

## Original Article

**Cite this article:** Bailey C, Doyle Z, Dearn J, Michael N, Kissane D (2020). Demoralization and chronic illness in rural Australia: A cross-sectional survey. *Palliative and Supportive Care* **18**, 271–276. <https://doi.org/10.1017/S1478951519000841>

Received: 30 October 2018

Revised: 29 August 2019

Accepted: 8 October 2019

**Key words:**

Chronic illness; Demoralization; Depression; Disease burden; Rural health

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**Abstract**

**Objective.** Demoralization is prevalent in patients with life-limiting chronic illnesses, many of whom reside in rural areas. These patients also have an increased risk of disease-related psychosocial burden due to the unique health barriers in this population. However, the factors affecting demoralization in this cohort are currently unknown. This study aimed to examine demoralization amongst the chronically ill in Lithgow, a town in rural New South Wales, Australia, and identify any correlated demographic, physical, and psychosocial factors in this population.

**Method.** A cross-sectional survey of 73 participants drawn from Lithgow Hospital, the adjoining retirement village and nursing home, assessing correlating demographic, physical, psychiatric, and psychosocial factors.

**Results.** The total mean score of the DS-II was 7.8 (SD 26.4), and high demoralization scores were associated with the level of education ( $p = 0.01$ ), comorbid condition ( $p = 0.04$ ), severity of symptom burden ( $p < 0.001$ ), depression ( $p < 0.001$ ), and psychological distress ( $p < 0.001$ ). Prevalence of serious demoralization in this population was 27.4% according to a cutoff of a DS-II score  $\geq 11$ . Of those, 11 (15%) met the criteria for clinical depression, leaving 9 (12.3%) of the cohort demoralized but not depressed.

**Significance of results.** Prevalence of demoralization was high in this population. In line with the existing literature, demoralization was associated with the level of education, symptom burden, and psychological distress, demonstrating that demoralization is a relevant psychometric factor in rural populations. Further stratification of the unique biopsychosocial factors at play in this population would contribute to better understanding the burdens experienced by people with chronic illness in this population and the nature of demoralization.

**Introduction**

Demoralization refers to a state of lowered morale and poor coping associated with severe life-limiting medical conditions, characterized by feelings of hopelessness, despair, and meaninglessness (Kissane et al., 2001; Grassi and Nanni, 2016). It is particularly prevalent in populations with advanced disease and chronic illnesses, where control over disease is limited and cure is uncertain, and contributes to depression, poor coping, and a desire for hastened death (Kissane et al., 2001, 2004; Sansone and Sansone, 2010; Robinson et al., 2016). It is measurable using the Demoralization Scale (DS), developed by Kissane et al. (2004), which was recently refined and revalidated by Robinson et al. (2016) as the DS-II. High DS-II scores are positively correlated with depression, physical symptoms, and desire to die, and it is a useful tool for clinicians to recognize and address signs associated with these disorders (Kissane et al., 2004; Robinson et al., 2015, 2016, 2017).

To date, the measurement of demoralization has not taken place in a rural setting. In Australia, this population is at an increased risk of chronic, life-limiting maladies, such as heart disease, diabetes, and vascular disease, as well as depression and anxiety (Clarke, 2007; AIHW, 2015). A lack of available health professionals and services in rural areas also adds to the psychosocial burden of these chronic diseases (Phillips, 2009; Kirby et al., 2016). These communities also have a greater proportion of vulnerable populations who typically have poorer health outcomes, such as Aboriginal and Torres Strait Islander peoples and people from low socio-economic households (Phillips, 2009; Kirby et al., 2016). However, rural communities may also foster protective factors against demoralization such as resilience, stoicism, and strong local support networks (Phillips, 2009; Kirby et al., 2016). In either

case, rural communities may have unique qualities that influence a patient's ability to cope with advanced illness and any associated feelings of helplessness and demoralization.

This study, therefore, aimed to examine demoralization in a rural cohort with chronic disease in Lithgow, a rural town in New South Wales, Australia, and assess associated factors that may be unique to this rural context.

## Methods

### Design

A single interviewer-administered scales assessing demoralization, mood, and symptom burden to a cross-sectional convenience sample of patients who consented to participate.

### Population

Lithgow is a town in the Central Tablelands of New South Wales, 140 km west of Sydney, with a population of 21,565 (ABS, 2016). 22% of the population is greater than 65 years old, compared with the national average of 15.8%. The most common ancestry in Lithgow is Australian or Angloceltic. Only 5.1% of households speaking a language other than English at home (ABS, 2016). 5.7% of the population are Aboriginal or Torres Strait Islander (ABS, 2016).

The major source of employment in Lithgow is in coal mining and aged care residential services, with a 7.7% unemployment rate, higher than the national average of 6.9%. 31% have a weekly income of less than \$650, compared with the national average of 20%. 17.8% of people in Lithgow report year 10 as their highest level of educational attainment, compared with 10.8% nationally. Most people in Lithgow travel using a car (69%), more than the national average of 61.5%.

### Recruitment

The study was approved by the Nepean Blue Mountain Local Health District ethics committee and the University of Notre Dame ethics committee. Participants were recruited from the ambulatory care clinic and general medical wards of Lithgow hospital by convenience sampling between May and August 2018. Recruitment also took place at an adjacent nursing home and retirement village. Participants were eligible for the study if they were greater than 18 years old; could comprehend spoken English and provide written informed consent (thereby excluding those with a cognitive impairment or diagnosis of dementia); resided within a rural or remote location according to the Australian Standard Geographical Classification of Remoteness Area (ASGC-RA, 2006) classification system (RA4 or RA5) at the time of recruitment; were well enough to participate; and had one or more chronic disease(s) determined by the Australian Institute of Health and Welfare to be responsible for a significantly increased burden of disease (cancer, pulmonary disease, liver disease, diabetes, osteoarthritis, rheumatoid arthritis, chronic kidney disease, cardiovascular disease, or depression).

### Measures

The Demoralization Scale-II (DS-II) was used to measure demoralization. The DS-II comprises 16 items rated on a three-point Likert scale with two subscales: meaning and purpose, and

distress and coping ability. Higher overall scores indicate higher levels of demoralization. The DS-II has demonstrated good internal reliability ( $\alpha = 0.89$ ) and test-retest reliability in previous studies (Robinson *et al.*, 2016). Scores  $\geq 11$  are considered clinically significant (Robinson *et al.*, 2016).

The Memorial Symptom Assessment Scale (MSAS) (Chang *et al.*, 2004) was used to measure symptom burden and health-related quality of life. The MSAS has demonstrated good reliability ( $\alpha = 0.82$ ) and has been extensively validated in palliative care studies. The MSAS comprises a total score and three subscale scores: global distress, physical symptomatology, and psychological distress.

The Patient Health Questionnaire-9 (PHQ-9) (Kroenke *et al.*, 2001) is a self-reported measure of depressive symptoms, comprising nine items representing the criteria for a major depressive episode (MDE), with scores greater than 15 indicative of MDE (Kroenke *et al.*, 2001). The PHQ-9 has demonstrated good internal reliability ( $\alpha = 0.89$ ) and construct validity with other health-related measures (Kroenke *et al.*, 2001).

The Charlson Comorbidity Index (CCI) was used to qualify the participant's chronic disease status (Charlson *et al.*, 1987). The index is divided into four categories based on the risk of dying associated with the conditions in each category. Categories are unequally weighted, with Category 1, 2, and 3 conditions counting for 1, 2, and 3 points, respectively, and the most severe Category 4 condition (metastatic solid tumor, AIDS) counting for 6 points. Every decade over 40 also counts for 1 point. The total overall point score reflects severity of comorbidity and one-year mortality. Illness-related information was also obtained from the participant's medical record with their consent to identify relevant comorbid conditions.

Participants were also asked about demographic factors such as age, gender, ethnicity, marital status, education level, religious status, and travel burden (distance traveled from the place of residence to specialist medical care, if any).

### Statistical analysis

Descriptive statistics were used to characterize the study sample. A DS-II score of  $\geq 11$  was used to identify clinically significant demoralization, in alignment with contemporary literature (Robinson *et al.*, 2016). The association between independent factors and the prevalence of demoralization was examined using Fisher's exact test. Spearman's rho was used to evaluate the independent associations between the significant independent variables and demoralization. All analyses utilized SPSS software (IBM Corp, 2017).

### Results

During the sampling period (May–August 2018), 80 patients were identified as appropriate for the study and invited to provide informed consent. A total of 75 participants completed the survey (response rate of 94%). Two participants were excluded from analysis, as they did not reside within a rural or remote area according to the current ASGC-RA criteria ( $\geq 4$ ). Of the five participants who declined to complete the study, three were due to lack of interest and two felt unwell, leaving 73 questionnaires to be considered for analysis. A summary of the demographic data is presented in Table 1. Tables 2–4 summarize the associations found between demoralization scores and socio-demographic, physical, and psychological factors, respectively.

**Table 1.** Summary characteristics of participants ( $N=73$ )

Gender, $N$ (%)	
Male	32 (43.8)
Female	41 (56.2)
Age, years	
Mean (SD)	68.8 (14.8)
≤65	25 (34.2)
>65	48 (65.8)
Ethnicity, $N$ (%)	
Australian	59 (80.8)
Other	14 (19.2)
Aboriginal status, $N$ (%)	
Aboriginal	6 (8.2)
Non-aboriginal	67 (91.8)
Education, $N$ (%)	
Primary School	6 (8.2)
Secondary School	41 (56.2)
Tertiary/University	20 (27.4)
Post-graduate/Masters	6 (8.2)
Marital status, $N$ (%)	
Married	38 (52.0)
Never married	13 (17.8)
Divorced	11 (15.1)
Widowed	11 (15.1)
Religious status, $N$ (%)	
Religious	34 (46.6)
Nonreligious	39 (53.4)
Rural classification of the place of residence, $N$ (%)	
Lithgow	68 (93.2)
Other	5 (6.8)
Years lived at current residence, $N$ (%)	
1–10	25 (34.2)
11–19	7 (9.6)
20+	38 (52.1)

### Prevalence of demoralization

The mean DS score was 7.8 (SD 26.4), and the median was 6 (IQR = 10). Overall, 20 participants (27.4%) were clinically demoralized, having a DS-II score  $\geq 11$ . Of these, the average demoralization score was 19.4 (SD 6.0), compared to a mean score of 3.5 (SD 3.2) in those with nonclinical demoralization scores ( $p < 0.001$ ). Both groups scored higher on the distress and coping subscale, with an average of 10.8 (SD 3.2) in the clinically demoralized versus 2.3 (SD 2.4) in the nonclinical group than on the meaning and purpose subscale, with scores averaging 8.7 (SD 4.4) versus 1.1 (SD 1.3), respectively. There was a significant difference in the mean scores of both subscales between the two groups ( $p < 0.001$ ).

### Demoralization and demographic factors

No significant statistical differences were observed between patients with and without demoralization with respect to the site, gender, ethnicity, aboriginal status, marital status, religious status, duration of time spent living in a rural area, or travel time taken to see a specialist (Table 2).

However, there was a significant association between the DS-II score and education level ( $p = 0.024$ ). Participants who finished school at a year 12 level or less were almost five times more likely to be demoralized (OR 4.87, 95% CI [1.21–28.87],  $p = 0.01$ ) than those with tertiary or post-graduate qualifications.

### Demoralization and physical factors

Demoralization was significantly associated with the overall Memorial Symptom Burden Score ( $p < 0.001$ ) measuring illness morbidity (Table 3). Demoralization was not significantly associated with severity of comorbidity (CCI score) but was significantly associated with having a CCI Category 2 condition ( $p = 0.04$ ).

### Demoralization and psychological factors

The average overall score on the PHQ-9 was 7.96 (SD = 6.75) (Table 4). Based on the PHQ-9 cutoff of 15 (Kroenke et al., 2001), 15 participants (20.5%) met the criteria for a MDE. There was a significant association between demoralization and the PHQ score ( $p < 0.001$ ), though there was no association with the PHQ-9 global distress subscale. Eleven participants (15.1%) were both demoralized and depressed, though nine participants (12.3%) were demoralized without meeting the criteria for depression.

There was also a significant association between the MSAS psychological subscale score of psychological morbidity and DS-II scores ( $p < 0.001$ ).

### Independent factors associated with demoralization

Regression analysis using Spearman's coefficient identified several factors correlated with the DS-II score and the DS-II subscales. Education ( $r_s = -0.259$ ,  $p = 0.027$ ) was negatively correlated with the DS-II score. A positive correlation was observed between the DS-II score and symptom burden (MSAS score) ( $r_s = 0.545$ ,  $p < 0.001$ ), and depression (PHQ score) ( $r_s = 0.682$ ,  $p < 0.001$ ). A significant percentage of the variance in DS-II scores can be attributed to the MSAS score ( $R^2 = 0.30$ ) and the PHQ score ( $R^2 = 0.47$ ), with lesser contributions from the level of education ( $R^2 = 0.07$ ) and the CCI score ( $R^2 = 0.05$ ). The CCI score was positively correlated with the DS-II meaning and purpose subscale score ( $r_s = 0.296$ ,  $p = 0.011$ ), but not with the overall DS-II score or the distress and coping ability subscale score.

### Discussion

This study expands existing literature utilizing the DS-II to identify demoralization in a population of people with advanced chronic illness, and identifies associated biological, psychological, and social factors.

This study found that prevalence of demoralization in this population was 27.4%, considerably higher than the 13%–18% prevalence estimated in a recent systematic review of demoralization studies (Robinson et al., 2015). Measurement factors may

**Table 2.** Demographic characteristics of participants with and without demoralization

Variable	Demoralized (DS-II $\geq 11$ ) N (%)	Not demoralized (DS-II $< 11$ ) N (%)	p-value <sup>a</sup>	OR	CI <sub>95%</sub>
Total no. of participants (N = 73)	20 (27.4)	53 (72.6)			
Gender (N = 73)					
Male	10 (50.0)	22 (41.5)	0.697	1.40	0.44–4.49
Female	10 (50.0)	31 (58.5)			
Age, years (N = 73)					
Mean (SD)	65.8 (14.7)	69.9 (14.8)	0.296 <sup>b</sup>		–1.95–3.75
$\geq 65$	13 (65.0)	35 (66.0)	0.999	0.96	0.32–2.81
$< 65$	7 (35.0)	18 (34.0)			
Ethnicity (N = 71)					
Australian	19 (95.0)	40 (75.5)	0.719	1.28	0.51–3.25
Other	1 (5.0)	13 (24.5)			
Aboriginality (N = 72)					
Aboriginal or Torres Strait Islander	2 (10.0)	4 (7.5)	0.999	1.36	0.11–10.42
Other	18 (90.0)	49 (92.5)			
Education (N = 73)					
$\leq$ Year 12	18 (90.0)	29 (54.7)	0.010	4.87	1.21–28.87
$>$ Year 12	2 (10.0)	24 (45.3)			
Marital status (N = 73)					
Single	9 (45.0)	26 (49.1)	0.964	0.85	0.26–2.69
Partner	11 (55.0)	27 (50.9)			
Religious (N = 72)					
Religious	10 (50.0)	24 (45.3)	0.921	1.21	0.38–3.84
Nonreligious	10 (50.0)	29 (54.7)			
Rural classification of residence (N = 73)					
Lithgow (ASGC-RA 4)	19 (95.0)	49 (92.5)	0.999	1.54	0.14–80.35
Other ( $\geq$ ASGC-RA 4)	1 (5.0)	4 (7.5)			
Years lived at residence (N = 73)					
1–7	4 (20.0)	17 (32.0)	0.337	–	–
8–15	4 (20.0)	9 (17.0)			
16–20	3 (15.0)	2 (3.8)			
$\geq 20$	11 (55.0)	25 (47.2)			
Travel distance to specialist health services (N = 62)					
Central West (Lithgow, Bathurst, Orange)	4 (20.0)	13 (24.5)	0.999	0.92	0.18–3.91
Metropolitan (Penrith, Sydney)	11 (55.0)	33 (62.3)			

<sup>a</sup>Fisher's exact test.<sup>b</sup>Two-sample independent *t*.

have contributed to this high rate, as the cutoff for demoralization was based on a DS-II score  $\geq 11$ , whereas other studies have used higher cutoff scores (Robinson et al., 2015). This cutoff was chosen to be consistent with the paper by Robinson et al. (2016), which set out the parameters of external validity for the DS-II, and to preserve the reliability of these results against existing literature. A small sample size with a large standard deviation (SD) of DS-II scores also prevented the use of other cutoff

measurements based on SD. The large variability in DS-II scores reflects the range of disease characteristics within the participant cohort, which ranged from patients with severe or palliative chronic illness to patients with less severe, well-managed chronic disease. This is consistent with other studies assessing demoralization in nonpalliative, noncancer populations, where scores are more variable and cohorts more heterogeneous (Clarke et al., 2005; Julião et al., 2016).

**Table 3.** Physical characteristics of participants with and without demoralization

Variable	Demoralized (DS-II $\geq 11$ ) N (%)	Not demoralized (DS-II $< 11$ ) N (%)	p-value <sup>a</sup>	95% CI
Charlson Comorbidity (CCI) score (N = 73)				
Mean total score (SD)	6.6 (2.4)	5.5 (2.9)	0.107 <sup>b</sup>	−0.25 to 2.45
Mild Comorbidity (0–6)	9 (45.0)	37 (69.8)	0.093	0.112–1.16
Severe Comorbidity (>7)	11 (55.0)	16 (30.2)		
Category 1 condition <sup>c</sup>	14 (70.0)	41 (77.4)	0.714	0.19–2.67
No Category 1 condition	6 (30.0)	12 (22.6)		
Category 2 condition <sup>d</sup>	12 (60.0)	16 (30.2)	0.040	1.05–11.7
No Category 2 condition	8 (40.0)	37 (69.8)		
Category 3 condition <sup>e</sup>	2 (10.0)	1 (1.9)	0.361	0.28–347.2
No Category 3 condition	18 (90.0)	52 (98.1)		
Category 4 condition <sup>f</sup>	5 (25.0)	9 (17.0)	0.641	0.37–6.47
No Category 4 condition	15 (75.0)	44 (83.0)		
Memorial Symptom Assessment (MSAS) score (N = 73)				
Mean total score (SD)	36.8 (16.0)	20.4 (14.3)	<0.001 <sup>b</sup>	8.08–24.72

<sup>a</sup>Fisher's exact test.<sup>b</sup>Two-sample independent t.<sup>c</sup>Category 1 conditions: Myocardial infarction, congestive heart failure, peripheral vascular disease, cerebrovascular disease, chronic pulmonary disease, connective tissue disease, peptic ulcer disease, mild liver disease, diabetes without end-organ damage.<sup>d</sup>Category 2 conditions: Hemiplegia, moderate to severe renal disease, diabetes with end-organ damage, tumor without metastases, leukemia.<sup>e</sup>Category 3 conditions: Moderate to severe liver disease.<sup>f</sup>Category 4 conditions: Metastatic solid tumor, AIDS.**Table 4.** Psychological characteristics of participants with and without demoralization

Variable	Demoralized (DS-II $\geq 11$ ) N (%)	Not demoralized (DS-II $< 11$ ) N (%)	p-value <sup>a</sup>	95% CI
Mean demoralization score (SD) (N = 73)	19.4 (6.0)	3.5 (3.2)	<0.001 <sup>b</sup>	12.98–18.82
Mean meaning and purpose subscale (SD) (N = 73)	8.7 (4.4)	1.1 (1.3)	<0.001 <sup>b</sup>	5.51–69.69
Mean distress and coping subscale (SD) (N = 73)	10.8 (3.2)	2.3 (2.4)	<0.001 <sup>b</sup>	6.88–10.11
Memorial Symptom Assessment (MSAS) score (N = 73)				
Mean psychological subscale score (SD)	10.2 (3.4)	3.8 (3.2)	<0.001 <sup>b</sup>	4.61–8.19
Patient Health Questionnaire (PHQ) score (N = 73)				
Total mean score (SD)	14.9 (6.3)	5.6 (4.9)	<0.001 <sup>b</sup>	6.10–12.50
Low (0–10)	7 (35.0)	42 (79.2)	<0.001	–
Moderate (11–14)	2 (10.0)	7 (13.2)		
High ( $\geq 15$ )	11 (55.0)	4 (7.5)		
Mean global distress index score (SD)	3.2 (1.7)	2.4 (2.5)	0.125 <sup>b</sup>	−0.23 to 1.83

<sup>a</sup>Fisher's exact test.<sup>b</sup>Two-sample independent t.

Alternatively, the high demoralization scores may reflect high total symptom burden scores measured by the MSAS in both groups compared to other studies (Tranmer et al., 2003; Robinson et al., 2015). Depression and distress scores were also high in this population, with total mean PHQ-9 scores relatively higher than existing literature utilizing the same measure in palliative and oncology populations (Robinson et al., 2016, 2017; Vehling et al., 2017; Ko et al., 2018). These results may reflect the higher levels of chronic illness and mental illness within rural Australian populations (Phillips, 2009; NRHA, 2010; Kirby et al., 2016).

A number of participants were demoralized without being depressed, and several participants met the criteria for depression without being greatly demoralized. These results are consistent with existing literature that suggests that though depression and demoralization can coexist, the two do not necessarily go together, and that demoralization is an independent measure of distress in its own right (Jacobsen, Maytal & Stern, 2007; Kissane, 2014; Tang et al., 2015; Tecuta et al., 2015).

Demoralization was also significantly correlated with a low level of education in this cohort. Education is known to affect



psychological well-being and quality of life, providing resources for coping with serious illness, but may also be a proxy for the influence of financial security, health literacy, or other socio-demographic factors influencing demoralization (Ko et al., 2018). Future studies controlling for these variables may help to elucidate the exact effect of education on demoralization and would be especially relevant in a rural context, where levels of education are generally lower than the national average (ABS, 2016), and associated with these other social determinants of health.

No other socio-demographic factors were significantly associated with demoralization in this study, which is interesting, as being single, socially isolated, younger, unemployed, and female have been correlated with demoralization in systematic reviews (Robinson et al., 2015). One can hypothesize that rural communities have a protective influence through their interconnectedness, although a specific measure of such social support would be needed to confirm this. More sensitive measures of socio-demographic burdens, particularly travel burden, are also needed in future studies to evaluate the impact of these factors on demoralization, especially in a rural context.

Further qualification of symptom and illness characteristics in the MSAS and CCI would also be useful to identify which symptoms, and which of the CCI Category 2 conditions, had the greatest association with demoralization. In particular, pain presence and severity may have been highly relevant, considering the significant impact it has been found to have on demoralization scores in other noncancer cohorts (Kissane, 2014; Deshields et al., 2017). However, the nonsignificant association between CCI measures and demoralization in this study is in line with the existing literature, where there is little association between demoralization and illness type and severity (Robinson et al., 2015, 2017).

Other limitations of the study include a small sample size, resulting in the inability to perform more detailed regression analysis of the data, as well as reliance on convenience sampling, which was also due to the small number of eligible participants. Saturation of recruitment was quickly reached, and without convenience sampling by a single investigator, participants might have been double counted. Future studies could address these shortcomings by including more healthcare sites across the region. This could also permit a wider geographical area to assess travel distance and place of residence as factors for evaluation, which was limited by ASGC-RA classifications.

Despite these shortcomings, this study provides evidence that the DS-II is a valid psychometric instrument in a rural population, with prevalence rates and associations with other psychometric tools congruent with other studies in the wider literature. This study demonstrates that demoralization is a relevant concept for people in rural populations, and future studies should continue to investigate the unique factors in this population that contribute to demoralization so as to alleviate this unique form of suffering in context.

**Acknowledgments.** The authors acknowledge the support of this project by residents, staff, and patients of Lithgow Hospital, Three Trees Aged Care nursing home, and Treewind Retirement Estates.

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