

Factors affecting provision of care services for patients with cancer living in the rural area: an integrative review

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Abstract

This paper explored individual- and system-level factors affecting the provision of care services for rural patients. An integrated literature review across four databases identified 22 studies from six countries. A focus on health and wellbeing and the influence of rurality was explored. Findings indicate physical and functional health in rural cancer patients is lower in comparison with urban areas. Influencing factors were socio-economic status, age, income, health literacy, control and self-efficacy. Enhancing the strengths and education of caregivers and their inclusion in service decision-making are paramount for rural cancer patients and for the wellbeing of the caregivers. Disparities in rural areas need to be explored with longitudinal research to understand the clinical, social and cultural characteristics in relation to remoteness. The use of innovative technologies has been recommended as an option to enhance the health access and enable quality care provision across rural areas.

Knowledge translation

- The facilitation of access to innovative health care to balance the disparities of rural people (telehealth, online support groups, follow-up phone calls, enticement for specialist care in rural areas).
- A holistic approach with education and support provided to the family is particularly important for rural patients as the family is a key source of social, emotional and informational support over the journey.

Introduction

Geographic location can be considered as one of the significant disparity indicators among cancer patients^{1,2} influencing access to appropriate professional and social support³. Research has highlighted that rurality is linked with higher level of morbidity and mortality in cancer patients². Disparity in rural areas can be divided into two levels: individual and system. The key factors at the individual level are the level of education, health literacy, income of the person and family, personal attitudes, social

norms¹, family responsibilities⁴, age, race, ethnicity⁵, as well as remoteness of the home environment. Factors related to system level can be lack of access to services, travel time and distance, insurance coverage, health care expenses and transportation¹⁵.

Rural patients with cancer have lower access and usage of health care services due to the distances from health services⁶ as well as fewer social and community support groups¹. The level of care and support that cancer patients receive during the transition to survivorship is critical. Patients and their carers confront the reality of moving from a supportive system within a health service to management of the continuing treatment effects in the home environment^{7,8}. Rural patients may be at higher risk of poor physical health outcomes, which can lead to mental health problems⁹ such as higher levels of distress, anxiety and depression².

Although there has been increasing research regarding the needs of cancer patients (health care, community, social care needs), there has been little focus on the care needs of patients in rural areas². The number of rural patients is under-examined in the

research and there has been limited research about their care, emotional and psychological health, and wellbeing¹⁰. In addition, there is a risk of generalisation from research exploring rural persons with cancer as rural characteristics and culture differ greatly^{6,11}. Furthermore, most of the research explores patients' experience, with little exploration of the experience of the carer¹².

The aim of this study was to:

1. Explore the most common research measurement for assessing care needs (for example, health care, community and social care) of rural cancer patients.
2. Explore the factors affecting provision of care services for patients with cancer living in the rural area.

Design

An integrative review framework was used to investigate the influencing factors to care for rural patients with cancer. An integrative review includes a diverse range of papers to provide a deep understanding of the health care issue. Hence, an integrative review can be beneficial in providing sound information which results in theoretical knowledge as well as facilitating translation of research to practice. However, an integrative review can be criticised for the possibility of bias, particularly in the analysis section, which can be resolved and/or strengthened by including analytical/advanced quantitative/qualitative analysis techniques¹³. An integrative review framework by Whittemore and Knaf¹³ was used, which included five stages: problem identification, literature search, data evaluation, data analysis and presentation.

Problem identification

This review used PIO framework (population, interest and outcome) for structuring the research question. The population included cancer patients, and carer/cancer caregivers; the interest was rural; and the outcomes were the provision of care services, including health care and community support services received. Question formulation occurred through regular meeting of the authors and consensus achieved two key questions:

1. What are the common research measurements for assessing care needs (for example, health care, community and social care) of rural cancer patients?
2. What are the individual- and system-level factors (facilitators and barriers) affecting provision of care services for patients with cancer living in rural areas?

Literature search

The following inclusion criteria were considered for this systematic literature review: inclusion of both quantitative and qualitative studies to explore both how the measure of care

needs was completed but also the context around rural patients' needs during cancer. The time period of 2006–2018 was used as there has been an increasing amount of research in rural areas during the past decade. We included articles that were with either patients or their carers, peer-reviewed, written in English, and that described a measure for assessing the care needs of patients/carers of rural cancer patients. Papers were excluded if they did not identify care needs assessment associated with cancer, or only a small part of the paper was related to care needs assessment; the main focus was on health and wellbeing outcomes of patients/carers and not on the influencing factors and care needs; or they were not related to any cancer diseases, but focused on the diagnosis of cancer. We excluded papers that concentrated on prevention; focused on screening programs; focused on interventions to decrease disparities, a very small proportion of the paper was about rural populations, exploring the death and survivor trends; focused on the diagnosis and treatment variations; focused on diagnosis differences/stages and review papers/protocols/commentaries/books and those that were not conducted during 2006–2018.

There is a variety of different definitions regarding the rural areas based on different countries, which is mainly based on the population size/density, degree of urbanisation, and distance to the metropolitan areas (for example, areas outside the metropolitan areas that have a population of at least 1000 persons per square mile)¹⁴. Rurality can be defined by other social and cultural characteristics that are beyond only the sample and density of the population¹⁵. In the current literature review, international studies that were conducted in rural areas and identified their population as rural were included, regardless of their definition of rurality. There are diverse definitions for caregivers. For example, it can be defined as unpaid care and services, other social ties which can include a diverse ranges of individuals from other family members, or friends, and neighbours who are experiencing illness and/or chronic issues¹⁶. For the purpose of this study, the definition provided by Wright and Leahey was used¹⁷, defining family/carer as individuals who are connected by strong emotional ties, with a high sense of belonging, and responsible for/a commitment to be involved in another's life.

Procedure and quality assessment

Four databases (CINAHL, Medline, PsychINFO, Informit Health – English language only) were searched using the following terms: “rural cancer patients” AND “carer” OR “cancer caregiver” AND “cancer” OR “oncology” AND “psychosocial resources” OR “health resources” AND “rural”. After removal of duplications and irrelevant articles, 54 papers remained. A further 25 papers were added through the reference list and snowballing. A total of 79 papers remained for further investigation. The remaining full-text articles were reviewed by the three authors (EC, AS and VF) and a further 57 articles were excluded based on the inclusion

and exclusion criteria (Figure 1). Data were extracted from the final 22 papers and entered into an Excel spreadsheet across the categories: author(s), year, country, study aim, research design, sample, care needs assessment, key findings, MMAT scores, and limitations of the research (Table 3).

For quality assessment, the Mixed Method Appraisal Tool (MMAT) was used¹⁸ as the validated tool, which is considered appropriate for reviews including different types of studies (for example, quantitative, qualitative and mixed method). MMAT provides a quality assessment from 0, 25, 50, 75 and 100, the higher number indicates the higher quality of the paper¹⁹.

Synthesis and analytical approach

Initial data were extracted from the primary papers; the main categories related to care needs and influencing factors to care for the patient and family as well as the key measurement tools for assessing the care needs of the patients in the context of the rural and remote areas. A content analysis was used including coding of the extracted data from the primary papers; creating categories by combining the relevant codes²⁰. In addition, the measurements (including both quantitative and qualitative) used for assessing care needs of the rural patients and their carers were categorised.

Results

Descriptive findings and measurement tools for assessing care needs

A total of 22 papers were included in the review. The majority of studies were conducted in United States (n=13), followed by Australia (n=6), Scotland (n=1), Germany (n=1) and Uganda (n=1). Studies included a diverse range of cancers, including: breast cancer (n=6), colorectal cancer (n=3), lung cancer (n=1), malignant

neoplasm (n=1) cancer and haematological cancers (n=1). A total of 10 studies did not focus on any specific cancer, rather explored a combination of cancers and/or advanced cancer as a general concept. The majority of studies were quantitative (n=14), followed by qualitative studies (n=5) and mixed-method studies (n=3). Studies measured patients' care needs and access to services. A number of recruitment methods were used, including mailed, paper-based, telephone-based or competed during treatment surveys¹⁵. Follow-up phone calls and incentives were reported to increase recruitment and retention^{11,21}. Most studies' response rate was less than 50%, highlighting the difficulties of recruitment and retention of rural patients.

The quantitative measurements included: a) socio-demographic variables, such as personal information, socio-economic status, disease status and determination of rurality/rural classification; and b) health and wellbeing comparison between cancer patients in rural and urban areas, including a comparison of subjective wellbeing and functional performance. The health and wellbeing outcomes were divided into interconnected factors, such as physical, psychological, social and behavioural health, c) measuring disparity levels and impacts of proximity to treatment facilities on the treatment choices. This included factors such as travel distance, travel patterns, access to services and the related consequences such as financial burden.

The qualitative aspects of care needs, focused on overall experience of cancer survivorship in rural areas, the issues related to the service provision, receiving information by patients/caregivers, their communication with providers and experience of health care providers in service provision to rural cancer patients. The qualitative aspect of the research provided an in-depth insight to the barriers of care provision.

Both quantitative and qualitative measurements indicated that the concept of rurality was a risk factor for low mental health, low quality of life, low physical wellbeing, poor self-rated health, higher level of distress, smoking and lower level of physical activities^{3,4,8,9,11,14,22,23}. A summary of the key variables/measurements for both quantitative and qualitative studies is provided in Tables 1 and 2.

Barriers and facilitators of care provision

Barriers and facilitators of the care provision were categorised into influencing factors at individual and system levels. Individual-level influencing factors concentrated on the socio-economic and/or psycho-social factors, while system-level factors focused on the community and organisational level influencing issues.

Influencing factors at individual level

Influencing factors at the individual level included socio-economic status, and psycho-social factors impacted the usage of health, social and community services.

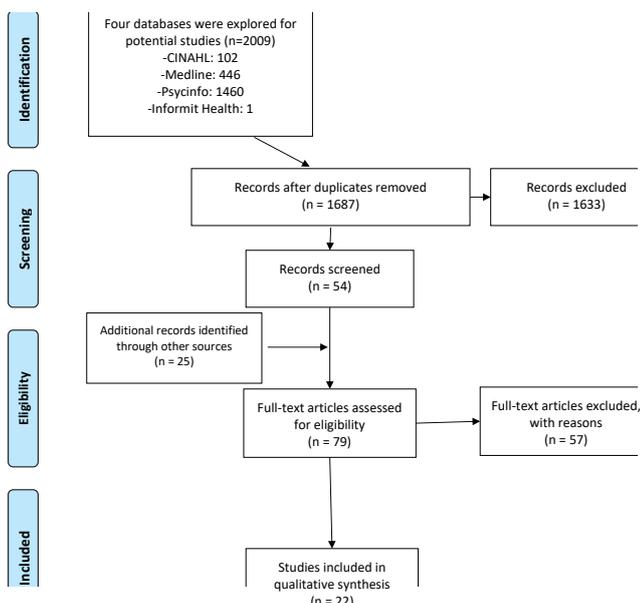


Figure 1: Prisma database search process

Table 1: Quantitative measurements for health and disparity level in rural cancer patients

Variables		Measurements
Socio-demographic variables	Personal information	Age, gender, marital status/relationship status, children, race/ethnicity place of residence race/ethnicity, sex
	Socio-economic status	Income/annual household income categories, home ownership, employment status, educational level
	Disease status	Physical health measure Cancer-specific: type, location, time since diagnosis, stage, treatment schedule Co-morbidities (i.e., diabetes, heart disease, stroke, asthma), amount of treatment completed
	Determination of rurality/rural classification	Access to medical care Travel related to their cancer, including distances travelled to visit their general practitioner and their treating specialists
	Other	The experience of death of close social member
Health and wellbeing outcomes	Physical health	Self-rated health (single question) Medical Outcomes Study 36-Item Short-Form Health Survey Physical co-morbidity Medical outcomes study 12-item short form health survey Physical health measure/check-up
	Psychological and mental health	HLC (health locus of control) Life satisfaction Depression scale Mental Health Resource Questionnaire (MHRQ) Hospital Anxiety and Depression Scale Distress Thermometer Perceived Stress Scale QoL using the Functional Assessment of Cancer Therapy (FACT-G) questionnaire Quality of life – Cancer survivors scale; attitudes towards mental health resources Mental health outcomes Psychological functioning Coping Stanford Emotional Self-Efficacy Scale – Cancer Psychiatric Epidemiology Research Interview Life Events Scale CSMH resources (cancer-specific mental health resources) and Mood Disturbance; Evaluation of the Questionnaire on Distress in Cancer Patients – Short form (QSC-R10) The Patient Health Questionnaire (PHQ-4 measurement of depression and anxiety)
	Social health	Doctor–patient relationship Social support seeking CUCLA Social Support
	Behavioural health	Physical activity (single question)
Measuring disparity levels	Geographic location	Geographic location of patients residences compared to providers Matching the postcode to urban/rural residence
	Travel time	Calculating “the travel time by computing the road distance between two population centroids: the patients and the providers’ zone improvement plan codes” Longitudinal cohort information in order to measure travel time to cancer treatment, living away from home for treatment, travel-related treatment decisions
	Disparity comparison	National health population characteristics Rural–urban residence; and their health status; to measure the disparity Locational and financial barriers to accessing care; financial and social impacts

Table 2: Qualitative variables exploring overall experience of cancer survivorship in rural area

Topic	Content
Information	<ul style="list-style-type: none"> - Physical aspect of the illness - Psychological aspect of the illness, including the first reaction to the illness, and how participants cope (emotionally and spiritually) - Social aspects of the illness (e.g., social burden, issues related to the social support perceived and received)
Services	<ul style="list-style-type: none"> - The services received by the individuals and their family members/carers - Disparities perceived about care provision by the individuals and their family members/carers - Patients and families feedback about the social, financial and informational /services/support - Barriers to seeking diagnosis - Perceived causes of and cures for cancer - Experiences with physicians and the out-of-hours services
Experience	<ul style="list-style-type: none"> - The experience of health providers (e.g., general practitioners) and their role in cancer management

The key socio-economic variables included education/health literacy/health-consciousness. A higher level of education and health literacy were among factors improving individual health beliefs, self-efficacy, understanding and attitude towards the service usage and help seeking^{8,24,25}. This was particularly evident in isolated rural areas where limited resources often meant less anonymity of care¹. Rurality was also related to a low level of information, lack of awareness or knowledge about the illness, available services, positive coping strategies^{8,24,25}, and lack of informational support^{26,27}. One of the possible reasons for this could be the result of a lack of constructive communication between service providers and patients/family members^{26,28}. In addition, living rurally results in lower access to the internet/health information and limited access to other social and community services, such as supportive survivors' cancer groups^{8,22}. In an American study investigating the survival care plans, a lower percentage of rural people (62%) received advice regarding cancer follow-up care in comparison to urban survivors (78%)²³.

The key psycho-social factors included self-efficacy and confidence, which could be affected by fear, sadness, courage and faith in the health care system, as well as the informal social support received. These factors consequently impacted patients' engagement and treatment²⁸. In addition, it was reported that patients with low emotional self-efficacy have a higher level of mood disturbances²⁵, which possibly impact their help seeking for support services. Some of the participants felt isolated and depressed as a result of being diagnosed with cancer and this continued during the process of treatment²⁸. Cancer patients' perception about the informal support they receive (for example, strong family relationships/support) influenced their service usage⁷. However, too much reliance on informal social support such as family resulted in a sense of coping, decreasing the use of more formal services²⁴. On the other hand, some of the cancer patients had concerns about family/children and being a burden to them²⁸ subsequently decreasing their

problem sharing and help-seeking strategies with family²⁴.

Influencing factors at system level

The most common cancer burden at the system level in the rural area was related to the distance/travel burden, which can result in social and financial burdens^{5,29-31}. Cancer survivors living in remote and rural areas had 17 times more financial and travelling burden³¹. In addition, travel burden resulted in the over-reliance on general practitioners due to limited access to specialist care⁵. Time and travel burden are of particular concern for those patients who may require more consultations or specific types of care due to undertaking specific procedures, or for older cancer patients^{30,31}.

Having a cancer diagnosis while living in rural areas can restrict the social inclusion of individuals in other informal and formal activities (for example, employment and recreation activities)^{1,9,14}. Social concerns and their link to the lack of availability/accessibility of services resulted in a higher level of cancer burden. The review highlighted that limited services including community and social care support were available for people with cancer in the rural areas^{1,26,28}.

Fewer health professionals desire to work in rural areas (due to travelling, distance or isolation), particularly in some specific areas such as mental health, influencing the availability of rural services^{9,32}. Corboy *et al.* suggested that appropriate health services and facilities must be available in the specific community to enable service use²⁴. It was also reported that diminished quality of life, mental health and wellbeing of rural patients^{1,22} are related to organisational factors (for example, limited mental and social services), and different psycho-social factors. The difference in societal acceptance of mental health in the rural community can be one of the main reasons impacting the creation of social and mental community support groups¹. However, according to Corboy *et al.*²⁴, some of the cancer patients (particularly males) as well as health care providers suggested that lack of service availability is not the main reason

Table 3: Characteristics and key findings of the included papers

Author(s), year, country	Study aim	Research design	Sample	Care needs assessment	Key findings	MIMAT scores	Limitations
Andrykowski, Steffens, Bush, Tucker 2014 USA	To identify disparities in mental health outcomes in lung cancer survivors associated with rurality of residence.	Quantitative survey Telephone interview	193 adults Lung cancer RR 26%	Demographic and clinical information, co-morbidity Medical Outcomes Study 36-Item Short-Form Health Survey Hospital Anxiety Depression Scale Distress Thermometer Perceived Stress Scale	- Poorer mental health outcomes in rural areas - Need to understand differences between different cancers	75% RR 26%	Lack of generalisation of the sample Need for longitudinal design
Andrykowski & Burris 2010 USA	To examine the use of mental health resources in rural and non-rural survivors.	Mixed-method survey Telephone interview	113 adults Rural: 51 Non-rural: 62 Breast, colorectal, haematological cancer RR 34%	Demographic and clinical information Mental Health Resource Questionnaire (MHRQ) assessing formal and informal mental health resources used	- No big difference between urban vs. rural - Poor access to mental services - Low level of social norm in access to mental health services in rural areas (stigma)	75% RR 4%	Small sample size; measures did not cover all the mental health resources Need for extended research
Baldwin, Cal, Larson, Doble, Wright, Goodman, Matthews, Hart 2008 USA	To examine the travel patterns and distances of rural and urban colorectal cancer (CRC) patients to 3 types of specialty cancer care services — surgery, medical oncology consultation, and radiation oncology consultation.	Descriptive quantitative Cross-sectional retrospective	2743 Patient records Colorectal cancer	Medicare survey claims analysed for: Geographic location of patients, their cancer care providers, the closest cancer care providers to their residences, distance in miles between patients and their actual or closest providers.	- Long distanced travelled for treatment - Need to understand cost benefit of services	100%	NA
Beck, Towlsley, Caserta, Lindau, Dudley 2009 USA	To examine the symptom experience, quality of life, and functional performance of urban and rural elderly cancer survivors at 1 and 3 months after the completion of initial treatment.	Mixed-methods survey Semi-structured interviews	62 adults All cancers No RR identified @12% from reported numbers	Brief pain inventory-short form General fatigue scale Pittsburgh quality index Geriatric depression scale-short form Health-related QoL, functional performance Qualitative interviews: story of the symptom experience	- High medical symptom burden for both rural and urban cancer patients - No significant difference in the illness symptoms in rural and urban areas - Low physical health status in rural cancer patients which shows higher level of treatment burden on this population in comparison with urban areas - Rural cancer patients require more education, knowledge and literacy regarding their illness, coping strategies and managing the symptoms of their illness	75% No RR	Small sample size for survey
Beraldi & Kuikk 2014 Germany	To establish whether mental health outcomes, attitudes towards cancer-specific mental health resources, and the availability of such resources differ between rural and urban cancer patients.	Quantitative survey	534 adults Colorectal cancer RR 89% 3 sets of follow up	Demographic and clinical information Distress Thermometer Questionnaire on stress in cancer patients QSC-R10 Patient health questionnaire PHQ-4 Determination of rurality Attitudes towards mental health resources Definition and investigation of CSMH resources	- Overall, the knowledge and usage of the CSMH resources was low in both urban and rural areas; however, rural patients have a better doctor-patient relationship - Positive relationships between patients and health providers are even more important than the instrumental support facilities	100%	No documentation on refusal to participate
Bettencourt, Talley, Molix, Schlegel, Westgate 2007 USA	To examine the moderating influence of rural residence on the associations between health locus of control beliefs and psychological wellbeing in breast cancer patients.	Quantitative	224 women Breast cancer RR 60% incentive of \$25	The Multidimensional Health Locus of Control Epidemiologic Studies Depression Scale Satisfaction with Life Scale	- Rurality impacts the health locus of control perceptions predicting psychological adaptation/adjustment. - Emphasise the positive role of the health care providers - Strong social networks, understanding culture and believes of rural people helps tailor strategies of treatment	100%	Modest recruitment rate Limited generalisation of the sample mainly Caucasian and Missouri

Table 3: Characteristics and key findings of the included papers (continued)

Author(s), year, country	Study aim	Research design	Sample	Care needs assessment	Key findings	MMAT scores	Limitations
Burris & Andrykowski 2010 USA	To identify disparities in mental health outcomes between rural and non-rural cancer survivors.	Quantitative survey Telephone interview	116 adults 54 rural, 62 non-rural Breast/hematologic colorectal cancer RR 34%	Demographic and clinical information Medical outcomes study 12-item short form health survey Hospital anxiety and depression scale Distress Thermometer Satisfaction with life scale Benefit finding questionnaire Quality of life—Cancer survivors scale	<ul style="list-style-type: none"> Poor mental health in rural areas such as depression, anxiety and distress Mental health disparities in rural areas Interventions required for increasing the usage of mental health services Lack of desire to work in the rural areas by professionals (due to travelling, distance) 	75% RR34%	Small sample size Lack of a healthy control group
Chan, Hart, Goodman 2006 USA	To compare the travel times, distances, and physician specialty use among such men, within the mix of all Medicare patients living in Alaska, Idaho, North Carolina, South Carolina, and Washington.	Quantitative retrospective design	2220841 patient records Medicare billing data.	Travel time for patients in relation to medical care and speciality care.	<ul style="list-style-type: none"> Low access to health care providers especially in terms of access to specialists Over reliance on the generalists/GPs for health issues Few health care visits and long distance travelling 	100%	Including 5 states, which limits the generalisation of the study, old data which may not indicate the current trends
Corboy, McDonald, McLaren 2011 Australia	The current study investigated perceived barriers to support service use among such men, within the framework of the Behavioral Model of Health Service Use.	Mixed-method survey Semi-structured interviews	82 men Prostate, other cancer No RR	Demographic information Awareness and use of services offering emotional support, psychosocial support Reasons for participation in formal support services	<ul style="list-style-type: none"> Low level of participation in formal support Service availability was not a factor of participation Influencing factors: family support and health beliefs 	100%	Small sample size, with focus on prostate cancer
DiSipio, Hayes, Newman, Aitken, Janda 2010 Australia	To examine the quality of life, measured by the Functional Assessment of Cancer Therapy (FACT) questionnaire.	Quantitative, longitudinal survey	1140 adults Urban n = 277 Non-urban n = 323 Breast cancer	QOL Functional Assessment of Cancer Therapy (FACT-G) questionnaire 12 months post-diagnosis	<ul style="list-style-type: none"> Quality of life related to breast cancer was low in rural areas Lower physical wellbeing in the rural areas 	100%	NA
Garrard, Femell, Wilson 2017 Australia	An exploration of adaptive functioning in rural families following a parental cancer diagnosis.	Qualitative family semi-structured interviews	10 families 34 participants General cancer RR 69%	Resiliency model of family adaptation	<ul style="list-style-type: none"> Strong family relationships valued Need for communication within family Families who identify as low-functioning are likely to benefit from interventions that promote adaptive communication and problem-solving skills 	100%	Small sample size, lack of generalisability
Hanks, Veitch, Harris 2008 Australia	To identify and compare the roles of urban, rural and remote general practitioners (GPs) in colorectal cancer (CRC) management.	Qualitative semi-structured interviews	15 general practitioners in rural areas Colorectal cancer RR 71%	NA	<ul style="list-style-type: none"> GPs provide holistic care including clinical, coordination and psychosocial care of the rural patients in comparison with the urban patients. More research is required to explore the factors helping GPs to work more effectively/productive in the rural areas 	100%	Small sample, limited in geographical spread
Livaudais, Thompson, Godina, Isias, Ibarra, Coronado 2010 USA	Cancer survivorship experiences were explored among Hispanic men and women with cancer and family members of cancer survivors.	Qualitative focus groups	31 women, 10 men General cancer No RR	Barriers to seeking diagnosis, reactions to and challenges faced after diagnosis. Experiences with physicians, available sources of cancer-related information.	<ul style="list-style-type: none"> Disbelief/fear/sadness VS. strength/courage/faith, and hope were the main answers to the diagnosis Psychological issues such as depression, isolation, worried about family Negative experience with the professionals, need for appropriate information, positive communication Connecting the survivors to different peers and support groups beneficial 	100%	NA

Table 3: Characteristics and key findings of the included papers (continued)

Author(s), year, country	Study aim	Research design	Sample	Care needs assessment	Key findings	MMAT scores	Limitations
Palash, Shaffer, Larson, Edsall, Chen, Koopman, Turner-Cobb, Kreshka, Graddy, Parsons 2006 USA	To evaluate the relationships of emotional self-efficacy, stressful life events, and social support with mood disturbance among women diagnosed with breast cancer who live in rural communities.	Quantitative Structured interview using survey	82 women Breast cancer RR 82%	Demographic and Medical Characteristics Stanford Emotional Self-Efficacy Scale-Cancer Psychiatric Epidemiology Research Interview Life Events Scale UCLA Social Support Inventory Mood Disturbance	<ul style="list-style-type: none"> Low emotional self-efficacy in rural women with breast cancer which can result in more mood disturbance More education programs/interventions required for enhancing the self-confidence and positive coping strategies to stressful life-events More comparative studies for the differences between level of social support in rural and urban cancer patients 	100%	Cross-sectional design; very limited ethnic variability (predominantly Caucasian).
Paul, Hall, Carey, Cameron, Clinton-McHarg 2013 Australia	To explore patient experiences of barriers to accessing care and associated financial and social impacts of the disease. Metropolitan versus non-metropolitan experiences were compared.	Quantitative Self-report survey.	268 adults Haematological cancers RR 37%	Socio-demographic and disease characteristics Locational and financial barriers to accessing care Financial and social impacts Depression anxiety stress scale	<ul style="list-style-type: none"> Cancer survivors living in remote and rural areas had 17 times more financial and traveling burden More flexibility is required for cancer patients who are still in workforce Addressing service disparities due to the distance is paramount in order to also decrease the other social and financial burdens 	75% RR 37%	Low response rate; cross-sectional design limiting the causative effect between barriers and impacts; under-representation of the barriers/impacts experienced by the full-time workers at the time of their diagnosis
Reid-Andrt and Cox 2010 USA	To examine the extent to which rural residence and social support seeking are associated with quality of life among breast cancer patients following chemotherapy.	Quantitative Survey	46 women Breast cancer No RR	Rurality Social Support Seeking Hesitation scale Psychological Functioning Beck depression inventory Functional Assessment Cancer Therapy –Breast	<ul style="list-style-type: none"> Rurality is linked with lower subjective and functional wellbeing, lower quality of life 	75% No RR	Small sample size
Selman, Higginson, Agupio, Dinat, Downing, Gwyther, Mashao, Mmoleli, Moll, Mpanga, Pamajajovic, Harding 2009 South Africa & Uganda	To explore the information needs of patients with progressive, life limiting disease and their family caregivers.	Qualitative Semi-structured interview	90 adults 38 family caregivers General cancer HIV No RR	Exploration of issues related to the illness Family roles and support Informational support and needs Believe in any religion/godi;	<ul style="list-style-type: none"> Lack of informational support from health providers results in using alternative sources of the information Lack of constructive communication between patients and health providers Recommendations for more effective and informative communications between patients/careers and health care providers Tailored support recognising family and cultural beliefs 	100%	Variations in interviews and disease states limits generalisability
Schlegel, Taley, Mollix, Bettencourt 2009 USA	The current study quantitatively examined the coping strategies employed by both rural and urban breast cancer patients while they were undergoing radiation therapy.	Quantitative descriptive Survey	232 women Breast cancer RR 93% survey completed in clinic	Socio-demographic and disease characteristics Rurality COPE scale Depression CES-D	<ul style="list-style-type: none"> Active coping and behavioural engagement strategies are important in decreasing the depressive symptoms in rural patients 	100%	Convenience sampling may reduce generalisability
Schootman, et al. 2013 USA	Comparison of risk behaviours, psychosocial factors, health outcomes, quality of life, and follow-up care of rural and urban cancer survivors in Missouri.	Descriptive quantitative Telephone interview	9530 adults with cancer RR 59%	Socio-demographic and disease characteristics Patient health questionnaire Self-rated health	<ul style="list-style-type: none"> Poor self-rated health, distress, and lower level of physical activities due to the limitations were reported more in rural populations. A lower percentage of rural people (62%) receive advice regarding cancer follow-up care in comparison to urban survivors (78%) 	100%	

Table 3: Characteristics and key findings of the included papers (continued)

Author(s), year, country	Study aim	Research design	Sample	Care needs assessment	Key findings	MMAT scores	Limitations
Weaver, Geiger, Lu, Case 2013 USA	To estimate the number of adult cancer survivors who reside in rural areas of the United States and to describe their self-reported health status relative to urban survivors.	Descriptive quantitative National Health Interview and Survey	30,000 to 40,000 surveys of adults with self-reported cancer RR 70%	Population Characteristics Rural-Urban Residence Medical outcomes SF-36 single question Kessler K-6	<ul style="list-style-type: none"> - Higher percent of rural survivors were non-Hispanic white, had lower level of socio-economic status - Worse health in all domains, poor health, psychological distress - Higher level of unemployment due to their health issues 	100%	Use of self-reported rather than registry-confirmed cancer history.
Worth, Boyd, Kendall, Heaney, Macleod, Cormie, Hockley, Murray 2006 Scotland	To explore the experiences and perceptions of out-of hours care of patients with advanced cancer, and with their informal and professional carers.	Qualitative in-depth interviews, Focus groups Telephone interviews	36 patients and carers with advanced cancer No RR	The call to the out-of-hours service (background to the call, decision to make the call, what happened during the call, what happened after the call?), How the out-of-hours services can improve? Issues regarding the out-of-hour services.	<ul style="list-style-type: none"> - Not enough services for home care - Hesitation for using call-out-of-hour services - Positive experience of informational support from the staff assist recovery journey 	100%	Difficulties for recruiting patients at the end of life, resulting in selection bias
Zucca, Boyes, Newling, Hall, Girts 2011 Australia	To describe travel burden and travel-related financial burden experienced by cancer patients over the first year after diagnosis.	Descriptive quantitative Self-report survey	1410 participants City: n = 890 Rural: n = 520 General cancer RR 44%	Socio-demographic and disease characteristics Travel time to cancer treatment, European organisation research and treatment cancer quality of life questionnaire EORTC QLQ-C30 Single item from Supportive care needs survey	<ul style="list-style-type: none"> - Travel burden for rural cancer patients which is associated with high financial burden. - More attention is requiring for travel and accommodation schemes to address the travel and financial burden and decrease the level of disparities 	75% RR 44%	

of lack of service usage, but rather not being proactive to look for the right service they may require (which needs to be dealt with on an individual level).

Discussion

Disparities in health care provision as well as social and community support services have a major impact on the health and wellbeing of rural cancer patients^{9,29,31}. This review highlighted the influencing factors to care needs of rural cancer patients. Exploration of individual aspects of stress, coping and adaptation were linked to influencing factors at system level such as rurality, access, availability of services and existing support system^{9,29,31}.

The analysis of the measurements used across the included articles highlighted the disparity of scales used and the difficulty in combining data to obtain higher level understanding of the experience and care needs of rural people with cancer. Two main areas were explored including health and wellbeing outcomes and inequality of care provision. Understanding the relationship between distance and travel time to the health outcomes provided an understanding of how the rurality increased the risk of lower health outcomes. Health and wellbeing had four areas of focus, which were explored to highlight the relationship between physical, mental, social and behaviours health in relation to remoteness.

Low self-efficacy was considered as one of the key barriers at the individual level in rural patients. Patients living with cancer may have feelings of hopelessness, lower level of quality of life and higher level of stigmatisation⁹. This can be due to experiencing a lower level of psycho-social support such as community and informal social support⁹ as well as active coping and behavioural engagement strategies¹⁵. Self-efficacy can be improved by tailored support and a focus on communication between health care providers and patients²⁰. The positive role of health care providers¹¹ has been showed to be even more important than the financial and instrumental support facilities²¹. Improving family support services and community-based models of support is paramount for support for rural patients on return to their home^{7,24}.

During treatment for cancer the patient is often closely supported by their carers and family members, thus there is significant disruption to the normal carer support processes^{33,34}. This may place extra stress and burden on carers and they may suffer negative-related health care problems due to challenges related to the cancer and treatment of their family member³⁵. A model of care which is patient- and carer-centred promotes the capacity of the patient to link with resources which are tailored to both them and their carer³⁶. The current review indicated that

the care needs and support services carers may require has been under-examined. However, the inclusion of the carers as part of the unit of care and empowering the patient and carer to be active in decision making enhances the strengths, wellbeing, capability and knowledge of the carers.

Distance and travel burden was one of the influencing factors highlighted at the system level, leading to other social and financial burdens^{22,30,31}. For example, there are few rural areas providing advanced levels of medical and surgical services^{22,30}, resulting in travelling long distances for treatment and being away from the family. According to DiSipio *et al.*²², women with breast cancer have to travel long distances (100 kilometres) and may be away from their home for 20–43 days for chemotherapy and radiotherapy, respectively, resulting in extra burden on the patients and their carers (for example, time burden, financial burden, and work burden) and subsequently may influence their quality of life.

In order to address travel and distance barriers, it is paramount to provide support for travel and accommodation for individuals/carers, which also help with financial burden and decrease the level of disparities²⁹. However, it may also be important to consider the cost-efficiency of these services in rural areas. Another solution is to encourage health professionals to work in rural areas to reduce the burden of travel^{37,38}, particularly in mental health areas³².

Community-based programs and family support services are needed in the local communities to build the capacity of individuals/carers and enhance the supporting social activities^{9,26}. Connecting cancer survivors to peers and support groups may help rural cancer patients and their carers to enhance their social abilities, information sharing, emotional support/advocacy support, and increase their access to more financial and/or instrumental resources²⁸. Having access to diverse sources of social support systems provide a type of insurance, a sense of belonging to a caring community, where help could be provided, if needed³⁹. However, the interventions need to be aligned, considering the specific characteristics of the rural cancer patients²⁶. Patient-mediated education and tailored support ensure that characteristics of the patient such as age, gender, health literacy, ethnicity, rurality and carer relationship are considered⁴⁰.

Recommendations for further research

Further research is required to explore the modifiable factors influencing disparities in rural areas. Both individual and system level variables should be considered including: spatial, social, economic, and cultural factors in rural areas which influence the treatment and survival of rural cancer patients¹¹. Longitudinal studies exploring the lived experience of survivors would provide a depth of understanding into the experience for rural patient and their families¹¹.

The important role of caregivers and/or family members in the recovery journey was highlighted by the research^{26,27}; however, there is a lack of depth with this focus⁴¹. Further studies which specifically focus on the care needs assessment of the carers, family members and close social ties of rural cancer patients would provide a deeper understanding of the patient and family trajectory. It is also recommended to engage consumers and their carers in cancer programs to formulate ways to address diverse factors at individual, organisational, and community levels that impact services access and use⁴².

Conclusion

The provision of holistic health care for rural people has challenges related to distance and cost. All the articles in this literature review demonstrated that the level of disparity is due to both the need to travel to receive care and the lack of quality care closer to home. However, there is limited focus on the carers and family members' burden during illness and treatment, leaving them at risk of physical and psychosocial distress. Future studies could consider modifiable factors which include the disparities in rural areas. Patient-mediated education and tailored support should be considered in order to provide an efficient and practical support to the family as a unit of care to ensure a holistic approach to recovery.

Limitation

Although this study aimed to explore the key influencing factors to care provision to both patients and carers as a unit of care, only two qualitative studies focused on the cancer patient and their carers as a unit of care.

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Conflict of interest

There are no conflicts of interest for any of the authors. The authors alone are responsible for the research process, analysis and writing of the paper.

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