Living with cancer in residential aged care facilities

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EXECUTIVE SUMMARY

The experience of people living with cancer who reside in residential aged care facilities (RACFs) is both poorly understood and under-researched. Demographic and health care service data is missing for this group of potentially vulnerable people. The number of people with cancer living in Australian RACFs is unknown. There are also no published figures specifically for cancer deaths in RACFs in Western Australia. From international studies, we know that people living with cancer in RACFs are older than other people with cancer, experience more disabilities and co-morbidities, spend more time in healthcare institutions, and have a poorer quality of life (Brandt, et al., 2005; Froggatt, 2001; Froggatt & Hoult, 2002; Goodman, Woolley, & Knight, 2003b; Jordhoy, et al., 2003; J. Kayser-Jones, 2002; J. Kayser-Jones, 2003). Nevertheless, past research has only given a limited insight into what it is like to live with cancer in a RACF. For a range of organisational and socio-cultural reasons, RACFs are challenging places to live and work in, and so it is vital to understand how these factors impact on people living with cancer and those working with them.

Our research set out to better understand the experiences of people living with cancer in Western Australian RACFs. While we had much to learn from international literature, which is summarised in this report, we believed it was important to address these issues within a local context. This context will also have relevance for other Australian states as Australian RACFs all face common organisational and socio-cultural challenges and many Australians fear there is a looming ‘aged care crisis’ (Lunn, 2012). In this report we aimed to provide basic demographic and health service data for people living with cancer in Western Australian RACFs. We also sought to deepen our understanding of the challenges people living with cancer in RACFs face in living a meaningful and satisfying life.

The study was conducted in two phases. Phase one used data from the Western Australian Data Linkage System to analyse information about people who died in Western Australia during the period of 1 July 2000 to 31 December 2002. We were particularly interested in people whose underlying cause of death was from cancer and whose place of death was either a residential aged care facility (RACF) or whose usual place of residence when they died was a RACF (the residents may have died elsewhere such as in hospital). We were also able to find the demographic details and health service use data for these people. Phase two of the study took a qualitative approach to investigate the experiences of people living with cancer in Western Australian RACFs from the perspective of residents with cancer, their families or friends and the staff in RACFs who had cared for residents with cancer.

Key findings

During the study period 22% of people gave their usual place of residence as a RACF. Of these 65% died in a RACF and the remainder died mainly in hospital. A further 5% of people moved to a RACF and died soon after. Eleven per cent of these people had cancer on their death certificate. From this we can surmise that at the time of data collection, at least 11% of residents in Western Australian RACFS live for some period with cancer. We are still unable to determine details about the average length of time people in RACFs live with cancer as this kind of information is not recorded. People living in RACFs who died with cancer appeared significantly more likely to have been admitted to hospital during the final year of life than people who died of non-cancer conditions. Of those who were admitted to hospital for at least an overnight stay, the total length of stay was longer for people with cancer than for others.
The difficulty we experienced in recruiting RACF residents to the study may appear as a limitation of our study. However, we believe this was also a key finding. Understandably, staff working in RACFs are very busy and research may not be a priority when they have more pressing responsibilities. However, the number of facilities who declined to take part in the study stated they had no residents with cancer, or more worryingly, said they would not be able to identify if they had residents with cancer; a cause of concern. The findings of the first stage of our research indicate that we would expect to find at least one in ten residents had cancer. It was disappointing that this issue was not seen as a priority for the majority of the RACFs we approached. We are very grateful to those facilities who supported the research, though they may not truly represent the residents who live with cancer in a Western Australian RACF. Indeed, our study may reflect the RACFs that provide a high level of supportive care to residents with cancer. The residents and their families certainly confirmed this observation as they valued the relationships that had with RACF staff. Our interviews with RACF staff also indicated that those who chose to participate in the study were very dedicated and supportive of residents with cancer.

When reviewing the interview transcripts it was immediately obvious that there is no one overarching narrative for people living with cancer in RACFs. The cancers and symptoms were diverse and often the experience was dependent on the type or the stage of the disease. As with previous research, we confirmed that people living with cancer in residential aged care facilities also have a range of co-morbidities. Often, for many of the residents, the symptoms merge into a ‘way of life’ which is restrictive and life limiting. However, it is difficult to disentangle the experience of cancer from what it may be like for someone else with an advanced chronic condition. Residents were generally reluctant to talk about their ‘cancer’, either by downplaying it, or avoiding direct questions about the condition. Although all made excuses for their reluctance to engage in social activities, such as being a solitary type of person, signs and symptoms of cancer, such as hair loss, colostomy bags or fatigue most likely contributed to their choice.

RACFs play a key role in reducing the burden of caring for an older person with cancer at home. Family members and close friends reported that their own health was at risk and their occupational engagement limited before their relative relocated to an RACF. While wanting to support their family members’ independence and level of autonomy, all were grateful that they no longer had the responsibility for providing both physical and emotional care. With the exception of one resident and his carer all residents and family carers were very satisfied with the care and support that they received in the RACF.

The theme of decreased occupational and social engagement arose as an overarching theme throughout all of the interviews with residents, family members/friends and staff. Where we were only able to uncover a limited view of the residents’ lives from single interviews with the residents themselves and their family members/friends, the staff’s insights helped us to get a fuller picture of the day to day realities of living with cancer in a RACF. Residents with cancer suffer like symptoms and similar concerns to other people living with cancer. However, while staff noted that pain, fatigue, loss of appetite and side effects of treatment such as nausea and hair loss were common, as well as fear about the future, they felt that people of an advanced aged with cancer have a decreased capacity to manage the illness.

The RACF staff also noted that residents with cancer are private and reluctant to discuss their cancer, either through stoicism or perceived stigma associated with the condition. Either way, they noted, as the residents’ cancers progressed and they became more dependent their need for privacy was subsumed by the requirement of hands on care. Staff believed that the residents’ withdrawal was directly related to the progression of cancer. The residents were often simply too tired to participate, especially when activities were scheduled for long periods (e.g. bus outing) or in the afternoon (e.g. bingo).
Conclusions

Our findings confirm that RACF residents living with cancer face additional burdens to those faced by other residents with long term chronic conditions that may have similar physical symptoms. Residents with cancer live with a progressively debilitating disease which reminds them of their uncertain future, yet older people find it difficult to talk about cancer. The extreme fatigue associated with many cancers and their treatments, coupled with possible perceived stigma, restricts residents from engaging in social activities which may occupy their days in a more satisfying and meaningful manner. RACF staff have reported that residents with cancer have specific needs and reach out for additional support. Often the staffing in Western Australian RACFs is insufficient to provide this level of care. The following report gives details of the full study and provides recommendations for how RACF residents with cancer may be better supported.
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STUDY OBJECTIVES

The objectives of the study were to:

1. Quantify the number of people who died from cancer in a residential aged care facility in WA over a 2.5-year period, and document their characteristics.

2. Describe the range of daily life experiences of people who have cancer and live in a RACF.

3. Understand the challenges and experiences of (i) the people who have cancer and live in a RACF, (ii) the families/friends of those people, and (iii) the staff in caring for and supporting people who have cancer and live in a RACF.

BACKGROUND

As the world population ages and more people are living longer, the number of new cases of malignant neoplasm in older people is rising. People aged 65 years and over makeup greater than 60% of all new diagnosed cases (American Society of Clinical Oncology, 2008). Cancer has become a major contributing factor to the total burden of disease, with 13% of all deaths worldwide attributed to cancer in 2004 (World Health Organisation, 2009). Despite advances in the detection and treatment of cancers, it remains a significant cause of death in Western Australia (WA), accounting for 30.7% of deaths in 2006 (Australian Bureau of Statistics, 2008; Threlfall & Thompson, 2007).

An older population also means that a greater number of people are now cared for in residential aged care facilities (RACFs) which include both nursing homes (high care accommodation) and hostels (low care accommodation). The Australian Bureau of Statistics (ABS) has projected that figures regarding the number of people aged 80 years and over requiring nursing home or hostel accommodation will increase by 63% from 520,000 people in 1998 to 1.4 million people by 2031 (Truscott, 2007). More than 75,000 people in Australia live in RACFs (McConigley, Toye, Goucke, & Kristjanson, 2008). A proportion of these people live with cancer and eventually they will die, in the RACF or in hospital, either as a direct consequence of the cancer or with cancer as a condition that may have contributed to the death (but was not directly attributable to the morbid train of events that led to the death). The number of people with cancer who live in Australian RACFs is unknown. Due to the increased occurrences of cancer it is envisaged that the number of people living with cancer in RACFs will increase.

Cancer is a chronic condition that may last for years. People with cancer often have an identifiable and expected trajectory of illness which includes a decline in their condition that indicates approaching death (Currow, Burns, & Abernethy, 2008; Forbes, 2001). Recent research found that while the majority of people in WA die either in hospital (48.6%) or in a private residence (20.2%), a significant proportion die in a RACF (18.2%) (McNamara & Rosenwax, 2007a). However, there are no published figures specifically for cancer deaths in RACFs in WA. Although figures from other countries suggest that anywhere between 10-25% of all cancer deaths are expected to occur in these facilities (Jordhoy et al., 2003; O'Brien, Johnston, Gao, & Dewar, 2007), a recent population-based survey exploring place of death for people with cancer and non-cancer in South Australia reports that only 5% of cancer patients died in RACFs (Currow, et al., 2008). Possible explanations could be that people with cancer more often receive palliative care and die within hospice or hospital settings or at home (Currow, et al., 2008).
It is likely that the increase in cancer-related deaths in the population will have significant implications for the delivery and resourcing of health services. An ageing population will mean that fewer people will be available to provide formal and informal care for an increasingly larger group of people approaching the end of their lives (National Centre for Social and Economic Modeling, 2004). Those living in RACFs will not be immune from this stark reality. Furthermore, the role of RACFs in providing end-of-life care is expanding, which will create an additional burden on them to meet residents’ and families’ expectations regarding adequate care (Brandt et al., 2005).

**Cancer in older people**

Older people affected by cancer frequently have different needs compared to the general population. Studies have shown that they are considered a vulnerable population due to other co-morbidities and complicated psycho-social needs. Older people are at higher risk for developing chronic health conditions, such as heart disease, or arthritis, that can adversely affect the treatment of and recovery from cancer (Steer et al., 2009; Wymenga, Slaets, & Sleijfer, 2001). Elderly people face added psycho-social issues, such as difficulties with the maintenance of autonomy, social exclusion and/or isolation, or a lack of access to social and family support and financial resources (American Society of Clinical Oncology, 2008). Although cancer occurs mostly in the older population, several studies have shown that people with cancer over the age of 65 are significantly under-represented in cancer clinical trials (American Society of Clinical Oncology, 2008; Wymenga, et al., 2001). This is because older adults often obtain irregular screening for cancer. Additionally, co-morbid conditions and perceived health vulnerability of older adults by physicians often leads to less aggressive treatment of cancer (Aziz & Bellizzi, 2008; Wymenga, et al., 2001). Functional dependence increases in the last few months of life in patients with cancer (Schubert, Gross, & Hurria, 2008). These health issues and complexities can be compounded when elderly patients live in a RACF.

**End of life in residential aged care**

Moving into a RACF is often seen as a source of anxiety and depression associated with the end-of-life (Cheek, Ballantyne, Byers, & Quan, 2007). Negative connotations about RACFs have been reported by many older people, their families, and the community (Jones, Cheek, & Ballantyne, 2002). Thus, unsurprisingly, moving into a RACF is rarely considered by older people and their families until it is absolutely necessary (Cheek, Ballantyne, Byers, & Quan, 2006). A small number of Western Australian people (2.6%) are transferred to a RACF in the terminal stages of their lives and die in that setting not long after the transfer (McNamara & Rosenwax, 2007a). Often people choose to move to RACFs because they have experienced a health-related crisis or they are in need of more intensive support services (Cheek, et al., 2007). In Australia hospitals are the most common entry point into nursing homes (Karmel, Gibson, Lloyd, & Anderson, 2009). There are a number of predictors for such a move including: the principle and additional diagnoses; dementia and related disorders; longer stays in hospital; usual residence in major cities; state or territory of the hospital admissions; care type prior to hospital discharge; and more than one episode of care during hospitalisation (Karmel, et al., 2009).

Research indicates that people who are approaching the end of life in RACFs are generally very unwell and experience a myriad of problems, including low fluid and food intake, weakness, shortness of breath, nausea, vomiting, pain, and reduced appetite (Brandt, et al., 2005; Jordhoy, et al., 2003). One US study reported that the physical facilities of the nursing home were inappropriate for the residents and their
families as residents were living in small, crowded, noisy, multi-bed rooms without adequate privacy (J. Kayser-Jones, 2003). In the same study, inadequate staffing and lack of supervision were also reported. This affected the provision of even basic care to the residents, including bathing, oral health care, assisting residents in consuming fluids and food and repositioning them in their beds (J. Kayser-Jones, 2003). An Australian study has found that approximately 50% of residents living in RACFs are malnourished (Gaskill et al., 2008). This finding is consistent with findings from other studies (Banks, Ash, Bauer, & Gaskill, 2007).

Cancer care in residential aged care

It is important to understand the characteristics of cancer patients who live in RACFs. However, the literature to date only provides a glimpse of what it is like to live with cancer in a RACF. Most studies paint a bleak picture of living with cancer in RACFs. Patients who are dying in nursing homes have the worst ratings in physical, emotional, cognitive, and social functioning compared to people dying in a hospital or at home (Wittenberg-Lyles & Sanchez-Reilly, 2008). These residents usually require help to perform one or more activities of daily living and mobilising (O’Brien et al., 2007). A Norwegian study reported that most of the residents lived alone prior to admission and were poorly educated, reported more disabilities, spent more time in healthcare institutions and had poorer health related quality of life (Jordhoy et al., 2003).

A US study analysed nursing home residents with cancer during admission and found that compared to other residents at admission, residents with cancer had daily pain, greater dependency in performing activities of daily living, experienced unstable health patterns and were more likely to be at the end of life (Buchanan, Barkley, Wang, & Kim, 2005). In another US study, residents with cancer also suffered from shortness of breath, weight loss and depression (Johnson et al., 2005). Potential barriers to symptom relief include: complex clinical situations, co-morbid illnesses, staff turnover and a lack of resources for diagnosis and treatment of severe complications of the illness (Duncan, Thompson, & Bott, 2008).

Although research has proven that treatment can be as effective and as equally well tolerated in older people as it is in younger patients (Berghmans, Tragas, & Sculier, 2002; Neugut et al., 2002), very few nursing home residents with cancer actually receive ongoing cancer treatment (Buchanan et al., 2005; Johnson, Teno, Bourbonniere, & Mor, 2005). In one study, less than 5% of all residents with cancer received chemotherapy or radiation therapy within two weeks of their admission to an aged care facility (Buchanan et al., 2005). Additionally, some mental health issues were not addressed. Despite almost 26% of residents with cancer also having a diagnosis of depression at admission, less than 7% had been assessed by a mental health specialist and more than 95% received no psychological or emotional therapy. Reasons why residents in nursing homes do not receive adequate and appropriate medical services requires further research; however, some potential contributing factors include, tumour type, co-morbidities, personal and family decisions, and nursing home policies and practices (O’Brien et al., 2007).

Pain management is a crucial aspect of cancer care. The treatment of pain has been identified as a major problem faced by nursing home residents with cancer (Buchanan et al., 2005; Clement, Bradley, & Lin, 2009). One study reported that residents with cancer were two times more likely to have severe pain compared with other residents. Furthermore, between 50% and 80% of residents in long term care experienced pain, which is often under-treated or totally ignored (Berry, 2007). Respondents who participated in a US state-wide survey on the barriers to effective management of pain in nursing homes believed that pain was sub-optimally managed. Barriers to effective treatment included: a lack of knowledge about pain management among nurses and physicians; a lack of diagnostic precision and a
standardized approach to treating pain; physicians’ personal attitudes; difficulty in choosing the right painkiller; and low hospice enrollment of nursing home residents (Tarzian & Hoffmann, 2004). Pain as a result of cancer also creates considerable distress amongst spouses and families. In a qualitative study conducted in nursing homes in the US, family members discussed dealing with the unpredictability of cancer and pain and how it influenced their decisions surrounding continued care (Berry, 2007). Pain was interpreted as a symbol of progression of the illness and eventual death. Furthermore, a lack of adequate and effective pain management created misunderstanding (Berry, 2007).

A study that evaluated organisational, market, policy and resident characteristics that impacted upon cancer care processes found that diagnosis and treatment of cancer was highly dependent on nursing home, market, and policy variables. According to the study findings, approximately 25% of the residents were diagnosed with cancer at or near death and only 61% of those received pain medication. Furthermore, residents living in nursing homes with a higher percentage of lower funded residents were less likely to receive any pain medication (Clement, et al., 2009). Another study found that as compared to other residents, those with cancer were more likely to experience excruciating pain, shortness of breath, weight loss, vomiting, diarrhoea, increased physical dependence and clinical deterioration within three months of admission, but were less likely to receive hospice care (Duncan, Bott, Thompson, & Gajewski, 2009). It appears that people with cancer who are approaching the end of life in RACFs are a vulnerable subgroup whose specific needs may be overlooked (Goodman, Woolley, & Knight, 2003a).

Some advances have been made, primarily in the United Kingdom, to improve the care of people with cancer in RACFs, but this has generally focused on the implementation of palliative care by community nurses (Froggatt, 2001; Froggatt & Hoult, 2002). This work has provided an insight into the challenges inherent in working within these institutions. Palliative care is both a philosophy of care provision and a model. Thus, to ignore the already existing culture of care in RACFs is a mistake (Froggatt, 2001). The author of the study also argued that education of staff in RACFs is likely to be insufficient to bring about change (Froggatt, 2001). This is consistent with other studies into changing practice within RACFs (Goodman, Woolley, & Knight, 2003b; Mozley et al., 2007). Multiple perspectives are needed to explore the realities of living, dying and caring for seriously ill older people in RACFs.

In this context, it is important to understand the individual experiences of people with cancer who are approaching the end of life in RACFs. Many of the symptom and treatment related issues identified above, along with the institutional features outlined, will be experienced by the individuals living with cancer in Western Australian RACFs. Despite the development of palliative care, there is a view that death and dying continues to be mismanaged (McNamara & Rosenwax, 2007b). While the statistics of improved access to services might look encouraging, they may mask the actual lived experience of individuals involved. Studies which explore the experiences of people with cancer approaching the end of life are not common (McNamara & Rosenwax, 2007b). Even less common is literature which examines the experiences of people with cancer approaching the end of life in a RACF, unless it is from the staff perspective (Irvin, 2000; Miskella & Avis, 1998). It is not surprising therefore that there is a recognised need to explore and document the experience of approaching the end of life within RACFs (Froggatt, 2001; Jordhoy, et al., 2003; J Kayser-Jones, 2002; McNamara & Rosenwax, 2007b).
METHODS

The study was completed in two phases. In Phase One, quantitative data was collected to answer objective one and in Phase Two qualitative data was collected to answer objectives two and three. The study was approved by Curtin’s Human Research Ethics Committee (HR89/2010) and the Health Department of Western Australia’s Confidentiality of Health Information Committee.

Phase one

Study design
A population-based, retrospective cohort study of the people who died in Western Australia during the period of 1 July 2000 to 31 December 2002 (n≈26000 deaths).

Data
Phase one of the study required the secondary analysis of data from Silver Chain (community-based nursing and palliative care) and two administrative health databases of the Western Australian Data Linkage System (WADLS) - the Mortality Register and the Hospital Morbidity Data System.

The Mortality Register contained information from death certificates. The death certificate is completed by a doctor or coroner and describes the cause of death. It consists of two parts. Part 1 of the Death Certificate lists the sequence of diseases or conditions that led directly to death (the ‘morbid train of events’). The last recorded cause in Part 1 of the Death Certificate is called the ‘Underlying Cause of Death’. Part 2 of the Death Certificate records other diseases or conditions that contributed to the death but were not directly attributable to the morbid train of events that led to death. This study used data from Part 1 only of the Death Certificate, specifically, the ‘underlying cause of death’.

The Silver Chain database provided information regarding home-based palliative care during the last 12 months of life. Silver Chain provides over 90 per cent of the home-based palliative care in Western Australia.

The Hospital Morbidity Data System provided information regarding hospital-based specialist palliative care during the last 12 months of life. Specialist palliative care admissions were identified from the Type of Episode of Care data item.

Analysis
Descriptive data was generated for all people who died over a 2.5-year period in WA. Of particular interest were people whose underlying cause of death, as recorded on part one of the death certificate, was from cancer and whose place of death was either a residential aged care facility (RACF) or whose usual place of residence when they died was a RACF (the residents may have died elsewhere such as in hospital). Outcome variables were place of death, use of specialist palliative care services (both hospital and community-based) in the last year of life, number of hospital admissions in the last year of life, total length of hospital admissions in the last year of life, emergency presentations and demographic information at death (age, gender, marital status, Aboriginality, geographical remoteness, usual place of residence and socio-economic disadvantage). The place of usual residence of each person categorised as RACF or ‘other’, and the place of death was categorised as RACF, hospital, hospice, or other place. After some preliminary descriptive tables, the file was restricted to include only those people whose usual residence was a RACF.
The profile of people with and without mention of cancer on the death certificate was calculated (frequencies and percentages for categorical variables, means and standard deviations for variables measured on a continuous scale). Chi-square and t-tests were used to compare the profiles between people with and without cancer listed on part one of their death certificates. P-values for categorical data were calculated using the Chi-square statistic while those for variables measured on a continuous scale were calculated using t-statistics. For statistical comparisons, a p-value < 0.05 was taken to indicate a statistically significant difference. Statistical analyses were conducted using the SAS software system (version 9.2, SAS Institute, Cary, NC USA, 2008).

Phase two

Study design
A fixed qualitative design was used in order to explore the experiences of people living with cancer residing in RACFs, their families and friends, and the staff at the RACFs. This approach allowed for an in-depth investigation into the experiences of the participants within this particular setting, but set particular parameters for exploration at the beginning of the research based upon an extensive literature review. The fixed design also requires all of the data to be analysed at the conclusion of data collection (Sarantakos, 2005).

Participants
A purposive sample of four RACFs in the Perth metropolitan area was selected. In all of the facilities that were selected, low care and high care accommodation is provided for residents. Once agreement from each facility was obtained, recruitment of residents, their families and friends, and staff commenced. Strategies for recruitment included presentations at staff meetings, the distribution of information sheets to potential participants at resident events, and direct liaison with staff and management. Those who expressed an interest in participating in the study were then selected based on a specific set of inclusion criteria.

The inclusion criteria for resident participants was that they needed to:
- Be living in an RACF.
- Have a diagnosis of cancer.
- Have knowledge of their diagnosis.
- Not be in the terminal stage of their condition.
- Be without significant cognitive impairment.
- Be able to communicate easily in English.

The inclusion criteria for family/friends were that they needed to:
- Be nominated by the resident (a person previously known to the resident; with whom the resident has a close relationship; and who visits him/her in the RACF on a regular basis).
- Have knowledge of their family member’s diagnosis.
- Not living in a RACF.
- Without significant cognitive impairment.
- Be able to communicate easily in English.

The inclusion criteria for staff were that they needed to:
- Be employed at the RACF for a minimum of three months.
- Have a significant amount of direct contact with residents.
- Be working greater than half of the full time equivalent hours.
- Be able to communicate easily in English.

The overall sample consisted of nine residents, seven family members, one friend, and 11 staff members. Not all residents had a family member/friend who was able to participate in an interview. One resident had two family members who were interviewed together. While residents and family/friends who participated were found from each of the four RACFs selected, staff participants were recruited from only two of the selected RACFs.

**Data**

A semi-structured interview schedule based on existing literature was developed for each of the three groups of people interviewed (see Appendix A, B and C). The resident and staff interview schedules were piloted prior to commencement of data collection. Each interview focussed on the knowledge and experience of the cancer condition; symptoms and concerns; impact on day to day activity; understanding of health; impact of the condition on the resident’s health; recollection and experience of services used; and hopes and wishes. Participants were encouraged to share their stories within the broad parameters of the interview schedule. Two interviewers completed the interviews with residents and their family/friends, though most were conducted by one primary interviewer. A third interviewer completed all of the interviews with the RACF staff. The resident interviews ranged from 18 to 88 minutes in length. Family and friends interviews ranged from 22 to 97 minutes in length and staff interviews ranged from 45 to 100 minutes in length. All interviews were recorded and later transcribed verbatim.

**Analysis**

Transcripts were analysed using constant comparison so that themes about the experience of living with cancer and approaching the end of life in a RACF emerged. Appropriate steps were taken to maximize the trustworthiness of the study. This included, research assistants receiving regular supervision from the study’s supervisors, the member checking of preliminary findings, the use of a variety of interviewing techniques (such as, verbal and non-verbal probing, reframing, clarifying, and summarising), and linking the findings and conclusions to data and theory.
RESULTS

Phase one

The full dataset for this study included 26882 people who died during the period under study. Of these people, 5800 (22%) gave a RACF as their usual place of residence. A table of usual place of residency by place of death is shown in Table 1. The Table indicates that 65 per cent of people who lived in a RACF, died in a RACF. The Table also indicates that five per cent of people who did not live in a RACF actually died in a RACF. While forming only a small proportion of non-RACF-residents, the number of deaths (n=1002) was considerable and accounted for 21 per cent of all deaths within RACFs (1002/4767). A number of these people were probably transferred to a RACF following discharge from hospital and then shortly after transfer, died in a RACF.

Table 1. Place of death for people according to their usual place of residence (RACF or elsewhere). The table shows the numbers of people, and the proportion of those within each place of residence category.

<table>
<thead>
<tr>
<th>Usual place of residence</th>
<th>Place of death</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>RACF</td>
<td>3765 (65%)</td>
<td>2035 (35%)</td>
</tr>
<tr>
<td>Elsewhere</td>
<td>1002 (5%)</td>
<td>20080 (95%)</td>
</tr>
<tr>
<td>Total</td>
<td>4767</td>
<td>22115</td>
</tr>
</tbody>
</table>

Eleven per cent (n=614) of the 5800 residents who lived in a RACF had a mention of cancer on their death certificate while the remaining 89 per cent (n=5186) had no mention of cancer. Table 2 indicates the proportion of people who died with and without cancer listed on part one of their death certificates by their place of death; being either hospice, hospital, RACF or other. For people who lived in a RACF, the greatest proportion of people, both with and without cancer, died in the RACF. There was little difference in proportions between these two groups of people and place of death except a slightly greater proportion of people who died with cancer and lived in a RACF, died in a hospice (6% vs 0.1%). Almost no people without cancer, and who lived in a RACF, died in a hospice. The proportion of people who died in a hospital or other place was very similar for those with and without cancer, suggesting that the increase in cancer-related deaths in a hospice was a result of transfer of these individuals from the RACF shortly before death. This also suggests that at the time this data was collected, the presence of cancer was generally regarded as a trigger to transfer people to a hospice, while people without cancer were often not identified for transfer.

Table 2. Place of death. Numbers in each cell are the percentages within each row (usual place of residence and cancer status).

<table>
<thead>
<tr>
<th>Usual place of residence is a RACF</th>
<th>Place of death</th>
<th>Total (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Hospice</td>
<td>Hospital</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No cancer</td>
<td>0.1%</td>
<td>24%</td>
</tr>
<tr>
<td>Cancer</td>
<td>6%</td>
<td>25%</td>
</tr>
<tr>
<td></td>
<td>5186</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No cancer</td>
<td>1%</td>
<td>59%</td>
</tr>
<tr>
<td>Cancer</td>
<td>18%</td>
<td>51%</td>
</tr>
<tr>
<td></td>
<td>13689</td>
<td></td>
</tr>
<tr>
<td>Total (n)</td>
<td>1490</td>
<td>13211</td>
</tr>
</tbody>
</table>
Tables 3 and 4 show the demographic and descriptive data relating to people who lived in a RACF with a comparison between people with cancer and people who did not have cancer on their death certificates.

**Table 3**: Demographic and descriptive data of people who died with and without cancer – categorical variables. The table includes all subjects whose usual place of residence was a RACF.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Died in a residential aged care facility</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Died with cancer (N=614)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Did not die with cancer (N=5186)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>62.9%</td>
<td>68.6%</td>
</tr>
<tr>
<td>Male</td>
<td>37.1%</td>
<td>31.4%</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>17.3%</td>
<td>17.1%</td>
</tr>
<tr>
<td>Single</td>
<td>6.5%</td>
<td>4.7%</td>
</tr>
<tr>
<td>Divorced</td>
<td>8.1%</td>
<td>6.1%</td>
</tr>
<tr>
<td>Widowed</td>
<td>60.3%</td>
<td>66.6%</td>
</tr>
<tr>
<td>Missing</td>
<td>7.8%</td>
<td>5.6%</td>
</tr>
<tr>
<td>Admitted to Hospital (in last 12 months)</td>
<td></td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>No</td>
<td>15.3%</td>
<td>40.3%</td>
</tr>
<tr>
<td>Yes</td>
<td>84.7%</td>
<td>59.7%</td>
</tr>
<tr>
<td>Length of hospital stay (only people admitted at least once)</td>
<td></td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Day case (no overnight stay)</td>
<td>73.6% (383/520)</td>
<td>97.5% (3019/3096)</td>
</tr>
<tr>
<td>At least overnight stay</td>
<td>26.4% (137/520)</td>
<td>2.5% (77/3096)</td>
</tr>
<tr>
<td>Palliative care (from silver chain +/- hospital)</td>
<td></td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>No</td>
<td>67.9%</td>
<td>97.6%</td>
</tr>
<tr>
<td>Yes</td>
<td>32.1%</td>
<td>2.4%</td>
</tr>
<tr>
<td>Measure of social disadvantage*</td>
<td></td>
<td>0.30</td>
</tr>
<tr>
<td>Most disadvantage</td>
<td>19.7%</td>
<td>18.2%</td>
</tr>
<tr>
<td>More disadvantage</td>
<td>17.4%</td>
<td>18.7%</td>
</tr>
<tr>
<td>Average / neutral</td>
<td>19.9%</td>
<td>19.2%</td>
</tr>
<tr>
<td>Less disadvantage</td>
<td>21.3%</td>
<td>19.2%</td>
</tr>
<tr>
<td>Least disadvantage</td>
<td>21.7%</td>
<td>24.8%</td>
</tr>
<tr>
<td>Place of Residence</td>
<td></td>
<td>0.90</td>
</tr>
<tr>
<td>Major city in WA</td>
<td>77.9%</td>
<td>78.1%</td>
</tr>
<tr>
<td>Other location in WA</td>
<td>22.2%</td>
<td>21.9%</td>
</tr>
<tr>
<td>Accessibility category (ARIA group)</td>
<td></td>
<td>0.13</td>
</tr>
<tr>
<td>Major city</td>
<td>72.6%</td>
<td>74.6%</td>
</tr>
<tr>
<td>Inner regional</td>
<td>16.8%</td>
<td>16.2%</td>
</tr>
<tr>
<td>Outer regional</td>
<td>8.1%</td>
<td>7.8%</td>
</tr>
<tr>
<td>Remote</td>
<td>1.0%</td>
<td>1.0%</td>
</tr>
<tr>
<td>Very remote</td>
<td>1.5%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Migratory</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Place of death</td>
<td></td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Hospice</td>
<td>5.9%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Hospital</td>
<td>24.6%</td>
<td>23.9%</td>
</tr>
<tr>
<td>Residential aged care facility</td>
<td>59.9%</td>
<td>65.5%</td>
</tr>
<tr>
<td>Some other location</td>
<td>9.6%</td>
<td>10.5%</td>
</tr>
</tbody>
</table>

* There were some missing data in this variable.
Table 4: Demographic and descriptive data – variables measured on a continuous scale.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Died with cancer and lived in a RACF</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes (mean, SD, N)</td>
<td>No (mean, SD, N)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>83.4 (9.4, n=614)</td>
<td>86.3 (8.9, n=5186)</td>
</tr>
<tr>
<td>Number of hospital admissions in last 12 months</td>
<td>3.1 (3.1, n=614)</td>
<td>1.9 (6.6, n=5186)</td>
</tr>
<tr>
<td>Total length of stay in hospital (only for people staying at least 1 day)</td>
<td>47.0 (56.8, n=137)</td>
<td>23.5 (43.4, n=77)</td>
</tr>
</tbody>
</table>

The number of people who lived and died in a residential aged care facility in WA over a 2.5-year period was only 614 people; a small proportion compared to all people who died during this period of time. In comparison with people who died without cancer, people with cancer who lived in a RACF were less likely to be female (63% vs 69%) or widowed (60% vs 67%) and were younger (mean ages of 83 vs 86 years). Due to the large population cohort, these differences appear statistically significant but the actual differences in demographic and descriptive data are not large. There appeared to be no relationship between social disadvantage and cancer with all groups similarly represented. People with cancer appeared significantly more likely to have been admitted to hospital during the final year of life (85% vs 60%), with a much larger proportion being for at least overnight stays than the people with non-cancer conditions (26% vs 3%). Of those who were admitted to hospital for at least an overnight stay, the total length of stay (days) was longer for people with cancer than others (possibly due to co-morbidities). One important finding is that palliative care (from hospital or Silver chain) was significantly more common for people with cancer (32% vs 2%), suggesting that palliative care is not widely available to people who live in a RACF and do not have cancer. Since Silver Chain palliative care is not delivered to RACFs, the provision of palliative care must have been delivered by the hospital(s).

Phase two

Four Western Australian Residential Aged Care Facilities participated in the study. They are broadly representative of the range of socio-economic areas in the metropolitan area of Perth and catered for both low and high care residents. However, it should be noted that we found it very difficult to enlist RACFs into the study. Many declined to be involved or reported they did not have residents with cancer or could not identify residents with cancer.

Specific themes arose for each of the three groups of participants, the residents, family and friends and the RACF staff; however, there were also some overarching trends. For residents and family/friends there were specific emotional and practical issues associated with living with cancer. However, for the family/friends the practical implications of caring were significantly reduced while the family member resided in the RACF. With both groups there was a significant tension between the desire for independence/autonomy and the concern about being a burden. Residents really wanted autonomy but were aware of their increasing frailty and did not want to be a burden, while family carers were relieved they did not have their previous burden of care but also wanted to support their loved ones’ autonomy. Another strong theme that emerged was the importance of the relationships between the residents and the RACF staff. The RACF staff can make a significant difference to the residents’ lives. For residents who do not move from their rooms, the staff provide daily contact, while for others they are the conduit that encourages and supports broader social interaction.
Two important points need to be made in relation to the qualitative results. First, there is no one
overarching narrative or story that can be told about cancer in RACFs. Just as the residents have a diverse
range of cancers, co-morbidities, and disease progressions, they also have a diverse range of preferences,
personalities and family support. Secondly, many of the challenges faced by residents living with cancer
appear similar to those faced by residents with other chronic conditions or general frailty. However, it is
important to note and attempt to understand the added burden of a cancer diagnosis and cancer
treatment side-effects that residents with cancer face. There is a significant physical, emotional and social
burden associated with cancer, particularly in relation to its capacity to reduce occupational engagement in
and enjoyment of life.

THE RESIDENTS

The nine participants who were residents of an RACF were aged from 58 to 95 years and had resided in the
RACF from two months to three years. They had a range of cancer diagnoses, co-morbidities and non-
related chronic conditions. Most had a family member who visited regularly but one participant, Jim, did
not have any family or friends visit (Table 4).

Table 4: Demographic details of residents and relationship to family members/friends

<table>
<thead>
<tr>
<th>RACF*</th>
<th>Resident*</th>
<th>Age</th>
<th>Type of Cancer</th>
<th>Length of stay in RACF</th>
<th>Family member/friend*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valley Care</td>
<td>June</td>
<td>91</td>
<td>Skin</td>
<td>3 years</td>
<td>Daughter – Jennie</td>
</tr>
<tr>
<td>Valley Care</td>
<td>Bill</td>
<td>88</td>
<td>Oesophagus</td>
<td>Missing data</td>
<td>Son – Alex</td>
</tr>
<tr>
<td>Coastal Care</td>
<td>Brian</td>
<td>72</td>
<td>Throat</td>
<td>Missing data</td>
<td>Friend – Keith</td>
</tr>
<tr>
<td>Riverside Care</td>
<td>Jim</td>
<td>76</td>
<td>Primary was prostate, now widely</td>
<td>3 years</td>
<td>No family or friends visit</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>spread. Has colostomy and urostomy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hillside Care</td>
<td>Eva</td>
<td>86</td>
<td>Breast</td>
<td>3 months</td>
<td>Daughter unavailable for interview</td>
</tr>
<tr>
<td>Hillside Care</td>
<td>Maree</td>
<td>58</td>
<td>Breast</td>
<td>18 months</td>
<td>Husband – Greg</td>
</tr>
<tr>
<td>Hillside Care</td>
<td>Kevin</td>
<td>95</td>
<td>Bladder</td>
<td>3 years</td>
<td>Wife – Molly</td>
</tr>
<tr>
<td>Hillside Care</td>
<td>Alan</td>
<td>87</td>
<td>Bladder</td>
<td>15 months</td>
<td>Wife – Kate</td>
</tr>
<tr>
<td>(City Centre)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hillside Care</td>
<td>Joy</td>
<td>89</td>
<td>Skin</td>
<td>2 months</td>
<td>Nephew – John and his wife Pamela</td>
</tr>
</tbody>
</table>

*RACFs, residents and family members/friends were all given pseudonyms to ensure confidentiality.

The interviews with participants revealed that most of the older adults living with cancer within RACFs were
not particularly interested in talking about their cancer and had to be drawn out carefully and respectfully
on the topic. For some of the residents, co-morbid health issues were of principle concern. So while cancer
was part of their lives, health problems unrelated to cancer, such as arthritis, bipolar disorder, heart
disease were sometimes of greater importance than the diagnosis and management of cancer itself. This
was more typical of participants who had types of cancer such as skin or breast cancer as co-morbid health
conditions had a greater impact on their ability to live their lives in the way they desired. However, for
others, the symptoms associated with cancer were quite debilitating:
And I can’t to this day… although I’ve got bit of a foggy idea of what went wrong ‘cause I’ve lost me legs from the knees down. They’re still there but they’re bloody useless…No [I haven’t had any other health problems] I think I’ve blown me nose two or three times. (Alan)

Nevertheless, as in Alan’s case, many older people in the study were unable to associate particular symptoms with specific conditions or chose not to. Their overwhelming symptoms ‘merge into one’ and the symptom becomes more of a problem than the diagnosis (for example, the loss of ability to walk).

**Emotional, physical and practical implications**

For some participants, the diagnosis of cancer had little impact on their daily lives. For others, the diagnosis of cancer had significant physical and emotional implications. Although not always necessarily a ‘death sentence’, the diagnosis was still a disruptive life changing event. While some participants were able to get used to the practical implications of living with cancer or the treatment, the emotional toll it took on their mental health and well-being was evident.

He said it [treatment] would give me a few more years, well it has done but it hasn’t sort of given me much comfort. I haven’t been able to accept it properly you know...But I got used to the idea of changing and looking after myself in the respect that I had to be very thorough in what I do you know and changing the [colostomy] bags and so that’s what I’m on. (Jim)

Living with the side-effects of the medication, pain, and sometimes changes to their physical appearance (such as loss of hair, a mastectomy, or blotches from skin cancer), often coupled with other co-morbidities, led to troubling negative outcomes in relation to participants’ engagement in activities and their emotional well-being. Some participants avoided interacting with other residents initially as they feared how others would perceive them. In a more extreme case, one participant talked about how the combination of chemotherapy, a mastectomy, and bipolar disorder made her feel unwell and incomplete, and pushed her towards depression and thoughts of suicide.

And I was really horrified when they told what had happened I just about had nothing left. I had a hook up for the five days I think and they just kept changing the antibiotics and just renewing it because I was so ill. So I contemplated suicide at that point...Yes so again in October I tried to commit suicide, I just couldn’t handle it anymore and when I’d been on the chemo I had fatigue. I didn’t get as tired as some people do but I was still really tired. I had nose bleeds, I had nausea, I felt like I was, some people vomit a lot but I just felt like I had morning sickness all the time. (Maree)

Some participants talked about the long-term practical implications associated with treatment that continued to have an ongoing effect on their lives and their mental and physical health and well-being. Participants discussed the changes they needed to make to their lifestyle; such as, minimising the amount of time spent in the sun without proper protection, practical implications of managing colostomy bags or having to give up eating solid food. Throughout these narratives, specific requirements (for example, the availability of toilets or pureed food) or the fear of something going wrong, influenced some participants’ decisions as to what activities to participate in and what outings they would go on, often limiting their occupational engagement. One participant discussed the practicalities of engaging in activities with the other residents.

At the moment I don’t do anything here ‘cause I can’t sit in the chairs for very long, you know I’ve always got to stay in here [their room]. Well it’s painful after a while and also if things down
here...are functioning sometimes they, you know they happen and I've just got to go and I would have to come back here and change it all again you know...It would just be more simpler for me to stay where I am and do the changes that I know I have to do and be more comfortable here so. (Jim)

Despite the cancer causing pain and the potential for embarrassment if not actively managed, humour was a method used by one participant to cope with the issues he faced.

I call it the five minute fuse...It's like the fuse of a bomb, it goes off and you've got five minutes to think about it...If you don't it goes down your leg...It's giving me back pain at night or the early morning when I first wake up and it helps by, I often ask for my, 'I'll have my three grams this morning if you will' and they laugh like hell, they know what I'm referring to. (Kevin)

**Maintaining independence**

For the majority of residents, the need to maintain independence was paramount. Most wished to maintain control over their health and the decisions they made whether it was in relation to the medications they took, their decision to move to an RACF, or how they spent their time in the RACF. Despite some participants reporting that they had initially feared moving to an RACF because it would impact on their independence, most participants did not feel that they had lost control over their lives.

So I haven't regretted it one bit. I think now well I should have done it when they first mentioned it but you don't, you think you're losing your independence and that I was going to lose me garden and things like that you know. (June)

While seven out of the nine participants relocated willingly to a RACF, two felt forced to relocate or were reluctant initially regarding the decision. For those who did not accept this decision, the loss of autonomy impacted on other aspects of their lives, such as the ability to appreciate and assimilate into the new environment and lifestyle.

I mean it's very nice as far as, you couldn't fault it as a place to stop...Anyone that would want a recommendation I would give that. I personally don't appreciate it as much as I should do because I didn't want to come...I didn't want to come and I didn't want to be put over here...I didn't feel like I was ready to come to it. (Eva)

Despite desiring to maintain independence, most participants were happy to relinquish control over certain activities of daily living such as ironing, washing, cooking, or cleaning. By decreasing their responsibilities, participants had less to worry about around their homes, such as their house deteriorating due to their inability to keep up with the required maintenance. Theoretically, these decreased responsibilities allowed more time for the residents to engage in desired occupations. However, the participants’ lived experiences often indicated a lack of occupational engagement compared to their previous levels. Of the nine participants interviewed, only one stated he had limited his engagement in activities directly as a result of his cancer. Instead, a lack of interest in the available activities in the RACFs was a common theme amongst participants, some even labelling the ones available as ‘childish’.

No I don’t really [attend any organised events] as I just can't be bothered...The things they have are too inane, they're too childish...I might be old but childish things I just can’t see any sense to it. (Kevin)
Social interaction

The majority of participants spoke of how they spent most of their time in their rooms engaging in solitary activities such as watching television, completing crossword puzzles or reading. While a few ventured out to socialise with other residents or engage in activities that were offered by the facilities, most talked about how they were ‘solitary type’ personalities or usually quiet, reserved people. Participants stated that while the other residents were typically pleasant and social interaction was always available if they wanted it, they were usually happier to remain in their rooms. The participants justified their limited form of social interaction through choice or entrenched personality traits, but fear also emerged as a common theme underpinning their decisions to engage in solitary activities. Despite getting along with other residents, fear of something going wrong with colostomy bags, fear of getting close to other residents should something happen to themselves or others, and fear of what others will think of their physical appearance were drivers for participants to remain engaged mostly in solitary activities in their rooms.

No I don’t, no. I like to be friends with everybody but no I don’t want to make a friend out of, I don’t want to get too close to anybody because you know I don’t think at our age, now this morning the lady over here fell and she’s in hospital now and you know and I thought well I know what it’s like to fall and I ended up in hospital...(June)

Relationships with medical professionals and staff

Most participants reported that a good relationship with staff and medical professionals was essential. These relationships had a direct bearing on whether or not the residents engaged in activities in the RACF. Participants on the whole had good relationships with staff members of the RACF. There was a common theme amongst participants that staff often went ‘above and beyond’ for the residents and they often provided a level of social interaction.

I know all the residents, I know all the staff [and] everybody knows me because I’m always around somewhere and I quite often, you know, I’ll stop for a chat with them. I love to, they all have their stories and they love to tell them. (Maree)

Having a good relationship and faith in a medical professional was important to some participants as it provided an emotional support and someone they could rely on. Of the four that discussed their relationship with medical professionals, three had positive things to say about a particular doctor or nurse. For one participant, a lack of faith in new medical professionals led to decreased attendance at appointments that were potentially critical to his health and well-being. He reported he could trust his previous doctor to find what was wrong and promptly relay the information and he would routinely see and confide in the doctor regarding his health issues. Having relocated, he would skip appointments because he did not have trust in the new medical team.

I had such faith in my own doctor over in Adelaide, you know he was such a genuine man. And he was able to sit and talk with you and he really, if anything was wrong he was on to it straightaway you know. But here it’s, it just doesn’t seem that they care the same you know what I mean? I have trips where I have to go into Royal Perth [hospital], I’m supposed to go every six months. And it’s been well over six months since I’ve been. (Jim)
Desire to not be a burden

Remaining strong and not burdening their families with their problems was a key theme throughout several interviews. This desire often influenced the participants’ decision to relocate to an RACF in search of increased assistance. While grateful to have supportive families, participants’ narratives often indicated that they would rather overcome their issues on their own and suffer in silence than burden their families through relying on them.

I didn’t call on Ray, my son, at all because he had enough with his mother-in-law you know? You don’t slog something that’s down… If I called on Jan [daughter] she would have tried to do the very best she could to come…But I wouldn’t do that…She had enough on her plate, she has had a plate full and a bit more. (Eva)

FAMILY AND FRIENDS

Burden of caring - Life before the RACF

The participants who were family or friends of the residents reported that caring for a loved one with a significant illness impacted greatly upon their lives both pre and post relocation to the RACF. Their experiences often went beyond simply looking after a loved one living with cancer. As echoed in the residents’ interviews, other co-morbid health conditions were frequently discussed in addition to the management of cancer. These co-morbidities impacted on the participants and the amount of care they needed to provide. Residents who experienced other co-morbid health conditions, as well as cancer, often required greater amounts of care. Consequently their carers were often not emotionally or physically able, or professionally qualified to provide the care needed. Some of the participants described how this took a negative toll on their own health, and ultimately, led to the decision of their loved one moving to an RACF.

Anyway her condition when she goes into the depressive state of bipolar is very difficult to manage as a person, as a non-carer, a person that is a spouse because it’s so full on. But, for my own health, I had to decide with Maree that the best move was 24 hour care. I’ll be close by and doctors on hand, nurses on hand, rather than making appointments was the best move that we could make for Maree’s health and mine also. (Greg, Maree’s husband)

Participants described the emotional impact caring had on their lives. Their narratives outlined how caring for a loved one consumed them. Constant worrying or concern about their loved one’s ability to look after themselves often caused a loss of independence for the participant. Their loved one’s needs were constant and resulted in a decrease in their own independent occupational engagement. Sometimes this went so far as to change the nature of their visits entirely, from a social engagement to being purely dedicated to getting chores done.

So but then probably after she got back from hospital that’s when we had stepped up and started to do more and it got to the point where we weren’t even having a social life with her. We were just going down there, cleaning, changing the sheets on the bed, fixing up, you know, reticulation, like anything that was wrong … and we were coming home at 8 o’clock at night. You’d go down the whole day because we’d have to fit so much in. (John, Joy’s nephew)

Along with the emotional implications of caring, side-effects of cancer medications and treatment options had physical implications for both the residents and their family and friends. Managing pressure sores and incontinence, cleaning, cooking, travelling to/from appointments and other needs, often complicated the
process of caring for a significant other in the home. The time and energy required for taking care of their loved one’s health problems meant that sometimes, participants were unable to fully look after themselves, resulting in a deterioration of their own health.

But here [at home] he would sit in the chair and then he’d say “oh I’ve wet myself, you’ll have to change me.” And he kept me, and I was really working at it to keep him clean and that sort of thing. And I just, I was losing a pound a week. I dropped down from 75 kilos to 50. I couldn’t manage that. I was losing my strength. (Molly, Kevin’s wife)

Life since relocation to a RACF

Participants described the process of locating an appropriate RACF as being very difficult. Limited knowledge of procedures surrounding entering an RACF, a lack of suitable facilities for those younger than 60 years of age, and finding time to travel to investigate different locations were some of the problems listed by participants. However, most of the participants’ narratives around caring for their family members altered significantly once their loved one relocated to an RACF. By knowing that their relative or friend was in good hands, receiving the care that they required for their condition, worries and concerns about their loved one’s safety and health were able to be dispelled.

Yeah no, she’s very, I’m very happy. I’m very contented because she’s happy and she’s settled. We know she’s safe and her needs are being looked after. (John, Joy’s nephew)

For the most part, participants described how residents now had a more stable daily routine to follow, with increased support both physically and emotionally. Extra care and support provided by the RACF meant that participants felt there was not much more they could do for their loved one. This decrease in worrying allowed participants to re-engage in their role as a family member, rather than a carer, unhindered.

Probably two or three times, probably at the moment it’s about twice a week [we’d visit] but then we’d take her out for a coffee or something or lunch. (Pamela, Joy’s relative)

Maintaining autonomy

As reflected in the residents’ interviews, the issue of their loved ones maintaining independence in everyday decisions was of great importance to the participants. For many, allowing their loved ones to maintain autonomy in decision making, yet still trying to meet their health needs was a delicate balancing act. Although staying at home without appropriate levels of care meant that some residents’ and participants’ health would deteriorate further, participants described how it was important to them that the decision to relocate was entirely up to their loved one. Planting the idea and strongly suggesting the positives of relocation, without forcing the decision, was as far as the majority of participants were prepared to go. Family members did not want their loved one to feel pressured into moving and therefore, ultimately unhappy with the overall decision.

And so again I talked to him. Is this alright? Is it alright with you? He was always part of every decision I’ve made with him because I feel that’s important that he’s not railroaded into going where he didn’t want to go. (Kate, Alan’s wife)

As seen in the residents’ interviews, those who felt forced to relocate or were reluctant to relocate felt they had lost some autonomy in the process and thus, experienced difficulty adjusting to the RACF. Therefore, allowing the decision to be their relatives was particularly important, as it led to residents relocating at a
time when they felt they were ready. Participants described a moment when their relative independently realised it was the right time to move. Despite initial hesitation, this relocation was echoed by most residents and participants as being the best thing that they could have done, as it allowed the residents to retain their independence and also to receive greater levels of care to suit their ongoing needs.

I said to mum, “it’s up to you, you don’t have to go but there is a room available for you if you want it.” She said “I will have it.” ... And I left there and when I got to her in [name] she’d already packed her bags. She’d packed her bags so she knew. But having that week on her own she realised then she couldn’t do the things that she could do before the operations. And it was just, it just hit me like a rock you know, but I knew it was the right thing for her. And then three months later she was telling everybody “you know Jennie wanted me to do this five years ago” and she said but I wished I had of because she felt so comfortable here and she felt so, still felt she had her independence. She didn’t lose her independence by coming here. (Jennie, June’s daughter)

Independence in decision-making surrounding engagement was also a common theme found in the interviews. Residents’ engagement in activities available at the RACF was described as minimal by most participants. This was similar to the results found in both the residents’ and staff interviews. However, the lack of engagement in facility activities was often not a direct impact of cancer, as found in the staff interviews, but more often an autonomous decision made by residents due to lack of interest. Participants discussed how staff members tried to involve their relatives in bus trips, happy hour, and other activities on offer. Although staff members encouraged engagement, residents were not forced to do so, allowing them to maintain their autonomy in this aspect of their lives.

Basically he just stays in his room. They have and I know a lot of the staff have tried really, really hard to get him down to the [name] Centre. They’ve tried really hard to get him out on bus tours, so he has gone out on a quite a few bus tours. But to my dad that’s never been on a bus tour, compared to what he’s used to you know what I mean. Yeah to get taken somewhere and have an ice cream or a cup of tea and brought back, that was not, it just didn’t really, it wasn’t quite enough adventure in it for him yeah. (Alex, Bill’s son)

Satisfaction with the RACF – the importance of staff

Being within the local community, having a homely feel, or decreasing social isolation were a few reasons listed by participants as to why they were satisfied with the RACF. However, the main overarching reason surrounding participants’ satisfaction was the level of care provided by the staff. Reiterating the findings from the residents’ interviews, staff promoted residents’ engagement in activities, increased their level of social interaction, were seen to go ‘above and beyond’ for residents, and were generally perceived as friendly and approachable. Participants depicted how staff took notice of their relatives’ moods, habits, and general level of health, informing them in regards to changes in their emotional or physical state, and thus, including them in the provision of care. Additionally, participants described how if they had their own concerns about their relative’s health or treatment, staff adequately responded to their queries. This inclusion of family members in their loved ones’ care helped to build trust between the participants and members of staff, increasing their overall satisfaction with the level of care provided.

Well I think his care there is good. I worked in aged care when I was an immigrant here many years ago and I think it’s good care. If ever I ask for anything it’s done. ... Yeah and I feel they
take notice of what I ask. Yeah I would have no qualms about his care there, I can’t imagine how they could do anything better really. (Kate, Alan’s wife)

The attitude of the staff towards a cancer diagnosis and treatment was important as to how the resident coped with their condition, and thus the participants’ satisfaction with the level of care provided. Staff were generally seen by participants to understand, acknowledge, and/or relate to the residents’ specific health conditions. For one participant, the effort staff provided in trying to promote positives and minimise the negatives of a cancer diagnosis and treatment was greatly appreciated, as their positive attitudes helped to provide an important emotional support for his wife.

But I’m not quite sure what else could be improved because they do everything possible to keep her stimulated and talk positive about this cancer, that it’s not that bad. And even when her hair was all falling out they said “well don’t worry, we’ll put a cap on and look at Greg, he’s got no hair either” and so on. So they look at the positive side and then they relate stories about how they know somebody or themselves who’ve suffered from this and they’ve come through it so there’s a lot of positive feedback given to Maree that is very beneficial. (Greg, Maree’s husband)

Similarly, dissatisfaction with the RACF was linked to whether family and friends or the resident liked the staff. While the narratives described overwhelmingly positive interactions with staff, one participant outlined how she was less than impressed with the RACF. A high proportion of staff speaking minimal English, coupled with a somewhat transient nature of employment and minimal supervision led to an inability of the resident to form meaningful relationships with the staff and overall dissatisfaction with the facility from both the resident and their family.

And he’s never really been happy there. ... He doesn’t like the fact that there’s an awful lot of foreign girls and boys. ... These carers don’t suit him. If they all spoke English he wouldn’t mind but see a lot of them can’t speak English. They’ve got a few words and that’s about it. ... Nothing is ever put away. When I go there I put it away because my instinct is to do it and I can’t help it. Things are left lying around, I get there and the laundry has come back and it’s still on the bed. That sort of thing is to my mind not good. The work is not supervised. This is the chief problem as far as I can see. There’s no one that does this supervision. There’s two carers that are trained. The rest of them are “come and goes”. (Molly, Kevin’s wife)

THE STAFF

The eleven participants who were staff working in a RACF were all female, aged from 30 to 59 years and had worked in the RACF from between one week (with experience elsewhere) and six years. Most had been in their current place of work for less than three years. Staff from all four RACFs were interviewed, with their jobs ranging from housekeeping to managerial positions. All had face to face contact with the residents on a daily basis. Nine of the staff were born outside of Australia.
Table 5: Demographic details of the RACF staff

<table>
<thead>
<tr>
<th>RACF*</th>
<th>Staff</th>
<th>Position at RACF</th>
<th>Age</th>
<th>Country of origin</th>
<th>Time in Australia</th>
<th>Time working in the RACF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valley Care</td>
<td>Mary</td>
<td>Registered Nurse, previously a personal carer</td>
<td>Missing Data</td>
<td>Kenya</td>
<td>4 years</td>
<td>2 years</td>
</tr>
<tr>
<td>Valley Care</td>
<td>Wahidah</td>
<td>Housekeeping</td>
<td>58</td>
<td>India</td>
<td>2½ years</td>
<td>1½ years</td>
</tr>
<tr>
<td>Valley Care</td>
<td>Joan</td>
<td>Physiotherapy assistant</td>
<td>59</td>
<td>England</td>
<td>33 years</td>
<td>3½ years</td>
</tr>
<tr>
<td>Riverside Care</td>
<td>Chadna</td>
<td>Physiotherapy assistant</td>
<td>30</td>
<td>India</td>
<td>2½ years</td>
<td>2½ years</td>
</tr>
<tr>
<td>Hillside Care</td>
<td>Lorraine</td>
<td>Management position</td>
<td>55</td>
<td>Scotland</td>
<td>28 years</td>
<td>6 years</td>
</tr>
<tr>
<td>Hillside Care</td>
<td>Sophie</td>
<td>Unit manager</td>
<td>Missing Data</td>
<td>Missing Data</td>
<td>Missing Data</td>
<td>Missing Data</td>
</tr>
<tr>
<td>RSL Menora</td>
<td>Christine</td>
<td>Clinical nurse manager</td>
<td>52</td>
<td>England</td>
<td>25 years</td>
<td>16 months</td>
</tr>
<tr>
<td>Hillside Care</td>
<td>Danielle</td>
<td>Occupational therapist</td>
<td>47</td>
<td>South Africa</td>
<td>5 years</td>
<td>2 years</td>
</tr>
<tr>
<td>Hillside Care</td>
<td>Connie</td>
<td>Enrolled nurse</td>
<td>47</td>
<td>Mauritius</td>
<td>43 years</td>
<td>1 week (4 years at another facility)</td>
</tr>
<tr>
<td>Hillside Care</td>
<td>Nancy</td>
<td>Care services manager</td>
<td>43</td>
<td>Ireland</td>
<td>5 years</td>
<td>3 years</td>
</tr>
<tr>
<td>Hillside Care</td>
<td>Maureen</td>
<td>Chaplain</td>
<td>55</td>
<td>Australia</td>
<td>N/A</td>
<td>6 months</td>
</tr>
</tbody>
</table>

*RACFs, residents and family members/friends were all given pseudonyms to ensure confidentiality

The staff reported that RACF residents living with cancer faced a number of day to day difficulties. However, they also noted a range of strategies that residents used to cope with and normalise the process of day to day life with cancer as a frail older person living in an institutionalised setting. As with the previous interviews with residents and family members, the overarching theme of decreased engagement in life for residents living with cancer emerged.
The challenges of living with cancer in a RACF

The staff participants noted that the residents living with cancer present with different types of cancer, and varying experiences regarding their symptomology and coping mechanisms. Residents experience physical symptoms and treatment-related issues similar to those evident in the wider cancer literature. The most common problems noted were the presence and management of pain, fatigue, loss of appetite and side effects of treatment such as nausea and hair loss. The emotional issues included fear about the future, pain, treatment and dying, and worry about their family and social image.

I think it’s fear of the unknown, they do have a fear of that. Where do I go, what’s going to happen to me and they’re afraid of the journey ahead. (Christine)

Also common to the general experience of cancer were the different coping methods identified, based on the stage of the residents’ condition. The residents who had received their diagnosis before coming into the facility, or who had had the diagnosis for a longer period of time, were generally more accepting of their condition. Those who received their diagnosis when they were already in the RACF or those who were in remission or in acute stages of the condition often had more difficulty accepting the condition and experienced feelings such as denial, questioning and anger.

Although she’s not religious she blames whoever has given this to her and she really struggles in accepting that she is sitting personally with this and she’s asking of course “why me”, where she was quite keen to just be frail. (Danielle)

However, the staff noted specific issues which may further complicate the experience of living with cancer for the residents. They may face additional issues due to their age, such as a decreased capacity to manage the physical manifestation of the illness, as well as the presence of often multiple comorbidities.

They feel that their age is against them, you know, if you’ve got cancer then you’re, I mean at a certain age you can either fight it or you can’t. (Connie)

The residents living with cancer were also perceived to be private and stoic in relation to their condition, and it was noted that the majority would not talk about their cancer with the staff.

No, no he does not talk about his cancer at all and even when I’ve tried to broach that with him he doesn’t speak about it. He says “oh well you know I’m alright, I’m alright you know”. I think it’s part of being stoic, you know it’s, men, that generation in particular, a lot of the men do not talk about their feelings and if he was to talk about his cancer he would have to talk about his fear and probably his fear of the way he would die or could die. (Maureen)

The RACF context limits the amount of privacy allowed to residents due to the close proximity of other residents and of the staff entering their rooms to perform their various duties. As the disease progresses residents living with cancer also often require increased assistance from nursing staff, resulting in decreased independence in activities of daily living.

She has to slow down now, because I remember earlier, you know, because she’d go and she’d shower herself ... now the carers do, the carers come. (Wahidah)
RACFs also often encompass quite a rigid routine, so as well as experiencing a decrease in independence, residents with cancer may also have little choice or control over their daily life. As a result, while many of the residents try to maintain as normal a life as possible, as their condition deteriorates, this becomes more and more difficult due to the associated reductions in privacy, independence, choice and control.

**Participation and social contact**

It was evident from the interviews with the staff that the residents’ physical symptoms of cancer impact on their participation and social contact with others. Of particular concern were pain, fatigue and nausea which often cause the residents to spend more time in their rooms and may prevent them from engaging in scheduled activities with other residents.

Because, for someone with cancer who’s got pain, who’s got, discomfort, for them to go and sit for a length of time would restrict them, they go down, they sit for as long as they can, when they’ve got their pain, they’ll get up, and they’ll, go for a walk or go back to their rooms or go into the lounge, so yeh, it would, time wise it would restrict them, discomfort and pain, to be able to fulfil or go through with the whole activity. (Joan)

As one interviewee described, the cancer can sometimes not only impact the residents’ participation in the social activities of the facility, but also their own leisure and self-care occupations within their own room.

Well she couldn’t do her knitting, she struggled dressing herself and she used to look forward to outings and then just plainly said no and also her family haven’t taken her out that much because she doesn’t benefit from it that much, it’s just very exhausting. (Danielle)

It was also noted that environmental constraints may further restrict residents’ participation if activities were only scheduled at a certain time of day, due their cancer-related symptoms such as pain and fatigue.

Most of them could probably still do most of the activities that are happening...but it’s whether the timing of it is right. So where they may be able to play bingo if it was in the morning, well bingo’s usually scheduled for the afternoon because in the morning the OTAs [occupational therapy assistants] are busy doing exercises and things like that. (Maureen)

The bus trips are in the afternoon now, so, by the afternoon, she knew she couldn’t go. (Joan)

The residents’ sense of self image was also identified as a barrier to their participation. The staff reported that the residents were often concerned about being identified as having cancer. This was noted as being particularly relevant when residents have externally presenting symptoms such as hair loss or stomas.

Sometimes they don’t, once again they don’t want to come out their room, they feel like they look like a horror show, they just do because especially if they’ve got a good head of hair before and they’ve got curls and everything. (Christine)
Dealing with the changing and deteriorating body caused by the disease process and treatment often resulted in isolation and withdrawal, with the residents spending a lot more time alone. This allows few opportunities for social engagement and for forming relationships, as one interviewee explained.

It can be isolating. Generally residents don’t go into one another’s rooms because that’s their private space. I think that they can invite someone into their room but you don’t see it very often and so for somebody who has cancer it may mean that they’re not seeing the people that they’ve built up friendships with. (Maureen)

**The need for appropriate support**

One of the key factors identified was that residents living with cancer reach out to others for support. This was frequently linked to the idea that the residents are unsure of how much time they have left and do not want to feel alone.

I mean everyone in here know their end’s coming, but when you’ve got cancer, you know your end’s coming quicker, and they reach out a lot more. (Joan)

They don’t talk about cancer it’s just you know, emotionally hanging onto the staff. (Chadna)

The majority of participants identified family as being an important support for the residents with cancer.

It is one of those things that everyone knows that it can mean that you’ve only got two years left or whatever it is, their family are probably the most important thing in their life at that point and I think connecting with their family. (Christine)

The staff also noted that if the residents living with cancer do not have regular contact with their family they often reach out and rely on the support of the staff. This may be particularly significant for those residents who are largely isolated to their rooms, as the staff are their main form of social contact. While many of the staff did admit to having close relationships with some of the residents, most described these more as friendly relationships rather than actual friendship. Even if some of the residents may not have actual friendships with staff, they still reach out for company, or simply to be acknowledged.

The only things they’ll ask for is they might ask you for something, you know can you get me this or can you get me that as a ‘breaking the ice’ to ‘you know I’m still here, I’m ok’. (Nancy)

They do have some staff on which they really, you know hang on and ask them this or that, try to keep them in their room so they can talk to them and all. (Lorraine)

One staff member also discussed the fact that residents were sometimes able to speak more openly about their cancer with staff who had been closely affected by cancer within their own lives, and that they feel more supported with the knowledge that the staff understand what they are going through. Spiritual and religious support was also mentioned by several of the staff as an important factor, especially with residents who were struggling with accepting their condition, or had a fear of the future and life after death.
STUDY LIMITATIONS

This was a small exploratory study where we hoped to uncover some of the challenges faced by people living with cancer in Western Australian RACFs. There were a number of limitations associated with the study. In the first phase we used a data set for secondary analysis which we have used in previous studies (McNamara, Rosenwax & Holman, 2006; McNamara & Rosenwax, 2007a; Rosenwax, McNamara, Blackmore & Holman, 2005; Rosenwax & McNamara, 2006). The data was ten years old and as a consequence the figure reported of 11% of residents with cancer on their death certificates is not current. We are in the process of securing more recent data from the Health Department of Western Australia and will repeat this study to provide a more up to date figure. It should be noted that this process is quite complex as place of death is not routinely collected and identifiable data is not usually released by the Health Department. The exercise is costly and time consuming which is why the researchers did not include more recent data in this small study.

The first phase of the study was reliant on the accuracy of diagnoses recorded on the death certificate and on the veracity of morbidity records. Data Linkage studies use administrative data which are not collected for research purposes. The information we provide cannot take into account the severity of symptoms and the individual circumstances of patients so only allow a limited view of health service use. Nevertheless, our study was able to establish that people with cancer who live in RACFs use hospital services more and for longer periods of time than residents who do not have cancer. In all, there is much scope for further quantitative studies on cancer in RACFs to truly understand the size of the issue.

As noted previously we found it difficult to recruit participants into the study. While measures were taken to work collaboratively with RACF managers, staff and residents to ensure success in recruitment of participants, we found that many of the RACFs we approached were reluctant to identify residents with cancer. Once identified, many of the residents were reluctant to discuss their cancer in an open fashion, which at times, gave the impression they may not have been fully aware of their diagnosis and its implications. We would have preferred a bigger sample size for the participants as we believe a greater number of interviews may have uncovered other issues, or in the very least further confirmed our findings.

CONCLUSIONS

Our study has been able to give an indication of the number of people who live and die with cancer in Residential Aged Care Facilities. Although these figures are now somewhat dated, they give an indication that living with cancer and caring for a RACF resident with cancer is an issue which needs to be addressed. Findings from an extensive literature review, as well as our own findings, indicate that residents in RACFs have a range of comorbidities. It is not simply ‘living with cancer’ but living with a range of complex symptoms overlaid with the anxiety of a cancer diagnosis and cancer treatments and side-effects. Our findings confirm that RACF residents living with cancer face additional burdens to those faced by other residents with long term chronic conditions that may have similar physical symptoms.

As cancer has a more predictable disease trajectory than other complex chronic conditions (Lunney, Lynn & Foley et al., 2003), a cancer diagnosis can be frightening and a sign of approaching death (McNamara, 2000). Although, recent medical advances in cancer treatment have challenged this view, older people often hold on to long held views about medical conditions. The residents’ reluctance to discuss their cancer diagnosis, which contrasted strongly with their willingness to discuss general symptoms and complaints,
confirms our view that RACF residents may suffer from perceived stigma associated with cancer. Although residents with cancer made excuses for their reclusive behaviours, RACF staff reported that residents with cancer were often anxious about their symptoms or so fatigued that they found it difficult to participate in social activities. Living with cancer reduces their ability to engage in meaningful and potentially enjoyable occupations.

Family members reported that the RACF provided a vital function in caring for their loved ones. Many felt that prior to their relative’s admission to the RACF, their own health and well-being suffered through the effects of providing both physical and emotional support. We believed it was important to interview family members of residents with cancer in order to get a further insight into the challenges of living with cancer in a RACF. However, in addition we gained insight into what it is like to be a carer for an older person with cancer. Carers face the same uncertainties as the person with cancer and require support as well.

RACF staff reported that residents with cancer have specific needs and reach out for additional support. Often the staffing in Australian RACFs is insufficient to provide this level of care. As well as providing important insights into what it is like for residents living with cancer in RACFs, our staff participants indicated the additional challenges that caring for a resident with cancer entails. Many indicated their desire for further training so that they can better support residents with cancer, most of whom have various comorbidities. Due to the increased occurrences of cancer it is envisaged that the number of people living with cancer in RACFs will increase. It is important, that policy makers in aged care anticipate this increase and provide sufficient resources to address the specific needs of residents with cancer.

RECOMMENDATIONS

- RACF staff, residents living with cancer and their families should be provided with educational training and resources about cancer, its prognosis, the associated physical and psychological symptoms, and appropriate means of symptom management and support. Ideally resources should be made available in a format that is accessible to older people, most of whom are not interested in internet sites and dense literature.
- Cancer specific support from palliative care services and Cancer Council staff would assist in the care of residents with cancer.
- RACFs need to be aware of the specific needs of residents with cancer and provide increased flexibility in the timing and types of facility activities. Training and resources will assist in meeting this recommendation.
- In line with Australia’s need for Aged Care Reform, increased funds need to be provided to RACFs for the care of residents with specific needs. Advocates for RACF residents with cancer are needed. These may include Aged Care providers as well as the Cancer Council.
- Further research is required to extend this exploratory study. This should include quantitative studies to provide recent figures on those with cancer in RACFs and their health service use. Further qualitative studies may help document the experiences of residents in a range of Australian RACFs, including those in rural and regional areas and those who cater to specific groups of clients, including Indigenous people and people from culturally and linguistically diverse backgrounds.
REFERENCES


