Diabetic retinopathy screening for Indigenous Australians in the Kimberley

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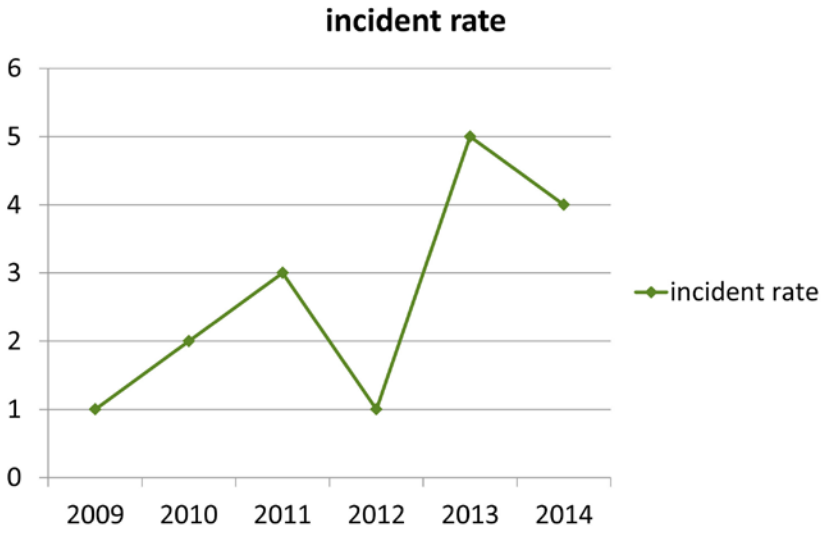
Description of the retinal camera screening program

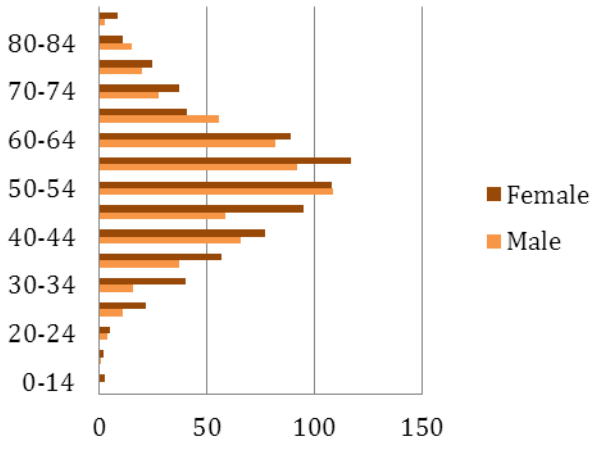
The Kimberley diabetic retinal screening program has been operating for over 20 years and during this time has experienced the peaks and troughs of success as is common when operating a program over a large land mass in an isolated area, with a mobile population ([1]). The retinal screening program has provided the Kimberley people with a screening service for the detection of diabetic eye disease. The means to detect diabetic retinopathy (DR) – a sight threatening condition with vision loss often occurring late - would otherwise be unavailable in many remote sites due to limited visits from ophthalmology and optometry services. The availability of such services is often hindered due to the logistical challenges of distance and seasonal conditions. During the 20 + years of operation, the incidence of type 2 diabetes has notably increased, with growing concern at the significant proportion of young adolescents presenting with the disease (Figure 1). (1 & 2, 5)

Figure 1 Incidence of type 2 diabetes in children aged <17 years in Kimberley Region, 2009 to 2014



Western Australia Children's Diabetes Database (WACDD)
(M. Shah 2015)

Figure 2 Age and gender distribution for patients in the retinal screening program, 2010 to 2014



There are multiple communities and six townships scattered throughout the Kimberley region. Distance and remoteness can cause difficulties in providing regular screening for the detection of diabetic eye disease. Improvements in delivery of diabetic eye health screening with the use of digital retinal cameras and ongoing training of operators has provided diabetic clients with a better delivery of regular eye health screening. There are 12 sites over the Kimberley region where cameras are situated. The qualifications of the camera operators range from reception staff, a bus driver, nurses and Aboriginal Health Workers (AHWs). Operators are trained in taking photos, performing visual acuities and giving basic diabetic eye health education to the client. The Eye Health Coordinator (EHC) provides additional screening with a small portable Canon camera for areas where no local camera is available or there is a lack of an operator. The retinal screening service has led to improved access to ophthalmology services and better eye health outcomes due to the close working relationship between the ophthalmology team based at Lions Eye Institute who read and grade the retinal photos sent from the region.

Within ten days, the findings are reported and sent back to the operator to follow up on recommendations, providing continuity of care and decreasing the impact of remoteness on isolated clients. When a patient develops DR, which is detected on screening, they are referred on for ophthalmology review.

This is done at the earliest opportunity at an appropriate location, usually a larger regional centre in the Kimberley. The time from detection to referral is based on the severity of DR detected in retinal photographs and subsequent ophthalmologist recommendation.

Education is provided to the operators and clients on a face-to-face basis by the EHC and the visiting ophthalmology and optometry teams. An annual Retinal Camera Operator Conference is held in Broome to provide further training and up-skilling opportunities for operators to assist them with educating their clients. During this conference, the operators are able to network with peers and discuss issues with ophthalmologists and optometrists. Awareness of this silent complication of diabetes and the need for regular eye health screening is promoted in community clinics. Should children present with a parent, the opportunity to educate the next generation is encouraged.

Retinal photography in Looma community

Strength and barriers of the program

To ensure the ongoing sustainability of the retinal screening program, issues regarding the provision of training and coordination of the program must be addressed.

The role of the EHC in training and supporting operators is imperative to the sustainability of the program. With the availability of statistical data, the EHC can identify sites where operators require up-skilling and support to provide a screening clinic.

Figure 3 Number and quality of retinal screening episodes in the Kimberley Region per month, 2012 to 2015

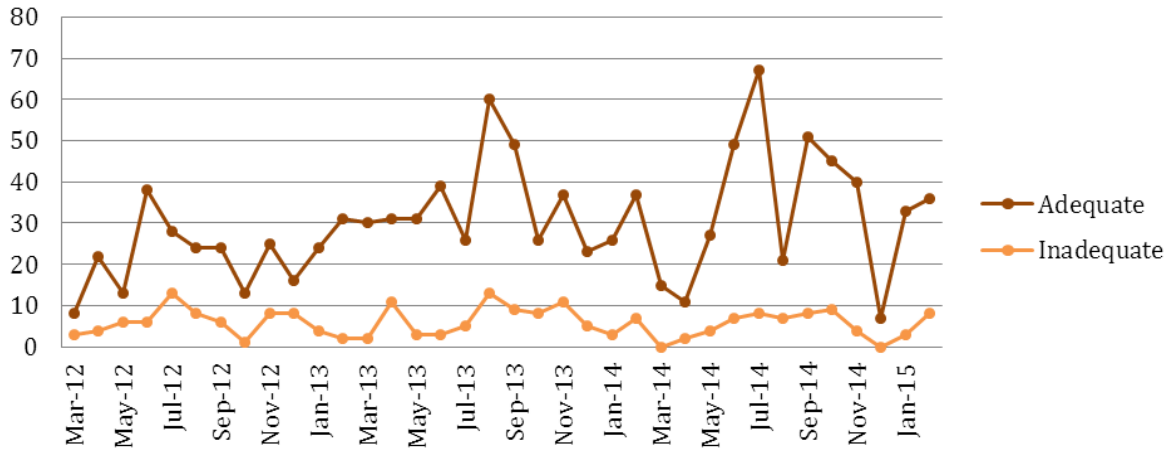


Figure 4 Percentage of screening episodes where visual acuity was recorded, 2010 to 2015

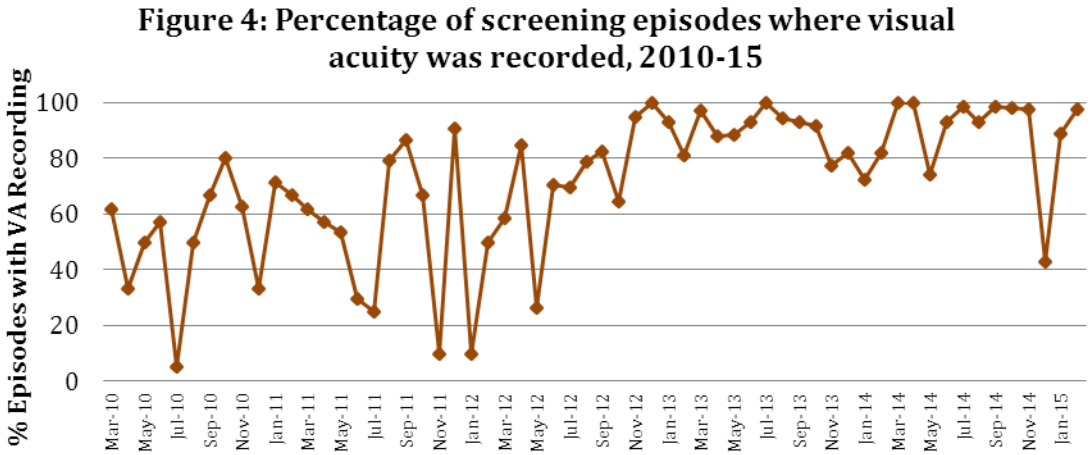


Figure 5 Follow up recommendations based on retinal screening episodes for Indigenous Australian patients, 2010 to 2014

	% Indigenous patients
Repeat photos in < 12 months	4.35
Repeat photos in 12 months	55.1
Repeat photos in 2 years	0.73
Optometry	10.3
Ophthamology	29.3
Discharge	0.09

This data depicts numbers screened at each site, quality of photo's, visual acuities performed and outcomes (Figures 3-5)

Although the presence of an EHC for the region is essential to the day to day running of the program and its sustainability, it is essential that the program not become centralised at a single centre. The sustained training and education of operators within different sites ensures that the ownership of the program is given to the community to provide diabetic eye health screening in their site. The Kimberley population is in continual movement as people travel between communities and towns to visit family. Health personnel also move into and out of the region on a regular basis. This makes the provision of continuity of care very difficult. [3]

To gain trust and rapport within the community and its people takes time. It is essential that non-Indigenous staff members undergo a cultural awareness orientation to assist with their understanding of the needs of their clients. The presence and role of Aboriginal Health Workers as camera operators in their community assists in gaining a client's trust and interest to participate. The Aboriginal Health Worker can advise other health personnel of cultural requirements, advise health services when clients have travelled to or from the community and provide information to health professionals on the best approach to interact with their clients.

10 – 18yr old adolescents developing diabetes can often go undiagnosed for years unless they present for acute care that requires screening blood tests, or in routine screening needs for pregnancy.[3,4] As type 2 diabetes is silent, a young person gaining or losing weight can be seen as normal in the community [3]. The added complication of diabetic eye disease being silent also leads to the potential of some severity of diabetic eye disease by the time the young person is diagnosed. In the Kimberley over the past 3 years, the diabetic retinal camera operators and remote area nurses have been encouraged to identify those at risk due to their large weight gains and family history [5]. Gestational diabetes is also on the increase and the subsequent increased risk of the foetus developing diabetes in adolescence contributes to a situation of ever increasing numbers of adolescents with diabetes, further exacerbating the potential risk of developing diabetic eye disease.[3,4]

Aboriginal Health Workers often take on the role of confident, educator and identifier of possible adolescent diabetics in their community. The diagnosis of diabetes in a young Indigenous person can lead to shame and noncompliance due to the natural desire to be a part of their peer group [3]. The support, encouragement and open dialogue of health professionals, with advice from Aboriginal Health Workers, can go a long way in assisting an adolescent to take control of their diabetes [5].

Accurate statistical data remains a problem when identifying numbers of diagnosed adolescent diabetics within the Kimberley and regional centres as communication between stakeholders can be sub-optimal. There also remains a lack of awareness of the need to increase focus on the screening of possible diabetic adolescents due to family history or obesity [3,4]. When adolescents and young adults are first diagnosed they may not be entered into the Diabetic Register and follow-up care may be limited. Information often remains anecdotal, provided by clinic staff or other health professionals visiting communities. Young men are often overlooked for diabetic screening as they do not present to clinic unless it is for an acute health episode. Men's clinics at community centres provide screening in a culturally appropriate setting where men are more likely to attend for routine screening and discussions with their peers.

Unfortunately when specialists visit, the young person is often not in community or does not present for review as a lack of debilitating symptoms can create a feeling of normality and well health[3]. Cultural requirements or the perceived importance of another task may also lead to non-attendance at appointments. This leads to delayed diagnosis, delayed screening and increased risk of eye health complications.

Over servicing by health professionals can cause reluctance from the client to present for routine screening. Many Indigenous diabetic clients have other comorbidities and endure a continual stream of testing, education and interaction.

Many find this invasive and decline further interaction. A long time period from diabetes onset increases the risk of undetected DR until the full impact of the complication has caused some degree of blindness. Working as a team with other health providers can lessen the degree of overwhelming health interaction and provide for the client a holistic approach which is more successful then multiple interactions.

The increase of cameras, especially in isolated communities, has made the issue of reaching sites and remoteness a lot easier. If there is not an operator at the site, the EHC is able to fly out to the community on a doctor flight and provide a screening service. This was not achievable when large cameras were used as space and weight is an issue in light aircraft and seasonal rains did not allow for transportation by road. The wet season can make capturing and screening of clients in some communities easier as people are not able to travel and more likely to attend the clinic.

Recommendations

There is a need for a strong focus on the 10 – 18yr old health checks with young people who have a family history of diabetes, large weight gain especially in a low birth weight baby or a baby of a gestational diabetic mother to detect possible diabetes early. [3,4,5]

There needs to be encouragement for the training of Aboriginal Health Workers who are able to educate and communicate with their community members for the need of healthy life style changes and the regular screening for the diabetic client.[5]

Increased communication between stake holders into the care of diabetic person especially the adolescent, will provide the client with continuity of care and decrease the risk of the client not being entered in the Diabetes Register, and not being provided with the health care they require.

Summary

As diabetes numbers increase within the Kimberley and the age of the diabetic client becomes younger, the diabetic retinal screening program becomes ever increasingly important. The program can bridge the gap of isolation and lack of regular diabetic eye screening, providing early detection of diabetic eye disease so intervention is not as severe and outcomes are improved to prevent blindness associated with diabetic eye disease.

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Presenter

Shelley Walters is the Kimberley Eye Health Coordinator based in Broome and is employed by Kimberley Aboriginal Medical Service. She has a nursing career spanning 37 years, starting as an Enrolled nurse before converting to Registered Nursing through Notre Dame University. Of the 37 years in nursing, 36 years has been the Kimberley Region of West Australia covering the areas of Remote Nursing, Accident and Emergency, Coordinator of Specialist Services, Ophthalmology, Coordinated and trained Retinal Camera operators in Diabetic Retinal Screening program and is a trained Haemodialysis nurse. Her passion is Diabetes and Renal disease especially in the area of young adolescents and what the future holds for the next generation. She loves to travel to isolated uninhabited areas in other countries with a special interest in Cultural Anthropology and has travelled the High Artic through Nordic countries, Greenland, Canada, Alaska and Russia visiting isolated Indigenous communities, the next big adventure is Mongolia. As a mother of 3 daughters who have been raised in isolated areas of the Kimberley and being a part of the Indigenous culture, she has witnessed the discrepancy between Indigenous and Non Indigenous quality of health.