your patient first by having a yarn. Before anything else.
– Explain what is happening using yarning and visual resources
– Family centred (not individual) approach
– Health professionals keep an open mind and be prepared to challenge own stereotypes of Aboriginal people
Recommendations
Deliver a holistic model of care

FG1 1543 – 1550  Can I just say if you wanted to do something to help blacks with diabetes, kidney problems, whatever, you’ve got to look at developing a holistic approach to it. I don’t care what it is but that holistic approach has to include the family, and even on occasions... even extended family. So you have to include them in so that they know how to look after people that have problems. At the moment there’s none of that or very little of it if it does happen. If we don’t have that holistic approach, we’re not going to last long. Bob
How do you do a yarning approach?

– **DO** be yourself
– **DO** find common ground (town they are from, football, music, art, fishing)
– **DO** take a collaborative approach
– **DON’T** appear that you know them better than they know themselves
Improve how we deliver education

FG4 1750-1753 Even if they get a... see through mannequin and say this is what's happening to your body, 'cause I'm not taking it all in. But then when this woman is sitting here (Bianca) saying she had diabetes first and then she had renal (then I take it in). Vanessa
Recommendations

– Increase prevention and early intervention
– Improve education for health professionals to ensure delivering consistent messages
– We need to work harder at making sure Aboriginal people are aware of diabetes services
Recommendations

– More Aboriginal Health Workers who are qualified diabetes educators
– Increase access by ensuring free services, free or subsidised medications, free transport
Outcomes

- The focus groups brought people together
- Monthly chronic disease support group for Aboriginal people started October 2015, local GP regularly attending
- Journal article published (findings)
- Book chapter (in press) describing our approach to the research
Where to from here?

– Yarning style medical consultations “clinical yarning”
– Holistic (family centred) models of care
Acknowledgements

– Community members who helped with design
– Reg Walker Jnr artwork
– Participants
– Volunteers who read participant quotes
– Billie Townsend