



Let's Yarn About Cancer

Loddon Mallee

Final Report

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Background

Loddon Mallee Aboriginal Reference Group (LMARG) was funded by Loddon Mallee Integrated Cancer Service (LMICS) for the *Let's yarn about cancer - Loddon Mallee* project.

Membership of LMARG is comprised of the following four Aboriginal Community Controlled Organisations (ACCOs) which cover six sites in total:

- Bendigo and District Aboriginal Co-operative (BDAC)
- Mallee District Aboriginal Services (MDAS) - Mildura, Swan Hill and Kerang
- Murray Valley Co-operative (MVAC)
- Njernda Aboriginal Cooperative (Njernda)

The *Let's yarn about cancer - Loddon Mallee* took an iterative, inductive, community-oriented approach to investigate Aboriginal health workers' (AHWs) cancer understandings and practice needs.

The need

Aboriginal and Torres Strait Islander Australians, compared with other Australians, experience a higher burden of cancer, higher incidence of cancers with poorer prognosis, higher mortality rates, disease diagnosis at a later stage, higher rates of comorbidities, and lower survival (Green, Cunningham et al. 2017). Reasons for these lower cancer survival rates in Aboriginal and Torres Strait Islander people compared to non-Indigenous Australian cancer patients are likely due to a variety of complex reasons. Although better understanding of cultural differences in attitudes to cancer and its treatment may translate into meaningful clinical and public health interventions to improve cancer survival in Aboriginal Australians (Valery, Coory et al. 2006).

Aboriginal concepts of health are different from Western biomedical perspectives of health (National Aboriginal Community Controlled Health Organisation 2016):

Aboriginal health means not just the physical well-being of an individual but refers to the social, emotional and cultural well-being of the whole Community in which each individual is able to achieve their full potential as a human being thereby bringing about the total well-being of their Community. It is a whole of life view and includes the cyclical concept of life-death-life.

ACCOs offer primary health care services that have been initiated, and are operated, by local Aboriginal communities to deliver holistic, comprehensive and culturally appropriate health care to the community which controls it (through a locally elected Board of Management),



responding to Aboriginal understandings of health and wellbeing. ACCOs deliver a comprehensive model of primary health care that is consistent with, yet predates, the definition of primary health care outlined in the Declaration of Alma Ata, and were the first organisations to offer comprehensive primary health care in Australia (Aboriginal Health & Medical Research Council 2015). ACCOs have been effective in increasing Aboriginal peoples' access to various areas of primary health care, including cancer and chronic disease prevention (Aboriginal Health & Medical Research Council 2015).

AHWs are central to the ACCOs model of care. In Australia, in the 1970s and 1980s, AHWs became significant members of primary health services workforce; this was in parallel with the emergence and growth of ACCOs which championed the roles of AHWs (Topp, Edelman et al. 2018). Initial ideas around the role of AHWs was comparable that of community healthcare workers in the international domain with a focus on activities such as health education, basic health care, and community health action. But as the AHW role developed in Australia, an important aspect of AHW practice came to include 'cultural brokerage' and the delivery of comprehensive and culturally safe primary health care services (Topp, Edelman et al. 2018). In current context, the role of AHWs may vary across organisations, but the primary role of AHWs is delivering health care, plus a cultural brokerage role to assist Aboriginal and non-Aboriginal health care providers and organisations to communicate better and overcome cultural barriers.

AHWs roles can encompass clinical, health promotion, education and leadership responsibilities (Abbott, Gordon et al. 2008). Although in some organisations there is increasing pressure for AHWs to spend most of their time on clinical activities which can be billed through the Medicare Benefits Scheme. AHWs are able to provide multiple, and overlapping, insights, as they hold clinical roles and community roles, along with their personal experiences as Aboriginal community members, carers and users of health services themselves.

Given the gap between Aboriginal and Torres Strait Islander and non-Indigenous Australians experiences and outcomes of cancer, there is increasing recognition that greater efforts are needed. In particular, research priorities to improve cancer control for Aboriginal and Torres Strait Islander include cancer prevention and early detection, culturally appropriate care for patients, survivors and their families, and health literacy; which should all be underpinned by community engagement, Aboriginal ownership, and partnership and collaboration (Morris, Anderson et al. 2017).



Project aim

Consistent with the research priorities detailed above, the aim of the *Let's yarn about cancer - Loddon Mallee* project was to investigate AHWs' understandings and needs in relation to cancer, and to consider what would be useful to support and inform their practice, given their work with clients and families experiencing cancer.

Methods

The project took an inductive approach to let AHW experiences emerge from discussions, rather than a prescriptive, pre-determined approach of what was needed. Inductive reasoning, by its very nature, is more open-ended and exploratory, especially at the beginning. Given the differences in Aboriginal cancer outcomes, an exploratory, culturally appropriate approach to understanding cancer needs in the region was deemed appropriate as it was likely to provide a better understanding of cultural differences in attitudes to cancer and its treatment (Valery, Coory et al. 2006).

The data collection method used was qualitative, semi-structured interviews. Qualitative methods, including semi-structured interviews, are appropriate when describing and seeking to understand people and their lived experiences (King and Horrocks 2010). Using semi-structured interviews allowed us to probe and seek clarification from the AHWs and for the AHWs to explain their experiences and to participate in a two-way conversation about their experiences. Additionally, qualitative research is useful for exploring complex social phenomena and for examining areas that may not be responsive to quantitative research (Pope and Mays 1995). Qualitative methods can be used to explore interactions, behaviours and meanings, values and experiences (Kitto, Chesters et al. 2008). In public health, qualitative methods can be useful to:

- consider and explain political, economic, social and cultural factors which influence health and illness;
- investigate the interactions between the different stakeholders relevant to the issue; and
- explore how individuals and communities interpret and understand health and illness (Baum 1995).

An interview guide for the semi-structured interviews was developed. This guide was reviewed by two people external to the project who worked with Aboriginal communities in relation to cancer, and their feedback taken into account. Topics covered in the interview guide included knowledge and understandings of cancer, experiences working with clients and their families



who have had cancer, cancer in relation to the AHW role, support services, mainstream services, and support and resources that might support AHWs in their cancer-related work.

Sampling and data collection

Using the LMARG network of ACCOs, initial contact was made with the health manager and/or clinic coordinator at each ACCO to explain the purpose of the *Let's Yarn About Cancer* project and the intention to interview AHWs. Feedback was sought from these managers/coordinators as to the most suitable way to conduct the interviews at their ACCO.

From these discussions, interviews with AHWs were conducted at all six ACCO sites within the LMARG catchment. A total of 18 AHWs were interviewed. Interviews took place on site at each ACCO, and were conducted with pairs, small groups, or with individual AHWs. The interview group size was determined by the preference of the managers and workers and to also ensure reduced impact on AHW work activities.

Interviews were conducted between March 2017 and August 2017. The interviews were recorded and transcribed. A copy of the transcription was provided to each interviewee after the interview, and they were given two weeks to review the interview and provide any feedback. Bendigo Health Human Research Ethics Committee provided ethical approval for the project in January 2017.

Data analysis

The data were analysed using thematic analysis. This type of analysis allows for inductive interpretation of the data, while also considering pre-existing theory (Liamputtong-Rice and Ezzy 1999). After each interview was completed, the Project Officer and the LMARG Working Together for Health (WTFH) Regional Coordinator discussed the interview noting emerging findings, areas of interest and similarities and differences. The Project Officer also made notes after each interview. When all the interviews were completed the Project Officer and WTFH Regional Coordinator held two meetings to commence initial data analysis. Data analysis was completed by the WTFH Regional Coordinator. This analysis involved reading and re-reading the transcripts, open coding the data through this process of repeated reading; discussing the emergent themes, further reading and re-reading, and then the refinement of the themes (Braun and Clarke 2006).



Findings

During each interview, we explored understandings of cancers, experiences of cancer with clients and families of clients, the AHW role and cancer, mainstream services and support needs. As these were qualitative semi-structured interviews other issues emerged from the interviews which AHWs highlighted as important to their practice and communities. It is also useful to note that at least three of the interview participants had direct and recent personal experiences of cancer, either as an individual or as a carer of someone with cancer. As such, some of the responses relate to their own cancer personal experiences and some responses relate to their role as AHWs. In this way, the AHWs provided varied insights, drawing on their clinical, community and personal perspectives. In the following section key themes are discussed.

Support provided by AHWs

Translators, advocates and system navigators

A key theme in the interviews was the role of AHWs as navigators of the system and translators of information related to their clients' cancer experiences, with one AHW noting "We spend a lot of time being an interpreter" (int #2). The need to act as a translator of information was apparent when supporting clients who were diagnosed with cancer, to help them understand their diagnosis and treatment:

We need to manage the lingo, I often don't know what they [doctors] are saying so what hope have members of our mob got, you know they use a lot of jargon and medical lingo (int #2)

and

Probably the biggest thing is being able to explain all that stuff to them, I am probably not the most appropriate person to explain some of this stuff to them but I know them and can often better explain stuff to them (int #5)

When AHWs attend medical appointments with clients they can provide further support and assistance, particularly if a client "don't talk much or are scared to ask stuff" (int #3). Then if they are assisting the client afterwards and in visiting the pharmacy they can provide further support:

I can say ok this one is for this and these ones are for that particular thing. I think it's handy when the health worker goes into see the Doc with the patient because they can



concentrate on listening and can ask questions so possibly remember more of what the doc says. (int #3)

AHWs also advocate for their clients in their interactions with different parts of the health system: “We as Aboriginal Health Workers, we are there to support, advocate on behalf of the client, and support the family as much as we can” (int #7).

In this project we found AHWs provide diverse and varied support to their clients with cancer, and to client families, supporting them to access different parts of the system. This can include providing or arranging transport, assisting with visits to the pharmacy, attending general practice and specialist medical appointments. For example “assistance in regard to accommodation mainly but also transport, or getting them to the hospital to see their loved ones at the beginning of their journey” (int #7).

Part of the community and available 24/7

A reality and tension inherent in the AHW role is that AHWs are community members as well as clinical workers, this means their professional responsibilities can merge with their personal lives.

Consistent with this an AHW explained “gee from the communities view we are in the job 24/7... I really love what I do it is just sometimes it becomes very stressful” (int #2). Another noted “A lot of community already have a high regard for health workers and think that they are able to help at any time” (int # 3).

The personal relationship and connections can also make the AHW role difficult:

One of the issues I see is attachment to the client. It's the biggest one you know, you know the family, you've know them sometimes for years, you know the kids, your kids know the kids, often play with them, go to school together. Sometimes you're related to them. That can cause some real issues. It makes it harder (int #2).

The professional role and community obligations of the AHW can also impact on their social and emotional wellbeing.

Social and emotional wellbeing

Working with clients with cancer present a significant social and emotional wellbeing issue for AHWs. The social and emotional burden of cancer was also significant for clients and their families.



AHWs

In addition to the practical forms of support, AHWs also provide social and emotional support to their clients and client families - "it's basically right up to the day that their last breath is taken. It's being there for them" (int #7). Another noted:

"you can sit there with them and talk for hours and get to know a lot more about them, some really interesting stories you haven't heard before, it's good but where you get that connection, that makes it harder when things start going bad.....We try to make our clients as comfortable as possible, whatever they need and stuff and we also tend to spend almost as much time with their families helping them with this, that and other stuff (int #2).

The social support that AHWs provide to clients and their families has an impact on the AHWs themselves. This may be because of the close relationships they develop when supporting their clients, and/or because they have existing relationships from community ties. There is the burden of managing their own social and emotional wellbeing as their client goes through the cancer journey.

Sometimes you would be travelling with people and they would break down crying in the car because they are tired of getting injections and their tired of getting medications and they are crying 'cause they know they don't have long to go and be with kids and stuff. It's hard to deal with. How are you supposed to deal with that? And you can't take it home with you. It gets really hard for us as they are community and we're members of that community and my kids are related to them. You see them on the street or at the pub so it's always there. (int#2)

Another explained: "you're feeling what those family members are feeling, you're also feeling the pain that that client is going through" (int #7).

There was some recognition of the need for self-care: "We need to look after ourselves as well as our patients 'cause if we get crook there is now one else to look after the patients" (int #2). In some instances AHWs used their own internal informal network to provide support to each other, but were aware that they could also access ACCO counsellors and/or employee assistance programs. One AHW stated "we just bounce stuff off each other and if that doesn't sort of give us what we need then we can go to a counsellor" (int #4).

Clients and their families

As previously noted, within the group of AHWs interviewed there were several with direct personal experiences of cancer, so they also spoke from client and carer perspectives. An



AHW expressed the loneliness and isolation they felt at diagnosis: “So when I found out about it here I felt really isolated because of the fact that I couldn’t bring it up to anybody, so it’s kind of like you’re alone, I guess” (int #3). Another worker noted “My whole, well, life sorted of changed at that moment. I had to take time off work and people didn’t know what was going on because I was just an emotional wreck” (int #4).

One worker who had professional and direct personal experience with cancer highlighted the impact of cancer on family relationships: “Cancer can and does have an impact on relationships, even close relationships are put at risk and under pressure” (int #1).

Another issue which impacted on families and their social and emotional wellbeing was travel for treatment: “It breaks people you know, we are having to deal with a lot of other people that want to be there for them or with them, especially family that want to be there with them in person but can’t afford it” (int #2).

The need for culturally safe and appropriate support

AHWs noted that there is a need for local, culturally appropriate and culturally safe support groups.

I know now that there is a carers’ group that happens around at the local health service I think once a week but that’s for carers of just general stuff, like someone that is having to look after nana 24/7 but it’s just more about somewhere to go for some time out for a few hours, I think it goes for like 2 hours. It’s also not Indigenous safe, more mainstream. Realistically we have enough trouble to get our own mob to open up so I don’t think they would in that situation you know what I mean. Being in a room with us they may talk about what the daily stresses might be or what’s going on (int #3).

Such groups might also reduce some of the load of AHWs in relation to their work with people with cancer: “it would have been great to have that extra support out there ... so we could concentrate on the stuff we needed to do (int #5).

Travel - cost and emotion

Several AHWs noted that the need to travel for treatment could cause financial and emotional issues. Travel for treatment sometimes involved big distances and potentially long periods of time away from country and family.

I couldn’t stay close to home, hundreds of kilometres of travel, away for up to six weeks... time away from family and community became a big burden, finances became hard, had a big impact on family and me. It all had a huge impact. Separation from family, country, was all an issue (int #3).



Some AHWs thought that more place-based services could have a positive impact on clients and their families. While there was some recognition that when traveling to Melbourne efforts might be made by Melbourne health services to provide support, this is not comparable with support that can be provided locally: "...so even some of the support they do get in Melbourne provided by community is not the same as it would be from their own mob" (int #5).

Reflections on interactions with mainstream services

There was recognition that mainstream services appear to be getting better at asking questions to determine Aboriginal and/or Torres Strait Islander identity. Yet AHWs bring a cultural understanding that is often missing in mainstream services, and people from a non-Indigenous background may miss the cultural context of what is taking place. One AHW explained: "It's also hard when you have others getting involved sometimes you spend a lot of time trying to calm things down, mainstream don't always understand what's going on" (int #2).

It was also noted that mainstream services seem to focus more on the individuals, this is in contrast with AHWs perception that AHWs and ACCOs, which will consider the family alongside the client:

If it's in the normal mainstream service, then they would tend to concentrate on client, whereas at our services they are more holistic so [we] look at impacts on family members etc (int #3).

Several AHWs noted the need for better communication between ACCOs and mainstream services so that AHWs know when their clients have been admitted or discharged, so they can better support them when they are back in the community.

There is really no communication between them and us to say if someone has been admitted, discharged or whatever... they have a whole list of people Indigenous people that have been at the hospital, so why can't they give the health service a call and say hey so and so has been admitted or discharged so we can then follow up and make sure they are ok and understand what's what, especially if they have been given new meds etc. and aren't sure of what to take and when. It really frustrates us when we have to sort out yet another thing. When they are getting discharged from the hospital like that the hospital is sending them out with like a big bag of medications like literally boxes of them (int #2).

There is opportunity to improve this system of discharge, linking patients with the wider health team: "I think there is sometimes an issue with the social support or the Aboriginal Liaison



Officer at the hospital when they are discharged... It's often pure luck that we catch up with them, straight after discharge as we are not informed that they are being discharged" (int #5).

For example, there is opportunity for the major hospital in the region, Bendigo Health, to better understand that its regionality means that it should work effectively with the multiple Aboriginal communities within its catchment, not just with BDAC, which is the local ACCO within the same regional city:

It seems that the AHLO's [Aboriginal Hospital Liaison Officer] role is to make contact with Aboriginal patients and family and provide support while they are inpatients. I think now we get a lot from Echuca, Swan Hill and Kerang for dialysis and with the cancer clinic it's going to be a lot more, so I think the job for the AHLO is going to get a lot bigger. Even for our own members, it would be good if an AHLO let us know that members are being discharged (int #5).

Additionally, there has been confusion around the role of AHLOs at Bendigo Health, particularly around whether AHLO roles are patient or system focused (i.e. are AHLOs there to support the patients visiting the health service, or is their main role to improve the way in which Bendigo Health works with Aboriginal people?).

Another issue raised by AHWs was the importance for AHLOs to be in an accessible and prominent location within a health service. For example, at Mildura Base Hospital "there are three [AHLOs] up there, two males and one female, and they are good but you don't see them as much anymore as they have moved from the main hospital to across the driveway to another building" (int #2).

The important role that frontline and front desk staff play in welcoming Aboriginal people to mainstream services was also highlighted:

The staff are pretty rude at the hospital, you walk in there and they just sort of look at you, its like they would rather just look at you than walk over and see what's going on or offer assistance. It is really the frontline staff - yeah I know everyone gets busy but that first point of contact can make a huge difference to how patients feel (int #4).

Medications

The management of medication at discharge from treatment was raised as an issue in a number of instances. AHWs felt that their clients were often discharged without having a good understanding of medications they had been given.

I would think that a medication review would be sent from the hospital to the clinic or the service. It should be on their discharge papers you know these are the medications



they are on now, what has been changed so their GP will be aware but then there is the possible long time frame between when they leave hospital and see their GP. It looks to some of them that the new meds they are given need to be taken as well as what they were on prior to going in for treatment.... a patient [was] sent home and they were given a list of what to take and when, but they couldn't read that well and it was just lucky that I was going to visit them in hospital and found out that they had been discharged, so I went to their home and they had said 'Oh I have got all of this to take. What do I do?' and it was like 'Well lets go and get a Webster pack today' and it was not an issue. So, that level of support from discharge is pretty important. They [the hospital] don't tend to contact us, so maybe even encouraging the patient to get them to contact us or even they contact us and let us know when they are being discharged so we can put things in place so they can have help around that sort of stuff. When they plan the discharge, it appears they don't talk to them about what they are taking, why they are taking it, and do you need support. (int #5).

Another issue identified was that pain management medications may be at risk of being taken by other members of a family, and not being available to the client that needs them:

I think one of the hardest things now is medication, it's a big issue. You know you get a client that's near end stage or at end stage and they are given a drug to manage pain but the drug goes missing or they don't work well enough. I found with my auntie that some of the kids took her drugs and sold them. Some people swap their drugs for illegal drugs which appear to be more effective sometimes, especially if they have been long term users of illegal drugs and stuff (int #2).

AHWs raised other issues around medication management which linked with communication issues between doctors and clients. For example, "Sometimes you get a patient come in after they have seen the doc or a specialist and they ask hey umm what's this medication for? What's it do?" (int #4). In another instance an AHW highlighted confusion around different brands of the same medication: "She had two types of medications and was taking both, they were the same medication just one was a like a trade name and she was taking both thinking they were different (int #3).

Communication

Along with issues around medication and communication, other communications issues were identified. Some of these issues related to medical language and clients' difficulties in understanding what they are being told, such as the "jargon and medical lingo (int #2)". In health services, generally, a deficit approach is often taken to communication issues,



positioning communication issues as predominantly issues of patient health literacy (i.e. framing the patient and their lack of literacy as the *problem* that requires *fixing*), yet one of the AHWs interviewed noted the importance of shifting the perspective and responsibility to how the health service can address communication issues: “It would be good if they could be trained to talk, umm, how to talk to our mob, like how to break things down so we understand what they’re talking about” (int#2)”.

Other concerns around communication related to the emotional state of people dealing with cancer – that when people are very emotional they cannot readily take in all the information they receive.

One AHW highlighted that traditionally Aboriginal clients have not been good at asking doctors questions: “For a lot of us we go see the Doc, get our meds then we just go away, because that’s how it been in the past, it’s been passed down through generations. We don’t ask questions and so we don’t get told stuff” (int #3). Another AHW noted the same issue “It’s just not normal for them to ask the questions and they believe the Doc should not be questioned” (int #5). Supporting clients in this communication with their medical team can be part of an AHW’s role: “I suppose it’s part of our job to educate our mob that it’s okay to ask questions of the doc. It’s about trust with them to like and confidence like in the Doc and the service, and the staff” (int #3). Issues of general literacy, along with the use of medical terminology can also have an impact: “some are illiterate, they can’t read properly, given they never went to school properly. That’s the illiterate side of it, not understanding the big medical terminology words, what does this mean, you know” (int #7).

Cancer as a killer and shame

Throughout the interviews there were strong themes that positioned cancer as a killer, and cancer as something that people were ashamed of and embarrassed about.

The AHWs perceived that clients thought of cancer as a killer and that clients believed that to receive a diagnosis in most cases would result in death. For example, “Up here as soon as they hear it, anything about cancer their perception is death, they don’t want to know, they just think its imminent” (int #4). Another noted “when you are an adult and you hear cancer and you think well that’s it, like I said it’s over” (int #3). This perception that all cancer results in death was also very strong for a few of the AHWs. One noted: “I know cancer is a very, very, big killer” (int #7). This fear of death caused by cancer also meant that another AHW avoided preventative checks: “I don’t go to the doctor, because of my fear of cancer” (int #6).

Cancer is not something easily spoken about by individuals or the community, “clients tend to want to keep everything private and don’t necessarily talk to family or others about their



cancer” (int # 1). AHWs perceived that cancer is seen by some community members as shameful and that it should be hidden and not spoken of: “for some it is embarrassing, like it’s their fault they have got it” (int #4). Although this theme was nuanced, as there was an interplay with social interaction and social isolation. If people felt that others would be scared of their cancer diagnosis then they may have been less likely to talk about it.

like I said before the word cancer is like it’s a scary thing especially for our mob like, when I found out, especially when family started to find out, a lot of them didn’t come near me. Just by the simple fact it scared them, that word scared them that much, you know what I mean (int #3).

This reticence to speak about cancer links with some of the social and emotional wellbeing issues identified, in particular social isolation.

Prevention

There was general recognition and understanding among the AHWs about the importance of prevention, although they still perceived there was a need for further community education.

“I think there is still a lot of people out there who aren’t aware of all of these new procedures and stuff that are in place, all these new treatments and things that are ways of trying to catch cancer I think a bit more education around this would certainly help in that area” (int #4).

Bowel cancer screening kits were also noted as an area where further education is needed:

“Often when we are talking to them we might ask the question did you get one of them cancer screening kits in the mail, Oh yeah, they will say ‘No I threw it out’. It’s about educating them why you shouldn’t throw it out” (int #5).

The influence of gender on screening and early detection was raised: “Yep the ladies are really good at this sort of thing and will go to the Docs more often, I go every six months for a check-up.... but the blokes have a really different view, we are bullet proof, I only go to the docs if I am crook (int #3). The gender of workers is also important. At one ACCO the benefit of having both male and female AHWs available to support screening was highlighted: “Men’s and Women’s business is not so bad now, as he does the men’s health check’s and I do the women’s ones, as otherwise it’s really hard asking them sort of questions” (int #2).

AHW training and support needs

Several AHWs highlighted their gaps in knowledge when working with cancer patients, and felt that they needed more training about cancer to help them better perform in their roles and to



support clients with cancer, as well as have a better understanding of the local service system. One AHW noted “At one stage I think I had four people that didn’t have long to live and I didn’t have no training to help me deal with it” (int #2). Another explained: “I have been in this role for over 12 months I don’t know a lot of this stuff. I think we need to be aware of what the services are out there, locally within the state and maybe even nationally for some of them. For some its radiation and chemotherapy in Melbourne, for others it’s all done here or it’s just chemotherapy or radiation done here” (int#5).

More specific examples about training needs included a desire for more advanced training in areas such as chronic care, integrated care, and medical terminology and how to translate this terminology for lay people. This desire to know more may be linked with their perception of their role as educators: “we’re educators for our community. We are the leaders; we are the role models for them” (int #7).

There was also a desire for AHWs to be able to come together to share their learnings and ways of working regarding cancer:

“it would be really good to have the opportunity to catch up with other Aboriginal Health Workers and Outreach workers and talk about what we do and how we do it, also to find out how they do stuff as well, even if it was only from Victoria or our local region. We don’t even really get the chance to catch up with AHWs from other services” (int #2).



Discussion and recommendations

The findings in this project highlight consistencies with previous research with other Aboriginal communities in diverse settings across Australia, and also identify the opportunity and need for changes within the Loddon Mallee region.

Diverse work and personal impacts

In this project, it was clear that AHWs play important role and diverse roles in supporting community members who have cancer. The AHW role comes with high community expectations, with AHWs seen to be responsible for fulfilling many roles and being “everything to everyone” (Mitchell and Hussey 2006 p.529, Topp, Edelman et al. 2018). Community members may want to talk with their AHW about issues outside of the AHW’s work hours. Additionally, being in, and of, the community they are servicing means that AHWs may have personal relationships with the clients they are supporting. This can be tiring and have an emotional impact (Mitchell and Hussey 2006). This was apparent in the expectation that AHWs and the community see them as being readily and constantly available to support the needs of their community. While this is commendable service provision it comes with a significant burden – AHWs in this project noted that they experience social and emotional issues from their work with cancer clients. We found that AHWs are currently accessing social and emotional support through their own informal networks, and may be aware of organisational employee support programs, but there is opportunity to consider whether more culturally, and practice, appropriate support mechanisms can be put in place or accessed. ***It may be useful to establish a peer support network for AHWs – this could be a general peer support network, but one of the functions and benefits would be to allow AHWs in the Loddon Mallee region to come together to yarn and share their learnings, experiences and knowledge of cancer.***

The concept of a peer network is consistent with recommendations from the Victorian Government’s evaluation of Koolin Balit, which recommended that there should be opportunities for greater coordination and sharing of good practice, including a need for more connection within some local areas (Department of Health & Human Services 2017).

Community experiences and understandings

The financial, emotional and cultural (time away from country and mob) costs of travelling for treatment are consistent with research from Western Australia, where Aboriginal patients travelling to Perth also found that travel for cancer treatment caused financial and emotional stress (Shahid, Finn et al. 2011).



There may be opportunity to consider if any services can be delivered more locally (i.e. leverage existing telehealth infrastructure).

There may be opportunity to make better use 'Integrated Team Care' teams where they exist within the region.¹

Our findings indicate that cancer is still very much perceived as a killer and shameful; this suggests there is still a need for more community-focused work that can highlight that people do survive cancer, as well as the importance of prevention and screening. It is important to note that Cancer Council Victoria is actively working in this space, offering Aboriginal Health Workers training on cancer screening, as well as cancer screening awareness sessions for community.

There may be opportunity for Cancer Council Victoria to develop further training to support AHWs in their work with cancer clients and survivors.

Some of the other social emotional issues identified in the interviews may be further explored in work being undertaken in the region as part of the Murray PHN led, and DHHS (VIC) funded, cancer survivorship project. The Murray PHN project includes working with MDAS to ensure their cancer patients have chronic disease care plans. As part of this project Murray PHN will then aggregate data from deidentified care plans to determine the most common referral pathways and psychosocial needs. This Murray PHN project will build upon the social and emotional issues identified in this project.

From the interviews within this project there were examples of survivorship and resilience. Other research which has investigated what supports positive experiences for Aboriginal people with cancer and found examples of people drawing on spirituality and faith and strength from past experiences, actively addressing cancer treatment and disease side effects, focusing on helping others; and, finding purpose and meaning in their life and their future (Tam, Garvey et al. 2018). There is opportunity within the region to leverage the survivorship stories, to help shift community understandings of cancer so that it is not seen simply as a 'killer', and that there are examples of Aboriginal survivorship to be celebrated. As part of Murray PHN led cancer survivorship project, a communication plan is currently being

¹ ITC is a Federal government initiative, with ITC services commissioned through Primary Health Networks (PHNs) across Australia. The aims of the ITC Program are to:

- contribute to improving health outcomes for Aboriginal and Torres Strait Islander people with chronic health conditions through access to care coordination, multidisciplinary care, and support for self-management; and
- improve access to culturally appropriate mainstream primary care services (including but not limited to general practice, allied health and specialists) for Aboriginal and Torres Strait Islander people.



developed with the project community working group. There may be opportunity to consider how Aboriginal survivorship stories could be linked with this communication plan.

Dissemination of survivorship stories from local communities may help improve community perceptions of cancer and potentially increase screening rates.

Storytelling through theatre can be an effective way to share messages about health issues. For example, Ilbjerri Theatre Company is currently touring 'Virus', which is the third instalment in Ilbjerri's trilogy about hepatitis C, a series aimed at breaking down the shame around hepatitis C and promoting healing for Aboriginal people living with hepatitis C.

At a state-wide level, there may be opportunity to commission Ilbjerri to develop a performance that addresses the cancer journey, including cancer survivorship, to change the discourse around cancer diagnosis in Aboriginal communities.

The finding that AHWs perceive there is a need for culturally appropriate support groups for Aboriginal cancer patients and their carers is consistent with the Loddon Mallee Region Cancer Services Plan, that stated that support groups should be responsive to culture needs, along with gender, age and cancer types (Health Consult 2017), and with recent research from Queensland (Meiklejohn, Arley et al. 2018).

There is opportunity for local, regional and state services to consider how culturally appropriate support might be provided for Aboriginal patients and carers.

Mainstream health services

The finding that AHWs perceive that their clients need a more inclusive and holistic service provision that includes family is similar to experiences of Aboriginal people using a mainstream service in Melbourne, who felt their experience and health were better if their family were welcome, and if staff engaged with their family (Wotherspoon and Williams 2018). Yet efforts within mainstream services to make such services more culturally inclusive and safe can involve internal power struggles around prioritising cultural safety and inclusion (Malatzky, Nixon et al. 2018), these issues should be considered and addressed when mainstream services try to make these changes.

Our findings also highlight the vital cultural broker role that AHWs play in supporting their clients in accessing and navigating mainstream health services. While the AHWs in this region do provide a 'navigation' role, Aboriginal cancer survivors have also identified the need for specific cancer patient navigators (Meiklejohn, Arley et al. 2018) to assist in navigating mainstream services. The concept of Aboriginal cancer patient navigators is also supported by other research which highlights the need of dedicated and focused care coordination to enable



Aboriginal people to receive adequate and appropriate patient-centred care (Reilly, Micklem et al. 2018). Peter MacCallum Cancer Centre is currently considering introducing patient navigators for Aboriginal clients; if this goes ahead there will be opportunity for other cancer services to learn from Peter MacCallum Cancer Centre experience of implementing patient navigators.

Consider if there is an opportunity for Aboriginal cancer patient navigator(s) in the Loddon Mallee region.

Our, and other research, findings highlight the need for moving beyond a predominantly individual and biomedical focus when working with Aboriginal patients. Arguably, enough is known about Aboriginal perspectives of health and wellbeing for oncology and other service providers to broaden their focus beyond biomedical care to support the practical, psychosocial and family needs of Aboriginal patients (Shahid, Finn et al. 2011).

There is a continuing need for mainstream services to better support Aboriginal family structures and cultural needs.

The issues identified relating to medications and discharge indicate there is a need to better link mainstream health services with ACCOs to improve the care of Aboriginal people with cancer.

Future projects could specifically investigate improving linkages between mainstream cancer services and ACCOs, particularly around admission and discharge, as well as how to improve medication management at discharge.

Additionally, given the size of Bendigo Health's catchment, as the major regional health service in the Loddon Mallee, consideration should be given to the number and gender of AHLOs employed by Bendigo Health. It appears, that compared to other regional health services, Bendigo Health employs a smaller number of AHLOs for the population it services. Also, messages to ACCOs around the role of the AHLOs have been confusing, with Bendigo Health at times indicating that these roles are systems focussed, which is in contrast with details promoted publicly through the Bendigo Health website² which highlight that the AHLOs' work is patient focused.

Review the number and gender of AHLOs employed by Bendigo Health, and compare with other regional health services.

² http://www.bendigohealth.org.au/Patient_Families_Services_Detail.asp?FAQID=1



Communication

Several communication issues were identified by the AHWs in this project, including the use of 'medical lingo' and Aboriginal patients being uncomfortable asking questions of doctors. Yet, Aboriginal people value dialogue and 'talk' within their healthcare communication, as it is critical for the experiences of care (Jennings, Bond et al. 2018). But talk can be positive or negative. Bad communication and talk can "reinforce powerlessness, through judgmental down-talk, medical jargon or withholding of talk" versus good communication can "empower clients with good, caring talk, delivered on the client's level" (Jennings, Bond et al. 2018 p.114). The use of medical jargon as discussed by our participants may be disempowering Aboriginal cancer patients.

There is opportunity for cancer services to consider how they can reduce this jargon and to be aware of, and address, power imbalances during interactions, as well as encourage Aboriginal patients to feel safe and confident in asking questions.

In addressing communication issues, AHWs have an important role acting as translators and advocates for their cancer clients. Our findings suggest there is still much opportunity to improve how doctors and mainstream health services communicate with their cancer patients and families. Cancer Council South Australia have developed and evaluated a *Cancer Healing Messages*³ flipchart and patient flyer to assist health professionals to explain cancer and the cancer journey to Aboriginal cancer patients and families. The evaluation found the resources to be useful and appropriate, but that effective use needs to be supported by a long-term implementation plan that includes training and education and promotion (Bierbaum, Plueckhahn et al. 2017).

There may be opportunity for a similar tool to be developed for a Victorian context.

Other project outputs

The project raised the profile of cancer within LMARG ACCOs. The connection this project provided LMARG and LMICS offered a conduit for LMARG to provide input into the 2017 Loddon Mallee Region Cancer Services Plan. The 'Health Consult' consultant developing the plan attended the December 2016 LMARG meeting to seek insights and feedback from the LMARG CEOs and other LMARG delegates in attendance.

³ <https://www.cancersa.org.au/assets/images/ATSI/Cancer%20Healing%20Messages%20flipchart%20English.pdf>



Additionally, learnings from the Let's Yarn About Cancer interviews were used to inform the LMARG submission to the *Optimal Care Pathways for Aboriginal and Torres Strait islander people with cancer*.

LMARG has also partnered with Monash University on an application to the Victorian Cancer Agency 2018 Improving Cancer Outcomes Collaborative Research Grants (the outcome of this grant application is currently unknown).

Strengths, limitations and challenges

A key strength of this project was that all ACCOs in the Loddon Mallee region participated in the project. This was achieved through ongoing communication and perseverance, as some sites required several visits to facilitate the interviews.

A limitation was that the project was only funded for one year for 0.5 FTE worker. This presented difficulties in terms of providing time for relationships to establish and limited opportunity to engage in deeper dialogue. It also resulted in the project officer leaving prior to project completion to seek other employment, which resulted in the project taking longer to complete than anticipated as another worker needed to complete the project. These negative outcomes of short-term funding in Aboriginal health programs have also been recognised in the Victorian Government's evaluations of the Koolin Balit strategy, which found that short-term, project-based funding can be detrimental to program continuity and community development (Department of Health & Human Services 2017). It is recommended that if LMICS continues to work with LMARG, or individuals ACCOs, on projects, that any such projects are funded for more than a year at a time. Ideally funding would be for a three-year period.

Conclusion

Considering the important roles of ACCOs, and AHWs within them, developing a project with ACCOs and AHWs as the key contributors and participants has allowed culturally and practice-informed understandings of cancer to form the basis of outcomes, findings and recommendations within this report.

This project has raised the profile of cancer as an issue among LMARG ACCOs and LMARG itself, and has resulted in several other cancer-specific activities being undertaken by LMARG.

There is opportunity for future collaboration between LMARG and LMICS, although any collaboration would benefit from a project of longer duration. This report will be shared with the project steering group members and other key stakeholders to progress discussions and potential projects around the issues and opportunities identified herein.



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