

RURAL PATIENTS AND FAMILIES EXPERIENCE OF ONCOLOGY TREATMENT IN QUEENSLAND

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Aims of the presentation

- Highlight the challenges of rural people with cancer
- Present their experience
- Explore the needs of rural people with cancer
- Recommendations for future research



Background

- Living in rural areas is often associated with a higher range of challenges internationally (Andrykowski & Burris, 2010; Watts et al., 2016)
- Fewer sources of health information and often poor internet and a lack of understanding of health related language (Garrard, Fennell, & Wilson, 2017).
- Approximately 30% of the population in Queensland live rurally
 - *over 1800 kms away - less resources and increased travelling distances.*
- Diagnosis and treatment may be similar for both rural and urban patients
 - *Diagnosis later*
 - *Survival 5-7% lower QOL lower*
 - *Use of services lower*
- Family members are often the **key support persons** during this time
 - *May not be with patient*
 - *Family functioning may be maintained or disrupted*
 - *Challenges of understanding information and supportive role*



Method

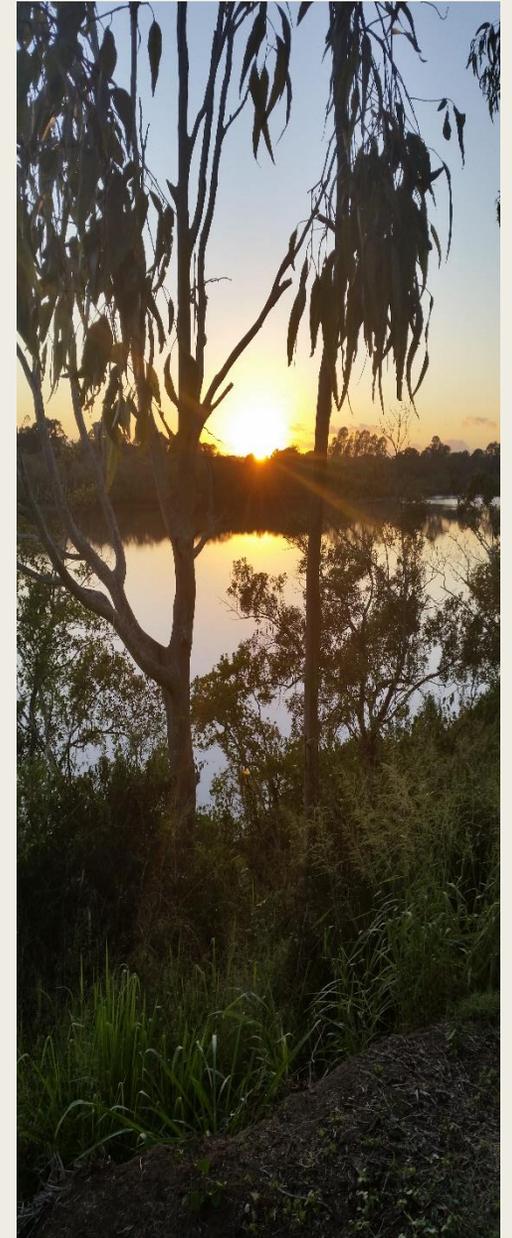
- An interpretive phenomenological approach
 - *14 semi structured telephone interviews*
 - *All pseudonym names used*
- Family Systems Framework to explore family as a unit of care
- Questions related to their experience, family strengths and support needs.

- Started being a Mixed method approach
 - *Surveys: SF36v2, HADS, SCN34 patient's only, FHI, F-COPES*
 - *only 3% of surveys returned 55 out of 400 sent*



Results

- Demographics
- Males 7 female 7
 - *both patients and carers*
- Age range 46 to 76 employed to retired
- Range of cancers
- Interviewed patient and family separately to ensure minimal distress
- Data saturation at 10 interviews



Results

- Questions started with tell me about your experience
 - *Leading into what strengths as a family*
 - Sharing problems, communication, spiritual strengths
 - *What support did you access*
 - Services, both informal and formal
 - *How did you find the council cancer support services*
- **Four main themes**
- Confronting diagnosis
- Working through the challenges
- Talking and sharing
- Negotiating support



Confronting diagnosis

- The reality of diagnosis!
 - *The travel, the cost, the time*
 - *What about my family, my work*
 - *How are we going to get through this?*
- *“in the beginning it’s like a bit surreal”*. Laurie [Patient 61y]
- *“When you do get diagnosed, you need somebody standing there with you”* Jay [patient 64y].
- Half of the participants had no one with them in the first diagnostic phase as it was expensive to travel and they were unsure of the outcomes.
 - *“I wasn’t expecting to be diagnosed with a cancer at all”* Buffy [patient 73y]



Working through the challenges

- **Decide on priorities**, keeping well after treatment when at home
 - *“so I had to – call the ambulance myself, I think it was like 4 times because I didn’t know what else to do, and I had no family or close friends, so I guess I did a lot of it on my own.” Laurie [Patient 61y]*
- **Organise travel**
 - *“Travel to treatment in city from hotel “it ended up being like about \$80 a week just for cabs” Don [husband 64y]*
 - *“The Cancer people organised the flights down” Buffy [patient 73y]*
- **Staying near treatment**
 - *“find places to stay as cheap as we can find cause we couldn’t afford - we’re not wealthy” Gladys [family 71y]*
- **Looking after the family**
 - *Back at the home I helped prepare meals, but I let her prepare meals if she felt like doing it, helped her with the children and everything that has to be done in the home when you've got two littlies Anne [family 69y]*
- *“Sometimes I got a bit down and I never told anyone. I had a bit of a cry because I just wanted my mum or my husband [who had died], ... I just missed them, I’d be a bit upset that night but by next morning, ..., I got on with it..” Jay [patient 64y]*



Travel and staying well

- Travelling home after treatment often over 2 hours
 - *“Travelling back, the last thing you want to do is get in the car and travel for an hour and a half, and I did doze. A little bit but, I was just a little too sick too, and all you want to do is lie down.” Jay [patient 64y]*
- *When their loved one got sick between treatments this just added burden*
 - *“When she got sick, that’s when it got hard. A couple of times she ended up in the Esk Hospital here, so I had to make it back out here, so it meant a lot of driving.” Don [family 64y]*



Talking and sharing

- Talking was often part of the healing process
- Different levels related to family connection
 - *“We both spoke about it, it’s better that way if we speak about it, like let it out more. I found the more I spoke about it, the better it was.”* Collie [wife 56y]
 - *“I sort of incubated myself in my little room because I didn't want to associate too much with any one else”* Greg [patient, 46y husband to Collie]
- For some talking outside the family was good
 - *“That made me feel good talking to somebody outside the family that I didn’t have to pretend with”.* Blakka [patient 56y, son of Gladys]
- For some not so helpful
 - *“They got me to go in to the cancer place and have counselling but I didn’t feel it was helpful because the girl was about 10 – well, she wasn’t really, but she seemed that old to me.”* Jay
- Country towns was also mixed if supportive
 - *Collie [wife 56y] noted “Like, in a country town, everyone sticks together.”*

Negotiating support

- This was divided with two main aspects informal and formal support
- Informal or family support
 - *“I felt very guilty because, you know, they have a young family and their lives are busy” Jay [patient 64y]*
- Getting information was not always meeting health literacy needs
 - *“I had no idea what radiotherapy was, I was just shell shocked when I found out I was going get radiation every day” Bill [patient 75y]*
- Breast care nurses as always so useful
 - *“You go into it blind with no idea of, it’s all very well getting the books and the brochures and everything but the people that I found that made a difference was at the beginning a breast cancer nurse and they like go through everything with you and you get a free bra and they give you a special like pillow thing that you get to hang over your arm after you have had surgery ... all their support was really good and of course all the staff there seem to be trained to deal – to deal with your emotions that’s really important.” [Laurie 61y]*
- *“It (CCQ) made life so much easier and took the strain off us a lot”*. Gladys [mother 71y]

Spiritual seeking gave hope

- Spiritual support including faith in God, finding support at church, a spiritual belief of some sort, and a positive attitude.
- A belief in God, both prayer and just a sense of a bigger being.
 - *“I do believe there is a God. But I think life is what you make it yourself, whether you believe in good or bad” Tom [patient 68y].*
- Collie [wife 56y] shared that, *“you’ve got to be brave and yeah, keep your chin up and just think positive”*.
- Pete [patient 64y] spoke about just being positive and believing in yourself, *“I believe in magic things happening”*.
- *Focus on life not the cancer even if you were the carer!*
 - *“So now I will work at the things that are important to me and that I want and I try really hard not to waste any of the time I have got left.” Anne [mother 69y]*

Discussion

- Recruitment was difficult
 - *Possibly only by persons doing well*
- Highlighted the challenges that rural patients and family with cancer face
- Strengths as a family and how they work through challenges
- Insight into travel challenges and the need for understanding of this factor
- Different communication styles
- Level of health literacy in rural patients
- Finding support and services at home were difficult highlighting the concerns of treatment, staying well, using family as support



Conclusion

- Rural patients with cancer and their families have significant challenges
- Strong sense of resilience
- Importance of providing support including accommodation when travelling for treatment
- Thorough family assessment and good communication skills important



Recommendations

- Need for nurses to identify and assist rural patients
- Provide opportunities to discuss
 - *Care for patient as a family unit*
 - *Travel*
 - *Accommodation*
 - *Treatment information in plain language and stepped out*
- Future research
 - *need ability to follow up with participants*
 - *personal researcher contact*



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