Sharing care the Kimberley way

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Introduction
The Kimberley Region of Western Australia (WA) covers a vast area 424,515 kms². This is twice the size of Victoria and three times the size of the United Kingdom (UK).¹

The Regional Resource Centre is based in Broome, distance to Derby is 220kms, , Fitzroy Crossing 396kms, Halls Creek 686kms, with Kununurra 1044kms and Wyndham 1055kms near to the Northern Territory border.

There are approximately 200 Aboriginal communities and pastoral leases across the Kimberley.² Most of these communities are remote and accessible only by airplane or four wheel drive vehicles. There are two distinct seasons in the Northern Region of Australia the Wet (October to April) and the Dry (May to September), many of these communities are inaccessible during the wet season.

Perth provides tertiary services for the Kimberley, and is situated 2400kms from Broome and approximately 3500kms from Kununurra.

The population of the Kimberley is estimated at approximately 47,000, 42% of whom are Aboriginal Australians.²

The majority of this population live in the West Kimberley primarily Broome. Five other towns across the Kimberley have a hospital and most have an Aboriginal Medical Service. Some remote communities have a clinic, 17 of which are managed by the Kimberley Aboriginal Medical Service Council (KAMSC) and 12 are managed by the WA Country Health Service (WACHS). Clinics may be staffed on a part time basis others will open daily. Remote Area Nurses (RAN) manage these clinics and provide an after hour’s emergency service. Doctors are rostered to attend these remote clinics from the nearest hospital. Emergency medical assistance and retrieval is provided by the Royal Flying Doctor Service (RFDS) in liaison with WACHS or KAMSC providing transfer to the nearest appropriate facility either within the region, Perth or Darwin NT.²

Background
Cancer Services for the Kimberley were instigated in 2006, following release of “The Clinical Services Framework” (2005)³ it was recognised that service provision for cancer care was lacking. This report highlighted the inequity of access to cancer care services and that there was fragmentation and lack of coordination for rural patients. It upheld that everybody within WA is entitled to the right treatment at the right time with the right team as close to home as possible.³

In 2006 the WA Cancer and Palliative Care Network (WACPCN) established positions for Cancer Nurse Coordinators in the seven WA rural areas, to coordinate and support patients locally.

Metropolitan Cancer Nurse Coordinator tumour specific positions were also established.⁴ This facilitated access, support and assistance with appropriate referral to Perth based services.

The Palliative Care Service established in 2003 consisted of a nurse based in Broome; regional palliative care provision defaulted to medical service providers, and nurses who had an interest in palliative care.

The 2005 Palliative Care in Western Australia report recommended improving regional care coordination and promoting links between specialist palliative care and rural palliative care services.⁵ In 2006 a model for rural palliative care was instigated resulting in Regional Palliative Nurse Coordinator positions established in 2007. The Rural Palliative Care Model in Western Australia was endorsed in 2008 (RPCM) by WACHS and the State Health Executive Forum.⁶
In 2009 a Regional Palliative Care Coordinator (RPCC) was appointed for the Kimberley. This position was supported by a Medical Palliative Care Consultant from Perth, using Telehealth video conferencing to link the region, the team developed to full capacity by 2011 with the addition of a Clinical Nurse (0.4FTE), a Social Worker (0.5FTE), an Administration Assistant (0.5FTE) and a full time Aboriginal Health Worker. The function of this team was to improve the coordination of care for patients who are diagnosed with life limiting disease, to ease their transition throughout the health care system, with the aim of keeping care as close to home as possible.

**Current situation**

Historically the Kimberley Cancer and Palliative Care services have been based in Broome.

The Rural Cancer Nurse Coordinator (RCNC) is based in Broome, a trial then commenced hosting the Palliative Care Coordinator in the East at Kununurra. This has been a positive move enhancing services in line with The Kimberley Cancer and Palliative Care Plan 2011-2015, which was published in 2011. Both services represent the state wide WA Cancer and Palliative Care Network which supports and mentors increasing personal, professional and strategic service development to maintain sustainable rural cancer and palliative care services.

The Kimberley Cancer and Palliative Care Team work in line with the WA Model of care for Cancer 2008 and the WA Rural Palliative Care Model 2008. These models require partnerships between rural and remote primary care and specialised services. The presence of the Palliative Care Coordinator in the East Kimberley enables promotion of the partnership between Cancer and Palliative Care and allows the services to be more accessible across the region.

Combined Cancer and Palliative Care “Road Shows” are taken through the Dampier Peninsula to One Arm Point in the north, through the central Kimberley to Fitzroy Crossing and Derby and to the east incorporating Halls Creek, Kununurra and Wyndham. These sessions are educational and instructional promoting both services, the individuality of each service, and demonstrating joint collaboration. Sessions are presented at clinics, communities, with GPs and nurses at each hospital. These trips also provide opportunities to visit clients and families personally.

Telehealth video conferencing with the RCNC, RPCC and the Broome team is held weekly to discuss clients, referrals, deaths and bereavement. These multidisciplinary sessions streamline the transition of care and provide clinical information about shared clients.

Each month through Medical Specialist Outreach Assistance Program (MSOAP) the Medical Palliative Care Consultant links in with the multidisciplinary team. Each hospital VC site can link in for consultation. These sessions provide a forum for education, inclusive of morbidity reviews facilitating evaluation of care.

The Coordinators of each service have daily contact to discuss clients, clarify referrals, plan education and promote the development of both services. In promoting Cancer and Palliative Care services recognition of boundaries are established to ensure appropriate referral and ongoing collaboration. This allows celebration of successes achieved in the provision of best care.

**Strong Commitment Bright Future**

The Kimberley Cancer and Palliative Care Coordinators have increased the profile of both services and improved care provision, through the regional educational road shows and establishing networks with GP’s and local health service providers.

This year the Kimberley has introduced the WA Liverpool Care Pathway (WA lcp) with Palliative Care Champions throughout the region. These “Champions” are the basis of improved end of life care which may begin with a referral from the RCNC.
We rely heavily on Telehealth, for communication, education, consultation and service development across the Kimberley. Broader utilisation of Telehealth between tertiary Oncology centres and the Kimberley would enhance services. This will lessen the financial and social burden on the patient, family, community and health service provider. The more remote areas will benefit as National Telehealth network facilities expand.

Over the next twelve months our aim is to develop an accessible, consistent, informative, topical and interactive Regional Telehealth Education Program. This will ensure that the whole region has opportunity to access contemporary information and education. This program will be delivered by both teams with topics and sessions planned and advertised inclusive of linking with Tertiary Centres for specialist sessions.

The challenges faced in service delivery in the Kimberley, can be met by approaches and attitudes that are positive, enthusiastic, achievable and practical.

Case study 1
C was a 47 year old Aboriginal woman from a remote community of approximately 450 people in the Kimberley; she had a caring husband and a large extended family including five children and grandchildren, with whom she lived. The community was established by a missionary order, now managed by a community committee. It has a health clinic managed by Remote Area Nurses (RAN). A Doctor travels by plane three times per fortnight to hold a clinic, the closest hospital is ten hours away by car on dirt roads.

C presented to the Clinic over some months, complaining of persistent epigastric, right upper abdominal pain and tenderness, vague right loin pain nausea and fatigue. C was treated for a urinary tract infection but the abdominal pain persisted increasing on her right side. She was admitted to the local hospital with possible gallstones. A CT at the Regional hospital indicated a large mass in the head of pancreas.

Three weeks later the case was discussed at an Upper Gastro-Intestinal Multidisciplinary Meeting in Perth involving the Surgical, Medical Oncology and Radiation Oncology teams. C’s tumour was deemed to be nonresectable; she was referred to Medical Oncology and Radiation Oncology for management. The Upper GI Cancer Nurse Coordinator in Perth referred C to the Kimberley RCNC who liaised with the clinic, the hospitals, and Patient Assisted Transport Scheme (PATS) for C and an escort to travel to Perth for further investigations and possible treatment.

Due to the possible stage and nature of her disease and remote location the RCNC discussed C with the Kimberley RPCC to facilitate transition between services in the future.

The RCNC was in the East Kimberley and able to connect with C and provide direction and support for her trip. Travel to Perth involves 3 separate flights taking a full day. As C had been to Perth before, the "Meet & Greet" option had been deemed unnecessary.

During her first two days in Perth C suffered increasing pain, she phoned her home community Clinic and the RCNC, before presenting to an Emergency Department. C was transferred across the city for her planned admission to her treating hospital. During this 22 day admission she had a biopsy under sedation confirming Ca Pancreas. A staging laparoscopy and intraoperative ultrasound found no evidence of peritoneal disease. An Endoscopic Retrograde Cholangiopancreatography (ERCP) highlighted a common bile duct stricture likely secondary to pancreatic cancer. A stent was inserted in the common bile duct. A second ERCP inserted a more permanent stent.

She was discharged home to her community with opioid analgesia and an outpatient treatment plan. After ten days C presented to the Clinic with increasing pain and her analgesia was increased.
A week later C returned to Perth for her outpatient appointments and presented again at an Emergency Department with pain where her medications were altered and she was discharged.

That same morning she was admitted to her treating hospital for pain management, she also attended prearranged Medical and Radiation Oncology appointments. A repeat CT showed a new finding of a liver mass. Her Medical Oncologist recommended Gemcitabine Chemotherapy as her best treatment option.9 10

While C was in Perth both the Metropolitan and the RCNC were exploring the feasibility of administering the Gemcitabine at her nearest hospital. The issues and logistics of providing the chemotherapy for C at this hospital were explored with input from local medical and nursing staff. Some challenges included weekly transfer of C, sourcing the drug from Perth, medical and clinical governance including safe administration.

C was to remain in Perth at an Aboriginal Hostel until her chemotherapy cycles were completed. She was discharged with opioid analgesia. Five days after her second treatment C was admitted to another hospital with sepsis, treated for a urinary tract infection. After 10 days C was transferred back to her treating hospital for further pain management and continuing treatment for her UTI. C continued to spike temperatures, blood cultures showed no bacterial growth, it was then thought that her temperatures could be due to tumour load. CT’s were reviewed, the pancreatic mass had enlarged and she had developed hepatic metastases despite 2 cycles of chemotherapy. Her Medical Oncologist decided that further treatment would not be beneficial. This was explained to C, she was lethargic, low in mood and commenced on corticosteroids.

A videoconference between the Metropolitan CNC and 10 family members in C’s home community was conducted to explain the prognosis. Retrospectively there was a large discrepancy in the community’s understanding of prognosis and expected outcomes in regard to C’s condition. This was not apparent to the CNC conducting the VC.

After the VC the Palliative/Oncology Unit in Perth phoned the Kimberley RPCC regarding discharge plans. There was limited understanding in Perth regarding the demographics both socially and geographically of C’s community, it’s remoteness and limited facilities for care of the terminally ill. A staged discharge involving transfer to the district hospital was initiated.

The RCNC clarified prognosis and disease progression to the clinic staff, explaining the transition to Palliative Care for symptom management and assistance in end of life issues.

RPCC contacted the Clinic to investigate the community’s willingness and ability to care for C. The RAN and clinic staff were willing to support C being home with family in her country. The community were keen to have C come home, a bed was sourced from the old Mission and the community agreed to purchase bedding. C and her carer were then transferred to the District Hospital in the Kimberley.

Arrangements were made for Cs husband and family to fly in to be with C. Clarification again was sought by the family on further possible treatment. The family felt that if she came home to her country she would get stronger and may be able to complete the chemotherapy and get better.

Whilst in the District Hospital C was stabilised on medications that could be administered in the remote community. Family wishes were sought, roles of carers defined and support from the community Clinic confirmed.

The Pharmacist, GPs, Clinic RAN and RPCC agreed on pain management strategies and care plans, appropriate medications for pain and symptom management were sent home with C. The clinic RAN agreed to home visits to administer and oversee medications. A syringe driver was to be delivered for use when necessary. Palliative Care and the hospital made it clear to the family and the clinic that should it all become too difficult or unmanageable then C could be transferred back to hospital.
C and husband made the arranged chartered flight to the Community, the rest of the family unfortunately missed the flight. A wheel chair was sent out the next day on the mail plane to enhance mobility, an air mattress was sent out later on a Drs Clinic Flight. Allied Health supplied equipment for her at home. The RAN identified a need for domestic assistance in the home, unfortunately this was not able to be provided.

RPCC provided support to the Clinic staff via phone and email, they were also provided with direct access to Doctors whom had agreed to be available for consultation and advice. The regular visiting Doctors agreed to support C being in the community.

For three weeks the family and RAN's cared for C in her home with many call outs. Ten days prior to death unnecessary medications were ceased. C continued on increasing doses of opioids and finally a syringe driver infusion was commenced to manage pain and anxiety. C died peacefully in her home with her husband and many relatives present.

**Case study 2**

M discovered a palpable left breast lump a year prior to presenting to her GP at the Aboriginal Medical Centre. An ultrasound showed a suspicious lesion, she was referred to the Breast Clinic at Royal Perth Hospital (RPH). A biopsy of the lump and fine needle aspirate of an axillary lymph node were taken.

On returning home she presented to her GP but expressed that she didn’t want to know the results, she was upset and angry when told that she did have cancer and would require treatment in Perth.

Social: - 52 year old Aboriginal woman living with her niece in Kununurra.

Two children – a son deceased and a daughter who lives in Broome with her partner and four children.

Medical:-smoking, excessive alcohol use, diabetes, ischaemic heart disease and hypertension.

M had a left wide local excision and axillary node clearance. Her pathology showed a 19mm grade 2 infiltrating ductal carcinoma, ER PR and Her2 positive, it was completely excised. Recovery was complicated by a wound site haematoma requiring further exploration and drain insertion. She was discharged with the drain and cared for by Hospital in the Home (HITH).

Full staging was completed, whole body CT, & bone scan found no evidence of metastatic spread. The Breast Multidisciplinary team meeting discussed best treatment and management options.

M had a positive prognosis of treatable early breast cancer. Following recovery from surgery she was prescribed treatment of six cycles Carboplatin/docetaxol chemotherapy in combination with 12 months of Trastuzumab (Herceptin). This is the most optimum treatment for early breast cancer in Her2 positive women hopefully reducing risk of recurrence. M would also require hormonal and radiotherapy, treatments and side effects were explained.

Following her first chemotherapy cycle M returned home. A week later she presented to Broome hospital neutropaenic with abdominal pain and diarrhoea. She was transferred to Perth with RFDS. The infection source was investigated- urine microscopy and stool culture clear. Bloods showed normal white cell count and anaemia, supplements were commenced. Her antihypertensive medication was increased, Loperamide controlled her diarrhoea and she was treated with intravenous (IV) antibiotics. M was discharged with oral antibiotics.

She remained in a Perth Aboriginal hostel with a brief trip home between her next two cycles and Medical Oncology reviews. She also attended Radiation Oncology consultation to discuss Radiotherapy post chemotherapy.

Prior to her next cycle M presented to RPH Emergency Department with a 4 day history of dysuria, confusion, abdominal pain and hypokalaemia. She was commenced on antibiotics. M's abdominal pain
resolved following aperients and subsequent bowel motion. She was discharged with aperients and potassium supplements.

Following her next cycle M returned to Broome staying with her niece. M was admitted to Broome hospital early April with generalised pain and lower leg oedema. Due to her recent chemotherapy she was treated as febrile neutropaenic, IV antibiotics were commenced. Pathology showed an elevated white cell count, anaemia, low platelets and hypokalaemia. The treating Doctor discussed M with her Medical Oncology team and she was discharged with oral antibiotics, potassium and iron supplements. M represented four days later feeling generally unwell with some shortness of breath and productive cough. M had not taken her oral antibiotics.

The RCNC first met M during this admission. She was uncommunicative and difficult to engage, the RCNC role was explained and contact details given. She was discharged on oral antibiotics again.

M returned to Perth to continue her treatment, where she represented at RPH emergency department with generalised abdominal and lower limb pain, loose stools and a productive cough. She was febrile neutropaenic and diagnosed with right lower lobe pneumonia and strongyloidosis. M’s contributing conditions were docetaxel fluid retention syndrome (DFRS), chemotherapy induced pancytopenia, hypokalaemia, hypomagnesemia and intertriginous candidiasis.

During this admission M appeared increasingly depressed and uncooperative. She started expressing views of discontinuing treatment and wishing to return home “back to her country”

In discussion with the treating medical team in Perth, the discharge planner and the Palliative Care social worker it was evident that M was becoming more difficult to manage with her refusal of care. The RCNC was contacted requesting assistance in finding family support, M wasn’t eating properly and was refusing to mobilise. Her niece agreed to go to Perth.

M was treated with IV antibiotics for infection and ivermectin for strongyloidosis. M refused to have pathology taken but agreed to transthoracic echocardiography which showed no vegetation but refused any further investigations. M developed bilateral pleural effusions with peripheral oedema associated with the DFRS. This was treated with potassium sparing diuretics and ongoing oxygen to maintain her saturations. The medical team wanted to address her acute medical issues prior to transfer but her refusal of treatment made this difficult. Referrals were made to all services whilst M was an inpatient at RPH; physiotherapy, dietetics, social work, discharge planner and continence advisor, M refused all services.

She was referred to the Palliative Care team at RPH, not because her acute issues were irreversible or her cancer untreatable but for symptom management. Further local management and opinion was requested because of her refusal to accept any intervention, she was then referred to the Kimberley Palliative Care team.

M’s Cancer treatment plan was for her to continue Herceptin for 11 cycles with 6 weeks of Radiotherapy in Perth. M refused this treatment, requesting to return home.

The Kimberley RPCC and RCNC communicated daily with the aim of returning M home to country so that her acute medical issues could be managed locally, her depression treated and her cancer management plan re-evaluated.

Investigations were made by the RCNC to see if the Herceptin could be administered locally. During an educational trip to the East Kimberley the issues surrounding the administration of Herceptin were discussed by the RCNC. An educational resource on Herceptin was presented to nursing staff and a Chemotherapy Credentialed Nurse identified. The Senior Medical Officer was willing to accept and oversee M’s care.

Again M refused all treatment and these plans were postponed.
M now required RFDS transfer as she was debilitated and oxygen dependant. Her physical condition further deteriorated when she developed MRSA bacteraemia secondary to thromboplebitis. A PICC line was inserted for two weeks of IV antibiotics. Initially M agreed to this treatment but she subsequently refused as her stay in Perth extended.

Following six weeks hospitalisation in Perth she was transferred to Kununurra and deemed Palliative due to her deteriorated condition and refusal of treatment. Education was given by the RPCC to nursing staff to promote symptom management and rehabilitation. M was advised that her breast cancer treatment could be reevaluated in the future. The hope was that M would be happier back in her country and would start to improve. This was a long and difficult process involving all members of the multi disciplinary care team and family members to encourage and support M. Her strength and general condition including her longstanding incontinence issues improved slowly and she was eventually walking with a frame. She was keen albeit unrealistic about discharge home and unhappy that she remained in hospital.

M was unable to live alone and needed someone to care for her. She wanted to stay in Kununurra but there was no family with capacity to provide the care required. Her only daughter lived in Broome. A family conference was arranged by the RPCC with all relevant stakeholders including M and her daughter H from Broome where all parties had input. M’s statement that she felt “stronger and happier” was supported by the medical and allied health teams. M’s daughter stated that she could care for M in Broome. M eventually agreed to move to Broome. Six weeks following her admission to Kununurra M was discharged to her daughter’s home in Broome.

M is not considered to be Palliative she is well and being cared for by her daughter. She has no wish to complete breast cancer treatment; her most recent CT scan indicates she is disease free. She continues on oxygen at home for her chronic lung condition. The Palliative Care Aboriginal Health Worker visits her weekly and the RCNC liaises with her GP.

M has expressed a desire to return to Kununurra, but at present there is still no family there to care for her. She continues to live in Broome overseen by both the Kimberley Cancer and Palliative Care teams.

**Recommendation**

Increasing and enhancing telehealth utilisation will broaden client care, education and networking for the Kimberley Cancer and Palliative Care Service within the region, state wide and nationally.

**References**

4. Platt V. Nurse Director WA Cancer and Palliative Care Network. Personal Communication Feb 2013


