Title: The experience and challenges of rural persons with cancer and their families.

Abstract

Objective: Approximately 30% of the population of Australia live over 180 kilometers from tertiary healthcare facilities. In rural areas there are fewer health resources and greater travelling distances for treatment. Family support for health care or illness prevention can either be strengthened or disrupted in times of need, yet family is a key aspect of the person's supportive network. This research sought to understand the experiences and challenges for persons with cancer and their families from rural Queensland.

Design: A qualitative study used 14 telephone interviews involving eight persons with cancer and six family members to understand their experience when travel for treatment was required.

Setting: Rural Queensland, Australia

Participants: Persons with cancer and family who stayed in Cancer Council Queensland Accommodation.

Results: Three themes developed; *confronting diagnosis*, *challenges*, and *negotiating support*.

Conclusions: Challenges included travel concerns and lack of services at home; however, family support and appreciating positive aspects were highlighted as part of the experience. This research identified a need for tailored support, which recognises their rurality. Open communication with health professionals helps identify specific needs and service barriers.

Keywords: rural, family, nursing, cancer, experience, Queensland

Summary of relevance**Problem statement**

The challenges of a cancer diagnosis are different when you live in a rural area, the travel considerations and lack of accessible support adds another layer of challenges for the person with cancer and their family.

What is already known on this subject;

- Rural persons have higher unmet needs during cancer treatment
- Later diagnosis of their cancer and lower survival rate
- Less health professional support close to home

What this paper adds

- This work presents a view of the challenges faced by rural persons with cancer and their family.
- The importance of communication is well known, however, this research highlights the need for ‘time to talk’ with the family and within the family.
- This research identifies the importance for health professionals to acknowledge rurality and tailor care for the home environment

▪ Introduction

Living in rural or remote areas will influence the person's ability to access health support and can influence health outcomes negatively (Whitehead, Jacob, Towell, Abu-qamar, & Cole-Heath, 2018). Disparities exist access to health care for people living in rural and remote areas, particularly screening for cancer and chronic disease, mental health support, palliative, paediatric care and specialist health services [services which focus on one aspect of health care provision] (Ding, Saunders, Cook, & Johnson, 2019; Gunn et al., 2019; Salehi, Frommolt, & Coyne, 2019). Barriers to the availability of services are often in relation to the ability of the health service to provide practitioners to work in rural and remote areas (Brown et al., 2017; Orda, Orda, Sen Gupta, & Knight, 2017).

Studies show that the survival rates for rural and remote persons in Australia are five to seven percent lower than in metropolitan areas, often due to the later diagnosis and lack of specialist follow up (Australian Institute of Health and Welfare, 2018; Gunn et al., 2019; Salehi et al., 2019). There are fewer sources of health information, lower health literacy levels and poor internet, which all influence access to health services (Garrard, Fennell, & Wilson, 2017). The geographical distance to a specialist health centre adds practical, financial and psychosocial challenges for the person and family (Butow et al., 2012; McGrath & Holewa, 2014).

The diagnosis of cancer will influence the person with cancer and their family over an extended period of time and living in rural and remote areas is a disadvantage to receiving tailored care (Salehi et al., 2019). Family will provide both physical and emotional support, however, for many people living in rural areas their support network is geographically separated from them (Garrard et al., 2017). The diagnosis and treatment may be similar in both rural and metropolitan areas, but the experience for rural person has increased challenges (Gunn et al., 2019). Access to face to face psychosocial support is difficult, due to the significant distances and costs of the services (Dasgupta et al., 2018; Pisu, Azuero, Benz, McNees, & Meneses, 2017; Salehi et al., 2019). People in rural areas

have different health seeking behaviours and needs particularly in relation to mental health services (Gunn et al., 2019).

Persons with cancer often fail to communicate their needs and distress with health professionals or their family (Coyne, 2013; Dieperink, Coyne, Creedy, & Ostergaard, 2017; Watts et al., 2016). In the rural setting this is accentuated due to separation from their family, leading to less sharing of information and interaction with the health professional as a family unit (Butow et al., 2012). This can lead to misunderstanding the needs of the person with cancer and their family leading to a level of unmet needs within the health system (Coyne, Grafton, Reid, & Marshall, 2017; Griffin et al., 2014).

The current study used the theoretical concepts of Family Systems Nursing in order to understand the rural family as a group of individuals with interrelated lives (Bell & Wright, 2015). This research investigated the 'family' as a unit of care to identify their experience and challenges with an emphasis on their experience in a rural area. The research question was 'What are the experiences, needs, and resources of persons with cancer and their families who travel for treatment?'

▪ **Method**

Design

A qualitative design using in-depth telephone interviews investigated the experience and challenges of rural persons and their family members in Queensland. University ethics [GU ref no: 2016/344] and Cancer Council Queensland approved the study and is consistent with the requirements of National Health and Medical Research Council of Australia ("Australian Code for the Responsible Conduct of Research," 2015). Written informed consent was obtained prior to all telephone interviews and a pseudonym was used for all reporting.

Setting

The participants for this study resided in rural Queensland and had stayed in Cancer Council Queensland [CCQ] accommodation during treatment. Rural is defined as living up to and over 180 km away from a major city, which is approximately 30% of the population of Australia (Australian

Rural persons with cancer and their family

Institute of Health and Welfare, 2018; Sabesan et al., 2011). Cancer Council is an Australian government organisation providing a range of services to persons with cancer and their families, and health professionals. Cancer Council provides accommodation close to hospitals for patients and their family to use whilst undergoing cancer treatment (Cancer Council Australia, 2019).

Participants

Cancer Council Queensland mailed study information and invitation for a telephone interview to 200 persons with cancer who had stayed in a Brisbane or Townsville lodge over a two-month period in 2016. Inclusion criteria was persons diagnosed with cancer, over 18 years and who speak English. No follow up was permitted from Cancer Council Queensland due to the confidentiality of records.

Data collection and analysis

The lead researcher, an experienced family researcher conducted telephone interviews using structured, open-ended questions, lasting between 45-60 minutes. Sixteen participants completed the consent for interview however only 14 interviews were completed. One participant died and one became too sick to complete the interview. The audio-taped interviews were professionally transcribed verbatim. Questions explored the challenges and experience of diagnosis and treatment and their experience of residing in the Cancer Council Queensland accommodation (See Table 1 for questions). A thematic analysis of the interview transcripts was completed as a two-step process, first inductive searching for themes related to the questions and then deductive, looking for a sense of the family and a deeper understanding of the experience (Braun & Clarke, 2006, 2014; Wright & Leahey, 2013). An excel table was developed from the initial concepts and refined through discussion and consensus within the research team [EC, VF, NS] (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). In keeping with the requirements for rigour and trustworthiness, transcripts and themes were reviewed by three participants to validate qualitative data and analysis (Silverman, 2003). Field notes and analysis tables formed part of the audit trail of the analysis to demonstrate auditability and integrity of the research.

Table 1 – Interview questions

Cancer experience	<p>Person with cancer: Tell me about your experience of cancer and how you managed your health and wellbeing?</p> <p>Family member; Tell me about your experience of caring for someone with cancer and how you managed your health and wellbeing?</p> <p>Can you tell me about your role when you cared for someone with cancer?</p> <p>How long have you been caring for someone with cancer?</p>
Strengths	<p>How do you share emotional expression?</p> <p>How do you share problems in the family?</p> <p>When you have difficulties how does your family work through problems?</p> <p>Can you tell me what helped you work through difficulties?</p>
Support needs	<p>Can you tell me what your supportive needs were since the cancer diagnosis?</p> <p>If you and your family need assistance, who would you normally ask for help? and why?</p> <p>Did you access any services when you were facing difficulties?</p> <p>Tell me about the formal support you have used; counsellors, health professionals.</p>
Experience of the specific services received from CCQ accommodation	<p>Tell me about your experience with the CCQ accommodation.</p> <p>Can you explain the sort of support you used from the CCQ?</p> <p>When you returned home did you still use the support from the CCQ and what sort of support were you using?</p> <p>What recommendations would you suggest to CCQ and the accommodation?</p>

Results

Fourteen participants, eight persons with cancer and six family members (Male n=7 Female n=7) completed individual telephone interviews. Overall, three couples provided a combined view of family experience while other participants spoke about their families' experience. Table 2 presents the interview participants demographics. The interviews were reviewed after each one as a continuous process of data analysis to develop a beginning understanding of concepts and identify data saturation.

Table 2 Interview participants' demographics

Family	Pseudonym	Participant	Gender	Age	Cancer Type
1	Laurie	Patient	Female	61	Breast
1	Don	Husband	Male	64	
2	Bob	Patient	Male	51	Skin
2	Gladys	Mother	Female	71	
3	Anne	Mother	Female	69	
4	Buffy	Patient	Female	73	Blood
5	Tom	Patient	Male	68	Stomach
6	Pat	Wife	Female	76	
7	Jay	Patient	Female	64	Breast
8	Bill	Patient	Male	75	Prostate
9	Greg	Patient	Male	46	Colorectal
9	Collie	Wife	Female	56	
10	Blakka	Patient	Male	56	Skin
11	Pete	Partner	Male	64	

The research team developed three themes from the findings; *confronting diagnosis*, *challenges*, and *negotiating support*. The themes overlap as the participants described different aspects of their cancer experience and recalled the challenges of living in a rural area and having cancer. The presentation of

these themes aims to provide an understanding from both the person with cancer and family members' perspective.

Confronting diagnosis

Confronting the diagnosis was the initial theme noted by all participants, particularly the person with cancer, who spoke in depth about this period. The initial shock, sense of disbelief of the cancer diagnosis, some shared the diagnosis, while others described a retreat from the world. *"I was in denial to be honest, and thankfully my son and his wife and family were here"* Jay [patient 64y]. *"We sort of kept it to ourselves. I think you're in shock and especially when they tell you it's rare"* Buffy [patient 73y]. Working through the shock was the first step in the diagnostic process and the importance of support at this time was imperative. Pat describes the diagnosis stage as very traumatic, after 45 years of marriage they had not had any problems now Phil had to go to Brisbane and she followed as soon as she could. *"Boom" it's like a bomb. It destroyed us – it tore us apart, you know, and it tore our emotions apart."* [Pat wife 76y]

For six families, diagnosis occurred quickly *"in the beginning it's like a bit surreal"*. Laurie [Patient 61y] and they had little notice to prepare for possible travel and related treatment whereas for five families there had been a delay in this process, allowing time to prepare.

So that's probably about six, seven weeks, yes. I understand that they've got to fit you in anyway, so that sort of didn't worry me. It gave me a bit of time to keep working a little bit and then sorting a few things out in that period. Greg [Patient 46y]

Working through the challenges

Working through the challenges of a cancer diagnosis related to getting through the treatment at home, or the tertiary hospital away from support and travelling to and from treatment. Challenges with the side effects from treatment often meant returning to hospital sooner than expected creating a further need to travel. Laurie [patient 61y] suffered febrile neutropenia several times *"so I had to – call the ambulance myself, I think it was like four 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."* Don [Husband to Laurie 64y], *"Basically walking out the door and trying to work, and hope like hell she could survive."*

Rural persons with cancer and their family

Travel challenges included time and financial burden, giving a sense that living in a rural area just added more challenges to the cancer diagnosis. Problems with finding accommodation and expenses of travelling for treatment were significant for all participants, however this comment really highlights the concerns.

Gladys [mother of Bob 71y] *“sometimes we slept in the car got up and went to a service station and had a shower and then to the hospital.”* Bob [patient 51y] *It was very physical at the time because of the distance and the hours we had to go down there. There was some real ringing around to find cheap places to stay ‘cause we couldn’t afford - we’re not wealthy.*

The travel time for treatment added a significant burden, particularly travelling home after chemotherapy. *“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 too sick, and all you want to do is lie down.”* Jay [patient 64y]. This aspect of travelling for care also influenced their connection to the hospital and not sharing their concerns with the staff for fear of readmission. Five participants described how their families were able to stay with them but this was also difficult as the supporting family put their life on hold while living at the Cancer Council Queensland accommodation.

During that time, I spent four weeks with her at the hospital in the quarters you live in and I virtually just went to all the treatments with her and supported her, sat there when I was there with her to have the chemotherapy and I always waited outside while she had the radiation.

Anne [mother 69y]

Negotiating support

Finding support and understanding what resources were available was discussed by all the participants. Informal support was mainly from their family and often required negotiation. Family were often overwhelmed with the cancer diagnosis or were just busy, trying to balance family life with the demands of rural living. The person with cancer described how family support helped them endure the treatment, although they were concerned about being a burden to their family. The family members interviewed did not share a sense of burden but rather a sense of worry.

I'm a pretty easy going sort of guy and just accepted what has to be has to be done. My wife took it pretty hard, though. We were transferred to Brisbane rather than Townsville for more support Tom [patient 68y]

Information was another challenge as it was not always at their level of understanding. *"I had no idea what radiotherapy was, I was just shell shocked when I found out I was going to get radiation every day"* Bill [patient 75y] For the two participants with breast cancer, the allocation of the specialist nurse made a difference with an increase in their understanding and generally feeling more supported. Different views were shared by the participants regarding the need for support and sharing about their cancer. Talking within the family was often part of the healing process, while five participants suggested they preferred not to talk about their cancer diagnosis.

"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]

On-line social networks were noted as being helpful to two of the younger male participants, Blakka and Bob. *"I prefer more on-line socialising Facebook"* Blakka [patient 56y]. Several of the women [Collie, Buffy, Jay, Laurie] shared about talking with the counsellor but although it was helpful they shared that talking with family or friends was just as useful. Laurie had an interesting comment about her experience with the counsellor.

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. Laurie [patient 61y]

There were positive and negatives about living in a rural area and participants talked about the support from the community. Collie [wife 56y] noted, *"Like, in a country town, everyone sticks together."* Spiritual support included faith in God, support from church, a belief or positive attitude. Self-efficacy and having a positive attitude were important in the recovery process. Collie [wife 56y] shared that, *"you've got to be brave and yeah, keep your chin up and just think positive"*. Overall participants shared a sense of adapting to a new routine and doing the best they could with their cancer journey. The instrumental support received from Cancer Council Queensland was very helpful including the transportation system, personnel and the accommodation facilities. The simple things, like morning Rural persons with cancer and their family

tea, and people to talk with and help with getting to the hospital that made a difference. *‘The van, getting the bus into the hospital, getting the bus home and the volunteers and the respect and the care that we got from them couldn't have been better.* Pete [partner 64y]

Discussion

This study has explored the experience and challenges of persons with a cancer diagnosis and their family members while living in rural areas. The challenges faced and their strengths as they worked together as a family unit were significant during the cancer journey. Living in rural areas was highlighted in the diagnosis phase where participants shared being alone and away from home. Living rurally resulted in increased costs associated with accessing healthcare. These challenges for rural persons are not specific to cancer and have been highlighted internationally (Salehi et al., 2019).

There has been an increase in the provision of support both financial and instrumental for rural persons, however the nurse has a pivotal role in ensuring the identification and assistance to link with the appropriate resources occurs (Cancer Council Australia, 2019).

For rural persons, strong family relationships and coping with adversity were identified as protective factors (Garrard et al., 2017). The adaptive ability of families, who can share distress and work together, enables a sense of hope often found in these rural families. Similar to previous research, communication styles influenced the connection with support both within the family and externally (Coyne, Dieperink, Østergaard, & Creedy, 2017). Communication of needs to the health professional is the key to tailored support but the health professional must allow time for discussion and support the family through this process of sharing their needs (Dieperink et al., 2017; Gilliss, Pan, & Davis, 2019). Often when people face health adversity they are unsure what assistance to ask for, particularly in rural areas where services may not be readily available.

Maintaining a work and life balance in a rural area was difficult as they were often away from home, which influenced the families' ability to provide support and soften the journey. Worry, fatigue and challenges are present for any person with cancer and their family (Watts et al., 2016) but travel adds an extra burden and this was reflected in the data. Finding appropriate support and information was a

concern. Psychological and physical unmet needs tend to be higher for rural persons due to a lack of services or lack of tailored service support (Gunn et al., 2019). Rural areas often have lower access rates to services due to less recognition of the needs for professional help (Andrykowski, Steffens, Bush, & Tucker, 2014). Organised support and accommodation were welcomed and reduced the burden and challenges of travelling for treatment (Butow et al., 2012). However, there were limited resources and lack of understanding of suitable resources when returning home, which can lead to anxiety and fears about understanding what is normal and where to seek help (Watts et al., 2016). The use of new technologies to support persons and families in rural areas may alleviate some of the distress related to distance and lack of support (Read Paul, Salmon, Sinnarajah, & Spice, 2019).

Living in rural areas had both positive and negative benefits related to a smaller community. The close support network of family and friends when available was positive; however, familiarity and maintaining confidentiality was noted as an issue when seeking help within the community (Watts et al., 2016). The balance of stressors that the person with cancer and their families deal with during treatment and the added challenges of travel and being away from home can overwhelm the person.

The participants' stories highlighted their lack of understanding of treatment and not knowing who to ask for help from. Health literacy is influenced by age, gender, socio-economic factors and engagement with the health system (McGinnis, 2017). Particularly, rural people have lower health literacy than people living in metropolitan areas (Watts et al., 2016). Understanding treatment, medication adherence and participation in supportive health measures is influenced by health literacy highlighting the need for assessment and tailored information for rural persons and family (McMurray & Cooper, 2017).

Limitations

This study has a strengths of depth of qualitative data, which was collected from across rural Queensland and allows understanding and extension of the current knowledge regarding challenges faced by rural persons and their family members. A limitation of this study was that the initial methodology was mixed method with a survey and interview phase however, a poor response rate for

the survey changed the focus of to be qualitative. The interview data provided a rich understanding of the challenges. No follow up was permitted so it is unclear why a poor response rate, however previous research has noted that fatigue and burden of treatment often influence recruitment of rural participants (Garrard et al., 2017). This study highlights the need for personal recruitment and follow up of diverse and difficult to access populations as evidenced in previous research who noted this improved participant numbers (Butow et al., 2012; Garrard et al., 2017; Kjaer et al., 2016).

Recommendations for clinical practice

There is a need for health professionals to focus on the family as the unit of care. For rural persons with cancer their family is often their main source of support and it is important to maintain family functioning over the course of cancer treatment for best outcomes. Nurses should routinely assess the family, identifying health literacy levels, who is the leader of the family, what are the strengths of the family, what resources do they have access to, and use when at home, and tailor supportive care to both person with cancer and their family. There is a need for mixed method research particularly exploring the development of nursing interventions, which can enable health professionals to provide tailored supportive care for rural persons with cancer.

Conclusion

This study has provided insight into the experiences and challenges of rural persons with cancer and their family. Working with people with cancer and family to understand their needs, including the challenges of travel, family coping patterns and communications styles are important aspects in ensuring appropriate support when they return to their homes. This research highlights the need for cancer centres to have guidelines to identify rural persons and assess their needs. Develop partnerships with the person with cancer and their family to meet the national and international standards of consumer partnerships (Australian Commission on Safety and Quality in Health Care, 2018).

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