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# A cross-sectional survey of the perspectives of older people in the Scottish Highlands on the management of their chronic pain.

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**A cross-sectional survey of the perspectives of older people in the Scottish Highlands on the management of their chronic pain**

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## **Abstract**

### **Background**

While there is evidence of suboptimal outcomes in older people with chronic pain, little emphasis has been placed on those in remote and rural settings.

### **Objective**

To describe the perspectives of older people in the Scottish Highlands on their chronic pain management.

### **Design**

Cross-sectional survey.

### **Setting**

NHS Highland, the most remote and rural geographical health board in Scotland.

### **Subjects**

Home-dwelling members of the public aged  $\geq 70$  years.

### **Methods**

Anonymised questionnaires were mailed to a random sample of 1800 older people. Questionnaire items were demographics, nature of any chronic pain, management regimens and perceived effectiveness. Validated scales were the Pain Disability Questionnaire and the Tampa Scale for Kinesiophobia.

### **Results**

Adjusted response rate was 39.3% (709/1755). One quarter (25.0%, n=177) were experiencing chronic pain, being more likely to live in deprived areas ( $p < 0.05$ ). Median pain intensity was 6 (IQR 4-7, 10 high), causing distress (median 5, IQR 3-7). Respondents largely consulted GPs (66.1%, n=117) with a minority (16.4%, n= 29) referred to a specialist pain clinic and few consulting other health professionals. Over three quarters (78.0%, n=138) were receiving prescribed medicines, most commonly paracetamol, alone (35.6%, n=63) or in combination with opioids (16.4%, n=29). One third (31.6%, n= 56) expressed a desire for more effective medicines; few reported using any non-pharmacological therapies. The median scores for the Pain Disability Questionnaire and Tampa Scale for Kinesiophobia were 74 (IQR 34-104.5, 150 high) and 40 (IQR 35-45, 68 high).

## **Conclusions**

Evidence of provision of appropriate integrated and person-centred chronic pain care is lacking.

## **Key Points**

- Chronic pain in older people resident in the Scottish Highlands was largely managed by GPs
- A minority were referred to pain specialists or had input from other members of the multidisciplinary team
- There was little use of non-pharmacological therapies and a desire for more effective medicines
- It appears that the biomedical approach is dominant over the integrated biopsychosocial mode

## **Keywords**

Aged; chronic pain; questionnaire; remote and rural; Scotland

## **Introduction**

Chronic pain, defined as 'pain that persists or recurs for longer than three months' [1], is highly prevalent in older people [2]. Consequences include impacting general wellbeing, quality of life and ability to function with increased healthcare utility and resource consumption [3, 4]. A review of meta-analyses, systematic reviews and clinical guidelines highlighted suboptimal patient outcomes and the need for a multimodal, integrated healthcare team approach [5]. The need for this at the global level was reiterated by the World Health Organization (WHO) as part of the Global Strategy and Action Plan on Ageing and Health [6].

There are specific challenges to the assessment and management of pain in older people due to several, and often interacting, factors including atypical manifestations of pain and associated challenges in biopsychosocial assessment. There are also alterations in pharmacokinetics and pharmacodynamics resulting in unpredictable responses to treatment, adverse effects and drug interactions. Potential issues of polypharmacy in older people also complicate medicines selection and adherence [7, 8]. While many countries and regions have developed evidence-based guidelines to support management, these do not commonly consider older people with multimorbidity and associated polypharmacy. Older people may also experience problems in accessing medicines and the array of other modes of treatments used in chronic pain management such as physiotherapy, psychology support and self- management techniques.

The Scottish Government '2020 Vision for Health and Social Care' articulates a strategy to improve the quality and outcomes of care for older people [9]. Specific attention is paid to chronic pain, with reviews of services highlighting that chronic pain is not prioritised and that management is fragmented and variable [10]. In 2018, 'Quality prescribing for chronic pain: A guide for improvement 2018-2021' was published, aiming to improve prescribing and integrating with non-pharmaceutical approaches [11]. Clinicians are encouraged to: ensure that patients are assessed properly; develop a clear, integrated person-centred management plan; pursue non-pharmacological approaches; follow a clinically appropriate approach to initiation of analgesia; and to review effectiveness, tolerability and adherence.

There are acknowledged difficulties associated with the provision of, and access to, healthcare within remote and rural areas, particularly for older people [12, 13]. NHS Highland is the largest geographical health board in Scotland with a population of around 310,000 (<10% of the Scottish population) and more than 40% living in 'remote rural' locations (settlements with a population <3,000 people and a drive time of >30 minutes to a settlement of ≥10,000) [14]. Recent studies in the Scottish Highlands highlighted

issues of access to, and convenience of, general medical practices and pharmacies, most notably for those aged  $\geq 60$  years [15, 16]. There is, however, a paucity of studies focusing on chronic pain management by older people in remote and rural areas. The aim of this study was to describe the perspectives of older people in the Scottish Highlands on their chronic pain management.

## **Methods**

### *Study design*

This study was a cross-sectional survey using a postal questionnaire.

### *Questionnaire development*

A draft questionnaire was developed with items on: demographics; nature and severity of any chronic pain; pain management regimens, including medicines, non-pharmaceutical approaches and alterations to lifestyle; and perceived effectiveness. Specific validated scales were the Pain Disability Questionnaire [17] and the Tampa Scale for Kinesiophobia [18]. The draft questionnaire was reviewed for face and content validity by several patients and individuals with expertise in policy, practice and research related to older people. Post-validation, the questionnaire was piloted in a random sample of 50 members of the public in NHS Highland, aged 70 years and over.

### *Data collection*

Members of the public aged 70 years and over within NHS Highland were included in the study, with those resident in care homes excluded. The questionnaire was mailed in November 2018 to a random sample of 1800 members of the public obtained from CACI, consumer database 'Ocean', a vast and powerful database containing 56 million United Kingdom (UK) names and addresses, with actual and modelled lifestyle data [19]. Chronic pain was defined in the questionnaire as, 'pain which lasts for 3 months or more'. Evidence based measures were adopted to maximise the response rate: two reminder mailings to non-respondents; invitation from academic/healthcare institutions; a participant information leaflet; and reply paid envelopes.

### *Analysis*

Data were entered into SPSS version 21.0, and analysed using descriptive and inferential statistics. Respondent postcodes were used to determine Scottish Index of Multiple Deprivation (SIMD) quintiles, and rurality using the 8-point Scottish Urban-Rural Classification [20]. Chi-square was used to test for any association between categorical

variables (e.g. age, gender) and (i) reporting chronic pain; and (ii) being referred to a specialist pain clinic. P-values  $\leq 0.05$  were considered statistically significant.

### *Ethics*

The study was approved by the ethics committee of the School of Pharmacy and Life Sciences at Robert Gordon University, United Kingdom (S139). As a survey of the public, the study was exempt from NHS ethical review.

## **Results**

### *Demographics*

Seven hundred and nine completed questionnaires were received, with a further 45 returned undelivered giving an adjusted response rate of 39.3%. One quarter of respondents (25.0%, n=177) stated that they were currently experiencing chronic pain. The demographics of all study respondents and those with chronic pain are presented in Table 1.

Of those with chronic pain, two thirds (66.0%, n=117) were 75 years and over, around one third (35.0%, n=62) lived alone, forty percent (40.7%, n=72) were living in remote rural or very remote rural areas and one quarter (23.2%, n=41) in the two most deprived categories. Those reporting chronic pain were more likely to be users of healthcare services (general practice, hospital, pharmacy; all  $p < 0.01$ ) and to live in deprived areas ( $p < 0.05$ ). While there was an association with educational level, the trend was not clear.

Table 1. Demographics of all respondents and comparison of those experiencing/ not experiencing chronic pain\*

	All respondents N= 709	Respondents experiencing chronic pain N= 177	Respondents not experiencing chronic pain N= 513	p-value (Chi-square)
Gender	% (n)	% (n)	% (n)	
Male	39.1 (277)	36.2 (64)	40.0 (205)	0.290
Female	43.6 (309)	46.9 (83)	42.7 (219)	
Missing	17.3 (123)	16.9 (30)	17.3 (89)	
Age (years)				
70-74	35.1 (249)	32.2 (57)	36.6 (188)	0.739
75-79	28.6 (203)	31.6 (56)	27.9 (143)	
80-84	17.6 (125)	18.6 (33)	17 (87)	
85-89	11.8 (84)	10.7 (19)	12.3 (63)	
≥90	5.4 (38)	5.1 (9)	5.1 (26)	
Missing	1.4 (10)	1.7 (3)	1.2 (6)	
Living alone				
Yes	29.2 (207)	35.0 (62)	26.9 (138)	0.235
No	47.1 (334)	48.6 (86)	46.8 (240)	
Missing	23.6 (167)	16.4 (29)	26.1 (134)	
Ethnicity				
White	98.2 (696)	100 (177)	97.9 (502)	0.402
Asian	0.3 (2)	0 (0)	0.4 (2)	
Missing	1.4 (10)	0 (0)	1.6 (8)	
Highest educational level				
University	12.4 (88)	11.3 (20)	13.1 (67)	<0.01
College	26.4 (187)	36.2 (64)	23.4 (120)	
School	57.3 (406)	51.4 (91)	59.3 (304)	
Missing	3.9 (28)	1.1 (2)	4.3 (22)	
Healthcare contacts in last 3 month				
GP	62.9 (446)	85.9 (152)	55.2 (283)	<0.001



Missing	2.7 (19)	1.1 (2)	2.9 (15)	
Hospital outpatient	32.2 (229)	55.4 (98)	24.4 (125)	<0.001
Missing	8.9 (63)	5.1 (9)	9.6 (49)	
Hospital inpatient	8.9 (63)	14.1 (25)	6.8 (35)	<0.01
Missing	12.1 (86)	10.7 (19)	12.1 (62)	
Pharmacy	68.7 (487)	78.5 (139)	66.1 (339)	<0.005
Missing	5.5 (39)	5.6 (10)	5.1 (26)	
Scottish Index of Multiple Deprivation				
1 (Most deprived)	4.1 (29)	6.8 (12)	3.3 (17)	<0.05
2	14.8 (105)	16.4 (29)	14.2 (73)	
3	36.4 (258)	28.2 (50)	39.0 (200)	
4	32.6 (231)	37.9 (67)	31.0 (159)	
5 (Least deprived)	11.7 (83)	10.2 (18)	12.1 (62)	
Missing	0.4 (3)	0.6 (1)	0.4 (2)	
Scottish Urban Rural classification				
1 (Large urban areas)	0.1 (1)	0 (0)	0.2 (1)	0.359
2 (Other urban areas)	27.8 (197)	20.9 (37)	30 (154)	
3 (Accessible small towns)	5.6 (40)	5.6 (10)	5.7 (29)	
4 (Remote small towns)	6.6 (47)	7.9 (14)	6.4 (33)	
5 (Very remote small towns)	9.7 (69)	9.0 (16)	10.1 (52)	
6 (Accessible rural)	8.7 (62)	11.3 (20)	8.2 (42)	
7 (Remote rural)	9.2 (65)	10.2 (18)	8.4 (43)	
8 (Very remote rural)	27.4 (194)	30.5 (54)	25.9 (133)	
Missing	4.8 (34)	4.5 (8)	5.1 (26)	

\*Missing data hence do not total 100%

### *Experiences of chronic pain*

Almost half (46.3%, n=82) of those with chronic pain reported a duration of more than five years. Multiple body sites were affected, the median number being three (IQR 2-5), most commonly lower back (48.0%, n=85), knees (46.9%, n=83) and hands (32.2%, n=57). The pain was described as 'aching' (72.9%, n=129), 'stabbing' (24.3%, n=43), 'sharp' (18.6%, n=33), 'shooting' (16.9%, n=30), 'numbness' (15.8%, n=28) and 'pins and needles' (11.3%, n=20). On a scale of 0 to 10 (highest), the pain was rated at a median intensity of 6 (IQR 4-7) causing distress (median 5, IQR 3-7), mostly affecting exercise (median 8, IQR 5-9), physical function (median 7, IQR 5-9), daily activities (median 7, IQR 4-8) and hobbies (median 7, IQR 3-8).

### *Management of chronic pain*

Respondents largely consulted general practitioners (GPs) for pain management (66.1%, n=117), with less hospital consultants (23.7%, n=42), physiotherapists (19.8%, n=35), nurses (9.6%, n=17) and pharmacists (9.6%, n=17). A minority of respondents (16.4%, n= 29) reported having being referred to a specialist pain clinic at some point. There were no statistically significant associations with any demographic variables and referral (Chi-square, all  $p > 0.05$ ). Few respondents reported using therapies of physiotherapy (9.1%, n=16), acupuncture (5.3%, n=9), hydrotherapy (4.5%, n=8), herbal remedies (4.5%, n= 8), osteopathy (4.1%, n=7), chiropracty (3.6%, n=6), transcutaneous electrical nerve stimulation (2.4%, n=4), homeopathy (1.1%, n=2), psychology (1.1%, n= 2) or hypnosis (1.1%, n= 2).

Over three quarters of respondents (78.0%, n=138) were receiving prescribed medicines for chronic pain, with almost two thirds (59.9%, n=106) receiving two medicines. Paracetamol was most common, either alone (35.6%, n=63) or in combination with opioids (16.4%, n=29). On a scale of 0 to 10 (highest), the median rating for the effectiveness of chronic pain medicines was 6 (IQR 5-8). Around one third (31.6%, n= 56) reported a desire for more effective medicines. A minority (14.7%, n=26) experienced gastrointestinal adverse effects, with less fatigue (6.2%, n= 11), feeling sore (1.7%, n=3), depression (1.7%, n=3), itch (1.1%, n=2), anxiousness (0.6%, n=1), sleep disturbances (0.6%, n=1), sleep apnoea (0.6%, n=1), urinary difficulties (0.6%, n=1) and hair loss (0.6%, n=1).

### *Impact of chronic pain*

The median overall score for the Pain Disability Questionnaire was 74 (IQR 34-104.5) on a scale of 0-150 (highest disability), with the responses to specific statements given in Table 2. The highest scores were for statements relating to having to take medicines

every day (median 8, IQR 2-10), affecting running or walking (median 8, IQR 5-9), work inside and outside the home (median 7, IQR 5-9), ability to lift overhead, gasp or reach for things (median 7, IQR 4-9), ability to lift objects off the floor, bend, stoop or squat (median 7, IQR 4-9) and interfering with recreational activities and hobbies (median 7, IQR 4-9.25).

Table 2. Responses to the Pain Disability Questionnaire (scale 0-10, highest disability) (N=177)

Statement (n= missing data)	Median (IQR)
Pain means I have to take medicine every day to control my pain (n=19)	8 (2-10)
Pain affects my ability to walk or run (n=14)	8 (5-9)
Pain interferes with my normal work inside and outside the home (n=15)	7 (5-9)
Pain affects my ability to lift overhead, gasp or reach for things (n=14)	7 (4-9)
Pain affects my ability to lift objects off the floor, bend, stoop or squat (n=15)	7 (4-9)
Pain interferes with recreational activities and hobbies important to me (n=15)	7 (4-9.25)
Pain affects my ability to sit or stand (n=21)	6 (2.25-8)
Pain forces me to see health professionals more often than before my pain began (n=19)	5 (1-10)
Pain interferes with my travel (n=16)	5 (2-8)
Pain interferes with my ability to see the people who are important to me as much as I would like (n=18)	5 (0-8)
I now feel more depressed, tense or anxious than before my pain began (n=18)	4 (0-8)
Pain interferes with my personal care (such as washing, dressing) (n=14)	3 (0-7)
Pain means I need the help of my family and friends to complete everyday tasks (n=18)	3 (0-7)
Emotional problems caused by pain interfere with my family, social activities (n=16)	3 (0-7)
Pain affects my income (n=39)	0 (0-3)

Responses to the Tampa Scale for Kinesiophobia questionnaire are given in Table 3. The median total score was 40 (IQR 35-45) on a scale of 17-68 (highest degree of kinesiophobia). More than two thirds (70.6%, n=125) agreed that pain let them know when to stop exercising so that they would not injure themselves. Around two thirds (67.8%, n=120) also agreed that simply being careful that not making any unnecessary movements was the safest thing to prevent pain from worsening and a similar number (63.2%, n=112) disagreed that even though something was causing a lot of pain, they did not think it was actually dangerous.

Table 3. Responses to the Tampa Scale for Kinesiophobia (n=177)\*

Statement	Responses, % (n)				
	Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree	Missing
I am afraid that I might injure myself if I exercise	25.4 (45)	18.6 (33)	37.9 (67)	10.7 (19)	6.8 (12)
If I were to try to overcome it, my pain would increase	17.5 (31)	22 (39)	34.5 (61)	15.8 (28)	9.6 (17)
My body is telling me I have something dangerously wrong when I feel pain	23.7 (42)	23.2 (41)	31.1 (55)	10.7 (19)	11.3 (20)
+My pain would probably be relieved if I were to exercise	6.2 (11)	28.8 (51)	26 (46)	26.6 (47)	12.4 (22)
People aren't taking my medical condition seriously	42.4 (75)	22.6 (40)	20.3 (36)	2.8 (5)	11.9 (21)
My accident has put my body at risk for the rest of my life	32.8 (58)	11.9 (21)	14.1 (25)	7.9 (14)	33.3 (59)
Pain always means I have injured my body	36.2 (64)	25.4 (45)	19.2 (34)	7.3 (13)	11.9 (21)
+Just because something aggravates my pain doesn't mean it is dangerous	24.3 (43)	34.5 (61)	13.6 (24)	14.7 (26)	13 (23)
I am afraid I might injure myself accidentally	23.2 (41)	18.1 (32)	35.6 (63)	11.9 (21)	11.3 (20)
Simply being careful that I do not make any unnecessary movements is the safest thing I can do to prevent my pain from worsening	9.6 (17)	10.7 (19)	48.6 (86)	19.2 (34)	11.9 (21)
I wouldn't have this much pain if there weren't something dangerous going on in my body	36.2 (64)	25.4 (45)	15.8 (28)	9 (16)	13.6 (24)
+Although my condition is painful, I would be better off if I were physically active	23.7 (42)	39.5 (70)	13 (23)	11.9 (21)	11.9 (21)
Pain lets me know when to stop exercising so that I do not injure myself	8.5 (15)	10.2 (18)	41.2 (73)	29.4 (52)	10.2 (18)
It is really not safe for a person with condition like mine to be physically active	41.2 (73)	22 (39)	15.3 (27)	11.3 (20)	10.2 (18)

I can't do all the things normal people do because it is too easy for me to get injured	27.1 (48)	18.6 (33)	29.9 (53)	13 (23)	11.3 (20)
+Even though something is causing me a lot of pain, I don't think it is actually dangerous	25.4 (45)	37.9 (67)	13 (23)	13.6 (24)	10.2 (18)
No one should have to exercise when he/she is in pain	18.6 (33)	28.2 (50)	26.6 (47)	16.4 (29)	10.2 (18)

\*Missing data hence do not total 100%; +Reverse scored

### *Views on chronic pain management*

While most responses were positive in terms of medicines knowledge and being confident in their ability to use their medicines, there were negative responses around specific aspects of chronic pain management. More than one quarter (28.2%, n=50) disagreed with the statement that, 'If I use my pain medicine as prescribed then my health will improve'. More than half (52.5%, n=93) agreed with 'I feel worried about using my pain medicine' and more than one quarter (29.3%, n=52) 'I feel sad about having to use so many pain medicines'.

## **Discussion**

### *Statement of key findings*

One quarter of respondents in this study were experiencing chronic pain, with almost half reporting a duration of more than five years and affecting a number of body sites. Pain was largely managed by GPs, with a minority referred to pain specialists or having had input from other members of the multidisciplinary team. Those experiencing chronic pain were significantly higher users of healthcare resources and living in more deprived areas. Paracetamol was the most commonly prescribed analgesic, alone or in combination with opioids, and few were using non-pharmaceutical therapies. Chronic pain affected many aspects of daily living and physical function, leading to kinesiophobia and sadness.

### *Strengths and weaknesses*

This study has added to the limited knowledge base of chronic pain management in older people in remote and rural settings. Several validated scales were included as part of the questionnaire. There are, however, several limitations; results could be affected by issues of response and recall bias, and the validity of self-reported data could not be

confirmed. Notably, it was not possible to obtain details of specific investigations or diagnoses from medical records. Furthermore, the study was conducted in a remote and rural area of Scotland hence results may not be generalisable to other areas of Scotland and beyond.

### *Interpretation*

Whilst acknowledging the challenges of assessing and managing chronic pain in older people, this study does indicate that evidence of the provision of appropriate integrated and person-centred care is lacking. This finding resonates with other studies in urban [21, 22], and remote and rural areas [12, 13] across the world. These also highlighted age as a key predictor for chronic pain and suboptimal management in older people who often report poor effectiveness. Findings are significant given the WHO global strategy [6] and the 2018-2021 Scottish government strategy for improving pain management [11]. In this study, chronic pain was largely managed by GPs with less involvement of the wider care team and minimal use of non-pharmaceutical approaches. It appears that the biomedical approach dominated over the integrated biopsychosocial mode which emphasises self-management and patient empowerment. There may also be a lack of public and practitioner awareness and understanding of such an approach and likely benefits. Evidence-based chronic pain management guidelines in Scotland, the UK and beyond highlight the key roles of psychological therapies including social support, physical therapies and complementary therapies [23, 24]. It is, however, worth noting that while physiotherapy and psychology are provided as part of the UK NHS, these services are capacity and resource limited. The cost of other therapies such as osteopathy and hypnotherapy have to be borne by the individual and are unlikely to be readily available in remote and rural areas. Indeed, recent cross-sectional surveys of older people in the Scottish Highlands identified issues of convenience of access to traditional services of GP practices and pharmacies [15, 16]. The lack of access to alternative therapies may explain the high utilisation of general practice and the reliance on ineffective medication strategies.

Respondents residing in deprived areas were significantly more likely to report experiencing chronic pain and also will be less able to be in a position to pay for non-NHS services. While the reason for this finding is unknown, a similar finding was highlighted in a study of older adults in England [25]. Furthermore, a survey conducted in the United States reported a higher prevalence chronic pain in those resident in rural compared to urban settings hence there may be several complex and inter-related factors which require further investigation [26].

The complexities of medicines selection in older adults with multimorbidity are well known and often not reflected in the recommendations of single disease state evidence-based guidelines. It would be inappropriate to comment on the suitability of medicines reported as prescribed for chronic pain given the lack of information on specific diagnoses, concomitant medical conditions and medicines. Attention should, however, be paid to the Scottish Polypharmacy Guidance [27] which recommends patient involvement in a seven step approach to medicines review for effectiveness and safety. Given that respondents reported their pain as being intense, causing distress, affecting exercise, physical function, daily activities and hobbies, and that one third expressed a desire for more effective medicines, there may be merit in reviewing their medicines regimen.

The scores of the Pain Disability Questionnaire indicated marked disability and those of the Tampa Scale for Kinesiophobia, revealed marked fear avoidance behaviour in relation to activity and their chronic pain. While most studies employing these tools have focused on targeted pain (e.g. back pain), there is evidence that a 'fear-avoidance phenomenon' has consequences of impaired functioning, increased negative mood, and levels of disability and thus must be addressed when managing chronic pain [28]. Clinically, this may indicate this patient group may benefit from more educational support from health care professionals, to understand their condition and pain, to reduce fear avoidance behaviour, beliefs and fears.

#### *Further research*

There may be merit in reviewing the current chronic pain management pathway for older, community dwelling people in remote and rural areas. This should involve all the key players with the ultimate aim of refining, piloting and testing the effectiveness, safety and cost-effectiveness.

#### *Conclusion*

Findings of this study of a community dwelling, older population in a remote and rural area of Scotland indicate that evidence of provision of appropriate integrated and person-centred chronic pain care is lacking. There may be merit in reviewing pain management pathways with focus on integrated, person-centred care involving the wider care team and focus on optimising pharmaceutical and non-pharmaceutical approaches.

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