## WHOLE PERSON CARE

**VOLUME 11 ● NUMBER 1 ● 2024 ● 20-33** 

# A MEDICAL STUDENT QUALITATIVE STUDY OF RURAL HEALTH CONCERNS, COMMUNITY DETERMINANTS AND WHOLE PERSON CARE

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**KEYWORDS**: Rural health, Medical students, Community determinants, Whole person care, Patient concerns

### **ABSTRACT**

Background: Following a short rural health placement in the second year of medical school five students opted, as an extra-curricular activity, to conduct an exploratory research project into the wellbeing and health concerns of rural residents in the Wheatbelt of Western Australia. The project was conducted in collaboration with the local shires. The aim was to document, analyse and understand the health concerns and experiences of rural residents.

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Methods: A phenomenological research approach was employed. Seventeen rural residents selected by the shires, and four key informants, responded to open-ended interviews. Their narratives were subjected to a thematic analysis.

Results: The narratives described a wide range of health concerns relating to health services, mental illness, transportation, accommodation, marginalisation of the community, bureaucratisation of administration, community fragmentation and the desire for community partnerships. Frustration and inconvenience from community factors were associated with anxiety, depression, isolation, and loss of wellbeing.

Discussion: The respondents described dysfunctional infrastructure and under resourcing in a local rural community. They defined numerous health concerns related to deficiencies in community cohesion and integration. They illustrated how whole person health is impacted by the infrastructure and services available within a rural community. The narratives highlight the need for adaptation at the community level, following the example of Health in All Policies. Participants also highlighted the need for clinicians trained in supporting the functioning of the whole person within a fragmented rural environment.

#### **BACKGROUND**

"...illness is always experienced within the context of a particular life and in light of personal hopes and aspirations".[1]

he new Curtin Medical School (CMS) conducts a rural placement in the Western Australian Wheatbelt for second year students (Medical Student Wheatbelt Immersion Program) to demonstrate how family and the social environment influences health and social wellbeing in rural communities. Addressing the needs of rural health is a specific mission of the CMS. The local Wheatbelt shires and community residents strongly support this mission.

Prior to the rural placement the epidemiological picture of higher mortality and morbidity in rural Australia[2] is presented to the students as well as the inequalities in resourcing rural health services[3]. During the placement, the students are introduced to the local rural community context such as schools, industry, farms, community facilities, health services and family life. They interact with many local individuals and integrate themselves into the community. This experience exposes them to challenging local human issues in rural health at both the community and individual level and stimulated student interest in the wellbeing of the whole person[4]. This is the point at which this project was first conceptualised.

Collaboration between medical schools and rural communities is supported by the state government in order to promote rural health. As an extension of the student placement, some shire members expressed the view that documentation of local health needs by students could be of benefit to the community. This

coincided with the interest of one of the authors (AH) to offer a more in-depth examination of rural health needs through a research project. Five students who had been enthused by their rural placement opted for this extra-curricular exploratory project to learn more of the individual health concerns and personal health experiences of local Wheatbelt residents.

Given the general health inequity and disadvantage of rural communities, including the Western Australian Wheatbelt[5], there was a good reason to initiate research into the local wheatbelt experience of rural health and wellness. For the students involved, this offered an opportunity to document and analyse individual narratives in order to understand the meaning of whole person care from the patient's perspective. For the purpose of this study, we defined 'whole person care' as providing the support and assistance necessary for individual wellbeing, independence, maintenance of function, achievement of personal goals and minimization of suffering. This concept embraces all supports and services an individual requires to maintain their quality of life. Given variation in the individual interpretation of 'health', the understanding of the experience of health, by necessity, needs to be described by the local participants themselves. Therefore, a strictly open-ended approach was adopted to learn about the community's subjective experience.

The aim was to document and understand the health concerns, experiences, and perspectives on wellbeing of Wheatbelt residents. The study was conducted by the students over the course of two years, concurrent with their medical school curriculum.

#### **METHODS**

Rural residents within the shires of Westonia and Merredin (population approximately 3,500) in the eastern Wheatbelt of Western Australia were interviewed. The study was developed and implemented in collaboration with these two shires and funded by the Wheatbelt East Regional Organisation of Councils (WEROC). Collaboration between Wheatbelt shires, Curtin and Notre Dame universities was already well established. The prospect of a joint research project was seen by the shires as a natural development. Planning and managing the project involved the active participation of the officers of the two shires and WEROC.

The participants were a convenience sample of 17 residents and four key informants invited by the shires. The selection was conducted by local shire officers. This was completed via a process of identifying local residents who were willing to be interviewed by the students. Both elderly and young residents were sought. No other criteria were applied. Most participants had already had some involvement with the university rural placement program which preceded the study. Fifteen of the participants were middle aged or elderly and two were in their early twenties. Three were male. Most were retired and were longstanding residents. A number were community volunteers and had served in key roles in the community over many years.

The focus on rural wellbeing is part of the Curtin University medical curriculum while the qualitative methodology to describe health concerns reflects the first author's (AH) career as a social scientist in public health and as a clinician in occupational medicine with a particular interest in disability and the patient's experience of illness. The other authors entered the project as medical students in the second year of the undergraduate medical program. They were self-selected on the basis of their interest in rural health and motivation to learn more about the subjective experience of health in marginalised communities.

A phenomenological research approach [6,7] was employed to disclose and elucidate the personal health experience of wheatbelt residents through subjective first-person narratives; the focus being the participants' own perspective obtained free from external directives. The aim was to determine the meaning of their health experiences to the individual. Interviews were open-ended and semi-structured using a general interview guide to prompt dialogue toward the resident's life experience, activities, social circumstances, opportunities, interests, and health concerns and services. The data were qualitative and experiential. Every effort was made to facilitate free and uninfluenced expression of the residents' opinions and experiences "allowing the phenomena to speak for themselves" [6].

The students underwent interview training prior to the data gathering. This followed discussion of the concept of wellbeing and of the importance of eliciting the respondents' perspective in order to understand the patient's subjective experience of illness. Interviews took place in participants' homes and in a shire office. The students interviewed in pairs, recording the content of the interview by hand. Interviews were 60 to 90 minutes in duration.

Ethics approval was granted by the Curtin University Ethics Committee following peer approval of the project by the Curtin Medical School. A participant information sheet and consent form were employed. Participation was voluntary and withdrawal at any time was acceptable.

#### **ANALYSIS**

The deidentified data were subjected to a content and thematic analysis to identify meaningful units or constituents [6] of the rural life experience. This was done in steps. Initially each researcher compiled a summary of the concerns and experiences documented in their handwritten interview notes. They also made note of any quotes they found particularly informative or poignant. The notes reflected each individual's experience and perspective and therefore varied in content and detail. These summaries were reviewed by the team and grouped according to their content area such as health care, housing, transport, etc. Based upon this initial thematic grouping the first author (AH) completed the final compilation of themes as presented in the results below. A report of results was circulated to all participants with acknowledgement of their participation. Feedback was received from the long-standing medical practitioner of the region who endorsed the findings as a valid description of the rural environment. No feedback was received from the other participants.

**RESULTS** 

The health concerns described by the respondents have been grouped, with some overlap, into eight general themes. The quotations which follow are provided by the participants and are included here to illustrate their concerns and experiences. The themes were referenced by a number of different participants (Figure 1), with many participants discussing more than one theme (Figure 2).

1. Concern over medical care

"Many of the town's difficulties relate to barriers to accessing care and to social inequalities."

Concern was expressed over multiple aspects of medical care delivery.

The centralisation of specialist and procedural services has resulted in increased reliance on the larger towns and the state capital. The need for increased travel, including over-night stays have become commonplace in order to access services which previously were locally available. Locally "there are insufficient staff" for doctor services, aged care, mental health, and allied health services. These deficiencies significantly affect residents with fewer personal resources and greater medical need.

Professional and lay opinion was expressed that the medical system is dysfunctional through lack of leadership, teamwork, supervision, and coordination. "There is a lack of support for primary care by tertiary services. Children taken to Perth for psychiatric emergencies return with no long-term care plan. Some doctors lack networks to facilitate linkage and access to other services. Pharmacy services are not adapted to geographic isolation. The town's health system may benefit from increased autonomy in deciding what services to provide."

There is an opinion that investment has been misdirected into capital development at the expense of human services and staffing. This is illustrated by extensive hospital expansion and restoration accompanied by the closure of some local services.

Communication within the doctor-patient relationship was a focus of concern. For example, doctors for whom English is not the first language are seen as a barrier to the seeking of care. An Australian doctor who understands Australian country life is seen as a strength to the system.

The structure and function of rural health services is seen as problematic. It is felt that the rural areas are underserviced and that the provision of services is not adapted to the need. A major concern is "the mismatch of acute medical services and the health needs of the aging population".

2. Concern over stress and mental illness

"Mental health has become a massive gap. The country is left to its own resources and self-medication is a big problem."

It was commented by a retired social services professional that "there are no appropriate services for acute mental health episodes other than transporting patients to the local police station." The absence of preventive mental health education is felt to be an underlying problem, compounded by a "deficiency in availability and access to services."

"Methamphetamine and alcohol are significant problems."

"The stress of farming is a major health problem which is growing, yet support is not here. Farmers will work 20 hours a day and without sleep they are at risk of cutting corners." In addition, "there is the stoicism of country people and a reluctance to ask for help. Most youth with mental health concerns do not seek help." The nature of farming imposes social isolation and stress, complicated by the hardship of climate change. For the farming community, depression and suicide are a major concern.

Many respondents expressed their support for the Blue Tree Project, in which dead trees are painted blue in a community initiative to raise awareness for depression and the risk of suicide.

## 3. Concern over transportation and mobility

"Social isolation"

Transportation and mobility were cited frequently as a significant concern for both young and old; affecting local movement within towns, between towns and travelling to Perth. Concern was expressed by the elderly over their increased need to access services and their reduced personal mobility.

Demographic change is resulting in a smaller young population available to assist parents and grandparents with transportation and fewer volunteers to help neighbours. The aging population is placing greater transport demands on public transportation and on neighbours and volunteers. Reference was made by some to a reluctance to ask neighbours for assistance.

Train services have been reduced, timetables changed to less convenient times, and some night-time bus services have been stopped. Some train stations have not provided ramp access. The closure of some local bus services has been an unwelcome change placing greater reliance on the shire for community busing. The distance to drive to regional centres can be dangerous, due to animals on the road at night. The placement of elderly family members in aged care facilities distant from their own hometown is increasing the travel demands on relatives. This is a source of separation and isolation.

These concerns over transportation are not infrequently associated with feelings of stress and anxiety. In the case of younger residents who live on farms, the hazards of night driving are a deterrent to seeking entertainment in town. This detracts from the community hub and reduces opportunities for young people to socialise and interact with their peers. For the elderly, the reduced capacity to drive and the prospect of losing one's driver's licence are common causes of concern.

Difficulties with transportation underlie multiple concerns such as loss of independence, social isolation, general inconvenience, and risks. However, resources such as access to a golf buggy, the provision of safe, smooth footpaths and a community bus service provided by the shire are greatly valued by the elderly.

## 4. Concern over housing and accommodation

"Poor accommodation is fragmenting the community. People are waiting for houses."

Concerns over accommodation and housing relate to the availability and location of appropriate housing for the elderly. Residential facilities may only be available in a distant town causing stress, isolation from friends and family and reduced independence.

## 5. Concern over an anti-rural bias

"There are negative views of the bush by people who don't know what goes on in the bush."

There is concern that the government does not identify with the circumstances and experience of the rural community. Furthermore, it was felt that government bodies lacked interest in understanding community circumstances and needs. "By contrast the community itself solves problems."

## 6. Concern over decision making

"Bureaucratisation is a significant barrier at multiple levels in health care including access, availability, continuity, coordination, patient satisfaction, quality and cost."

At the level of the whole community there is concern that decision-making and policy formulation is done centrally, without involvement, consultation or consideration of the local community and local providers. Numerous healthcare issues are attributed to centralised planning without local involvement. There is disappointment and frustration over community feedback going unheeded. Inflexibility is obstructing responsiveness to local needs and circumstances.

## 7. Concern over fragmentation of the community

"A big tragedy"

Many concerns relate to a breakdown in the social fabric of the community due to a perceived steady decline in community integrity, cohesion, and sustainability. Despite this, nearly everyone interviewed expressed strong affection for the country and rural living. Residents planning to move to the city were doing so only through force of circumstances and with regret.

Rural urban migration is affecting young and old. Limited educational and employment opportunities are cited as important reasons for young people leaving or planning to leave the country. Interesting career opportunities are not associated with living in a country town. Life in the country is not perceived as providing

young people with a long-term future. Reference was made to generations being separated through parents remaining in the country while the younger generation pursue their lives in larger centres. Consequently, aging parents in the country lack local family help and rely on community support from volunteers, neighbours and services. Family members need to commute long distances to see one another which brings with it unavoidable difficulties. Concern was expressed over the increasing difficulty to find volunteers to provide essential services. This was attributed to the ageing demographic and fewer younger people in the community.

The family farm has been the mainstay of the Wheatbelt but now "30% of the farms are corporate, run by managers and FIFO (fly-in-fly-out) workers whose lives and families are elsewhere". This industrial change is seen as undermining the traditional social structure of the country and is described as "a big tragedy". This is detracting from the social capital of the region and reducing community self-sufficiency while increasing reliance on services. The loss of the position of community officer is perceived as a backwards step and one that fails to respond to the need for community development.

There is concern over alienation within the rural community, presenting in various ways. Reference was made to the presence of racism, ageism, and rejection of newcomers by some sections of the community.

## 8. The desire for partnership

"We know the problems."

There is concern over the complexity and multiplicity of issues facing the Wheatbelt. While the problems are well known to the community, the solutions are not. There is a desire for partnerships to find ways to manage issues and to promote advocacy and change. Collaboration with universities was cited as a desirable partnership. This could help document the need for change and promote awareness of rural health and wellbeing issues.

#### **DISCUSSION**

Community-level factors were identified overwhelmingly as the major source of health concerns to individuals at the local level. Infrastructure such as health care, transport, housing, and their governance were described as unresponsive to rural health and wellbeing needs. The problems identified included a broad range of complex, interweaved community determinants of health related to demographic changes, socio-economic factors, rural geography, resource provision, industrial changes, educational and career opportunities. These population-level findings are consistent with major sources of Australian rural health data[2,3,8,9] and illustrate the importance of the strategy of Health in All Policies[10] to health and wellbeing at the local level. At the same time, this defines the role of the whole community environment as a health determinant. It also demonstrates the scope of the demand on the clinician to practice with sufficient wholeness to facilitate the patient's optimal functioning in an unsupportive social context.

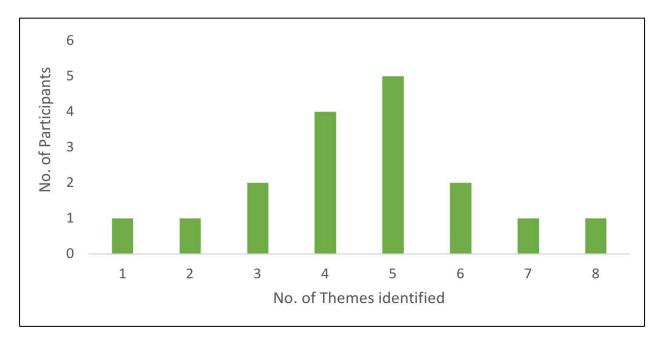


Fig 1. Number of themes identified by each participant

This association of community dysfunction and health is consistent with the extensive scientific evidence relating suicide[11], mental illness[12] and general morbidity, mortality, and life expectancy[13] to loss of community cohesion.

The participants have illustrated how ecological principles of community cohesion[14] are not being met:

- 1. Service sectors are functioning as silos without application of the principle of holism or consideration of interdependence and relationships within a wider system.
- 2. The steady decline in local social capital and resources such as services, and career and educational opportunities signal unsustainability within the community.
- 3. Loss of demographic diversity is weakening community capacity to cope with functional demands on self-reliance and volunteerism.
- 4. Community equilibrium and balance is being lost through outward migration, the aging demographic and loss of family farm ownership.
- 5. The network of interdependence within the community is being weakened while dependence on external resources is being imposed upon the community.

The result is a social tension in rural communities. While participants recognise the problems in the community; they feel disempowered to change the situation. They feel marginalised and excluded from consultation, planning and decision making. Community governance is perceived as being top-down without local participation.

In addition to the frustration and inconvenience associated with service infrastructure the participants acknowledge the presence of generic problems such as intrinsic health risks of farming, geographic isolation of rural life, climate, and the stoic personality of rural people.

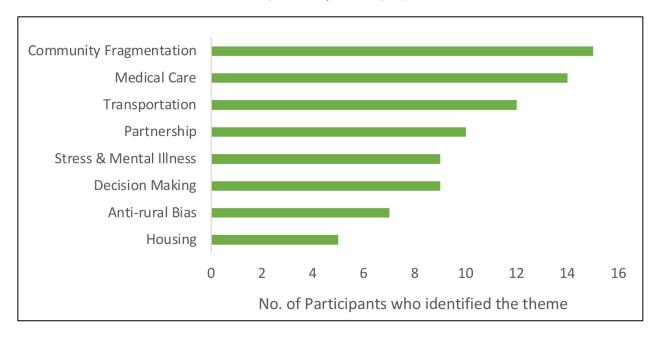


Fig 2. Frequency of theme identification by participants

These findings stress the importance the local community environment plays in whole person care and health. Familiarity with the patient's social environment and acknowledgement of its importance to the patient is therefore an important baseline for the clinician. A critical step in whole person care is understanding the local environment from the patient's perspective and knowing the patient's experience of how personal functioning in everyday life is impacted by their environment. As Eric Cassell[15] points out the clinician needs to address the patient's own goals and purposes. Our findings highlight the need of the clinician to consider the obstacles to these goals and purposes posed by the patient's own community circumstances and experience. Then knowing the patient's personal situation; the clinician can utilise both medical and social prescribing[16] to guide the patient in adapting to their situation to achieve optimal wellbeing and functioning. Of clinical relevance and of specific concern in everyday living to the participants in this study were such things as access to help, maintaining independence, isolation and contact with others, coping with stress, depression and anxiety, securing safety and the need to travel due to physical isolation. The medical and social demand on healthcare in this rural setting requires both public health and whole person care to be applied with an understanding of the community context. Healthcare with a strong orientation towards the social environment has much to offer. Hopefully local support from medical schools and governments will continue to grow.

In reflecting on the methodology used in this project the qualitative phenomenological approach has facilitated the free expression of the residents' views. From the perspective of the student researchers, the experience of designing, interviewing, and analysing these narrative data has provided an in-depth exposure to individual and community issues in rural health and their joint relevance to whole person care. The participants' stories have provided both a holistic systems view of the community and a personal perspective on individual rural lived experience.

The partnership of university and wheatbelt shires has provided a valuable collaborative framework for education, research, and the enhancement of understanding of the local health experience of the rural community. The active involvement of students in the documentation and analysis of the participants' health concerns has increased awareness of the subjective experience of health at the local level which is essential to whole person care. This is a win-win partnership.

The sobering message from this project is the inequity and marginalisation of rural communities. This is despite the overwhelming evidence that loss of community connectedness and integrity is a major determinant of ill health, loss of wellbeing and general social dysfunction. This disempowerment is associated with a perceived anti-rural bias and exclusion of the community from its own policies and decision making. The belief of rural residents that the community should be included as a respected equal in planning and policy making has been echoed widely. Writing in support of consumer involvement in global health, Nigel Crisp characterised the change which is needed as "turning the world upside down"[17]. The residents defined community development as a major unmet need for rural health. Indigenous Australian authors writing on community development propose an approach based on "listening, respecting, acknowledging, trusting, relating and understanding."[18] This captures the sentiment that would respond favourably to current rural health concerns.

It is hoped that this project adds positively to the voice of the community and participating shires in their desire for evidence to support advocacy for local development and services. The project has given the students a role in contributing to the local community which generously hosts the rural placement of medical students. For the students the in-depth exposure to the personal experiences of local residences provides the opportunity to identify previously unidentified career opportunities in rural health and whole person care where health providers are greatly needed.

A number of limitations need to be acknowledged. Resources were limited. As an extra-curricular activity student time and availability were constrained. No academic credit or formal time were allocated and therefore progress relied entirely on personal commitment and interest. There was no precedent for undergraduate student research in the new medical school and an administrative framework for this type of activity was not yet in place. Funding was limited to external community funds for travel and accommodation.

The scope of the project was shaped by the students' prior rural health placement in which the health of the elderly featured prominently. Aged care was also a high priority for the wheatbelt shires, and this was a research topic they readily endorsed and for which recruits could be easily found. For these reasons a convenience sample was selected by the shires. This sample was biased toward the elderly and those involved in the community. As a consequence, health concerns of other age groups and occupational groups were potentially underrepresented. While the data identified community-wide concerns there was no specific focus on children, youth, families, the working middle aged and Indigenous groups. Hand-written notetaking and failure to audio-record the interviews led to loss of some detail and precision in data gathering. This was compensated for, to a degree, by each pair of interviewers documenting the interview and by validation of the findings by a key informant.

Follow-up interviews would have increased understanding of the issues which would have benefitted both the community and the students' educational experience. It is reassuring to note the consistency of our findings with other larger studies of Australian rural health. Limiting the study to two towns was not the intention. Support and funding from WEROC to include the three other towns in the area had been approved but unfortunately this could not be pursued due to the COVID-19 pandemic. To date the opportunity to use this project to contribute to the CMS curriculum has not yet arisen. Strengths of the project were involvement of the students in all aspects of the research. The phenomenological approach demonstrated the relevance of the person's individual experience of health. Documentation and analysis of the patient's narrative and the focus on wellbeing illustrated to the students a method to help understand social disadvantage.

#### ACKNOWLEDGEMENTS

Acceptance by the Curtin Medical School of an extra-curricular student research project provided the opportunity to pursue this project. The rural health placement for medical students was made possible through Rural Health West, Wheatbelt East Regional Organisation of Councils (WEROC), West Australian Primary Health Alliance, Curtin University, Notre Dame University and the commitment and hospitality of local organisations and the many billeting families who hosted the students. The research project was made possible through the direct involvement of the Westonia and Merredin Shires and the willing residents and key informants who were interviewed.

#### **CONFLICT OF INTEREST**

There are no competing interests.

#### **FUNDING**

Funding was generously provided by the Wheatbelt East Regional Organisation of Councils.

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## Biographical note

Andrew Harper works as an occupational physician. He is trained in public health and behavioural sciences. He has had an academic career in clinical epidemiology, medical education, and occupational health. His principal interests are the patient's experience of health and the role of the community environment in health and wellbeing.

The co-authors came to this study as second year medical students stimulated to understand the lived experience of rural health. Two had undergraduate degrees, one in nursing (Kahla Edwards) and the other in science (Tessa Corbett) and three had started medical school directly from high school. Now they have all graduated in medicine and are practicing as junior doctors.