Does pain matter in the Australian Royal Commission into Aged Care Quality and Safety? A text mining study

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A R T I C L E   I N F O

A B S T R A C T

Background: Pain is often poorly documented, assessed and managed in the Australian aged care sector. The Australian Government called for the Royal Commission into Aged Care Quality and Safety (RC) to investigate the serious concerns, neglects and abuses including the inadequate pain management seen in the sector. This study examined the degree to which the RC discussed the issue of pain in their published reports and recommendations.
Methods: A text mining study with a computer-assisted term frequency analysis identified mentions of the word "pain" in the text of two key reports produced by the RC: the Interim Report and the Final Report. Main outcome measures included frequency of mentions of "pain", cumulative percentile rank of the word "pain", proportion of words that were "pain", and frequency of mentions of the word "pain" in quotes.
Results: The word "pain" was mentioned often in the Interim Report ($n = 10$, 0.03% of all words, 87th percentile) and the Final Report ($n = 218$, 0.05% of all words, 97th percentile). However, the word "pain" was absent from final recommendations of the RC.
Conclusions: Although the RC discussed pain in their reports, the topic was omitted from recommendations, reflecting a lack of attention to the presented evidence. Without specific recommendations for pain management, a disconnection may arise between targeted polices, programs and funding schemes, and the clinical practice. Thus, older adults living in the community and residential aged care homes may remain vulnerable.

1. Introduction

In Australia, 4.2 million people (16% of the population) are aged 65 years and above [1]. In 2020, a total of 335,889 people were using residential aged care (permanent or respite, 189,954), home care (142,436), or transition care (3499) in Australia. Approximately 58% of residential care recipients and 30% of those accessing home support were over 85 years old [1]. These age groups are susceptible to frailty, pain, and care dependence [1–3].

Recognising and managing pain is a fundamental human right for all individuals, regardless of their age, gender, and cognitive status [4].

Older Australians, including those living in residential aged care homes (RACHs), are particularly vulnerable to under-recognition and under-treatment of pain, due to multiple factors, such as inadequate pain assessment and management, comorbidities, stoicism, and cognitive impairment [5]. According to the Australian Pain Society, the estimated prevalence of pain in this group exceeds 90% [6]. This is particularly problematic in residents who are no longer able to self-report the presence, nature and/or intensity of pain, such as those living with dementia or cognitive impairment. This latter group constitutes at least 52% of people living in the Australian RACHs [6]. Uncontrolled pain can lead to multiple negative clinical, social, and care

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outcomes, such as delirium, immobility, behavioural disturbances, inappropriate pharmacotherapy (e.g., psychotropic polypharmacy), caregiver distress, and reduced quality of life [3].

In Australia, some aged care services were accused of neglect and suboptimal clinical and social care including lack of proper documentation, assessment, and management practices (e.g., pain). To shed light on the current deficits of the aged care system, the Australian Government announced the Royal Commission into Aged Care Quality and Safety in 2018 (hereby denoted as RC). The RC held hearings across Australia in all capital cities and some regional locations. Over the enquiry period (8 October 2018 to 1 March 2021), the RC received a total of 10,574 submissions, 6,800 telephone calls to an information line, and heard 641 witnesses. The population of interest targeted by the RC were recipients of aged care services, including those living in RACHs.

In October 2019 (after one year of enquiry), the RC released an Interim Report, entitled *Neglect*, which summarised their findings and drew the conclusion that the Australian aged care system failed to meet the needs of citizens receiving aged care [7]. In February 2021, the RC released their Final Report, *Care, Dignity and Respect*, which outlined a vision of a new aged care system [8].

The RC examined key clinical issues, such as pain and pain-related aspects, including pain assessment, pain management, and pain monitoring. This study aimed to examine the degree and context in which the RC discussed pain in their reports and recommendations. We conducted a term frequency analysis (detecting the presence of the word "pain") of RC reports, to examine where the topic of pain was most prevalent and absent.

2. Materials and methods

2.1. Ethical considerations

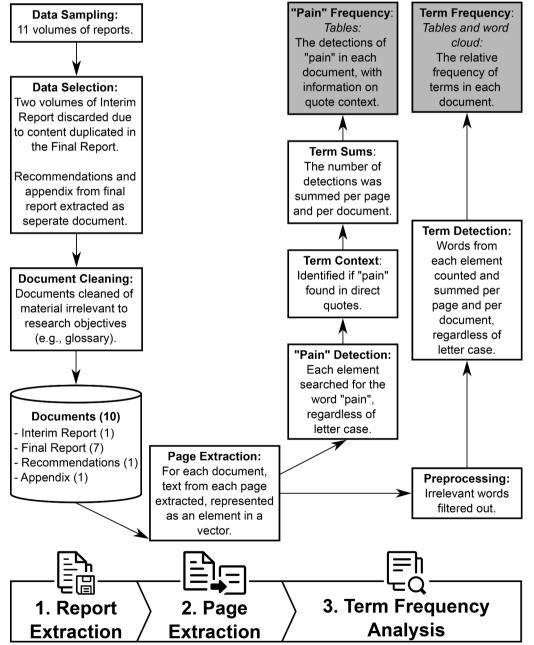As the RC reports are publicly available, no ethics approval was

Fig. 1. Term frequency analysis to detect the presence of "pain" in the Royal Commission reports.

The three major steps of the analysis are featured in the bottom-most bar. Each square is a stage of the analysis, with the final output shaded in grey, and the connecting arrows indicate the sequence of analysis. The cylinder outlines data used for analysis, which we have shared in an online repository (https://osf.io/6kst8/). Boxes and cylinders align, such that the process is vertically above the relevant analysis step (e.g., document cleaning is part of report extraction).

required for this study. This article does not contain any personal medical information or images.

2.2. Study design and method of analysis

We adopted a text mining approach [9] that used a three-step term frequency analysis [10] to categorise pain-related content in the Interim and Final Reports of the RC, as outlined in Fig. 1. A blind, independent analysis was conducted between June and August 2021 by two researchers who used similar methods to achieve identical results. Analysis was conducted using the R programming language version 4.1.0 [11]. Our analysis script is available for download at: https://osf.io/6kst8/.

2.2.1. Steps of analysis

2.2.1.1. Step 1: report extraction. Text for analysis was obtained from the two major reports of the RC: the Interim Report and the Final Report. Released on 31 October 2019, the Interim Report, entitled *Neglect*, consisted of three volumes. Of those areas discussed by the Report, pain management was identified as a key issue that requires an immediate action. The Final Report was titled *Care, Dignity and Respect,* and comprised of eight volumes that covered the following: summary and recommendations (Volume 1), current system (Volume 2), new system (Volumes 3A and 3B), hearing overviews and case studies (Volumes 4A, 4B, 4C), and appendices (Volume 5). The RC reports were downloaded from the RC website [7,8] and saved in Portable Document Format (PDF).

Interim Report Volume 2 was not included in the analysis as it contained duplicate content that also appeared in Final Report Volume 4A. Similarly, after removing duplicate content from Interim Report Volume 3, the report consisted of lists of exhibits and of evidence presented to the commission. For this reason, this report was also not included in the analysis.

Final Report Volume 1 contains the final 148 recommendations made by the RC. These recommendations, hereby referred to as 'Recommendations', were extracted and removed from the report and analysed separately. Lastly, Final Report Volume 5, which consisted primarily of appendices, will be referred to as 'Appendices' in this paper. Thus, ten documents were analysed: one volume of the Interim Report, seven volumes of the Final Report, the Recommendations, and the Appendix.

The front (i.e., cover page, contents, non-numerically numbered pages, publishing details, blank pages) and end matter (i.e., glossaries) were removed from each report. The first and last lines of each page (i.e., headers and page numbers), and endnotes from each chapter were also removed.

2.2.1.2. Step 2: page extraction. The text from each report was extracted and divided into separate pages.

2.2.1.3. Step 3: term frequency analysis. To examine the degree and context in which the RC reports discussed pain, we completed a term frequency analysis which involved automatically detecting the word "pain" in texts. To avoid matching words that contained pain as a subset of their letters (e.g., "Spain"), a search restricted to complete words was performed. For each report volume, we calculated the occurrences of the word "pain", the proportion of words that were "pain" (as a percentage), and the cumulative percentile rank of the word "pain". Additionally, we reported occurrences of the word "pain" appearing in quotes, defined as lines starting with nine or ten whitespaces (i.e., quotes formatted as indented blocks of text) or text appearing in-between a single left and single right quotation marks (i.e., inline quotes). It is worth noting that we did not mine for the term analgesic/analgesia as the RC referred to this as pain relief and therefore it was identified under the word "pain".

Alongside descriptive statistics for detections of the word "pain", we reported a word cloud of frequent terms across reports and the top ten most frequent words in each report, to provide context for the interpretation of our findings. Before calculating frequencies, we excluded words with minimal meaning. This included stop words (commonly occurring words in the English language, such as "the"), found in the onix, smart, and snowball stop word lists available in the tidytext R package [12]. Additionally, two members of the research team identified further words to exclude, due to the nature of the RC reports (e.g., locations/dates, terms such as hearing/transcript, or "commission" or "royal"). Excluded words are presented in the supplementary material.

3. Results

Table 1 presents the descriptive statistics of the occurrences of the word "pain" by report and volume. Pain was mentioned a total of 245 times within the RC reports. The word "pain" was most prevalent for Volume 4A of the Final Report (99th percentile), which concerned hearing overviews and case studies. This is the case for both global ($n = 133$ occurrences) and in-quote contexts ($n = 17$ occurrences). Across all volumes in the report, the use of the word "pain" was in the 87th (Interim Report) and 97th (Final Report) percentile in word frequency (Table 2).

Fig. 2 presents a word cloud of common words across reports. Relative to other words, the word 'pain' is very small graphically reflecting its lack of importance across all reports. Table 3 shows the top ten most frequently occurring words in each report. Comparing the most frequent words in the reports to the most frequent words in the final recommendations made by the RC, there is a degree of overlap, suggesting that key terms and issues discussed in the report are reflected in the recommendations. However, the issue of pain is not directly addressed in any of the 148 final recommendations ($n = 0$ occurrences), despite its prevalence in the Interim Report and Final Report.

4. Discussion

This study aimed to identify the frequency and context in which "pain" was discussed in the reports of the RC, an independent public investigation/enquiry into the serious concerns and abuses in Australian aged care which involved holding public hearings, calling witnesses

Table 1
Detections of the word "pain" (raw count and proportion as a percentage), cumulative percentile of the use of the word "pain", and the number of instances where the word "pain" occurred in quotes, for each volume of each Royal Commision report.

| Volume | Total detections | | | *n* Detections in quotes |
	n	%	Cumulative percentile	
Interim Report				
Summary & Recommendations				
Volume 1	10	0.03	87.09	4
Final Report				
Summary				
Volume 1	8	0.02	83.44	0
Current System				
Volume 2	37	0.08	96.26	5
New System				
Volume 3A	8	0.01	78.80	3
Volume 3B	5	0.01	65.15	1
Hearing Overviews/Case Studies				
Volume 4A	133	0.25	99.17	17
Volume 4B	17	0.02	87.17	6
Volume 4C	10	0.02	80.85	4
Recommendations	0	0.00	0.00	0
Appendices	17	0.09	96.58	0

Table 2
Overall detections of the word "pain" (raw count and proportion as a percentage), cumulative percentile of the use of the word "pain", and the number of instances where the word "pain" occurred in quotes.

Report	Total detections			
	n	%	Cumulative percentile	*n* Detections in quotes
Interim	10	0.03	87.09	4
Final	218	0.05	97.44	36
Recommendations	0	0.00	0.00	0
Appendices	17	0.09	96.58	0

under oath, and generating evidence. We found discussions of pain were most prevalent in reports of overviews on hearings and case studies. The word "pain" was absent from the final recommendations of the RC, despite an otherwise large degree of congruence of words used in the recommendations and other reports. This suggests that evidence offered to the RC on pain was not translated into pain-specific recommendations.

To our knowledge, this study is the first analysis of the RC reports. Though, two studies have analysed the transcripts from RC hearings. First, a content analysis of concepts from a testimony revealed contextual factors, such as resources and culture, can impact across myriad domains of aged care [13]. Second, a qualitative analysis of testimony transcripts identified the moral disengagement featured in Australian aged care [14]. The authors drew specifically on testimonies of pain to exemplify the absence of human relatedness in routinised care and the evidence of dehumanised and mechanistic care routines, stripping bodies of their personal characteristics, functions, and worth. Combined with our findings, this small literature on the RC reports reveals that pain characterises the experiences of those engaging with aged care services. The impact of pain extends beyond physical suffering and function, to include quality of life and experiences of moral injustice [14]. As such, pain relief is one of the greatest 'end of life' priorities, according to seriously ill patients, bereaved family members, physicians, and other care providers [15].

Public policy is critical in shaping and transforming clinical practice within the aged care sector. A good example is the United States where legislating and implementing the 1987 Omnibus Budget Reconciliation Act resulted in a reduction of the inappropriate use of psychotropic medications in RACHs [16]. In Australia, aged care reforms over the last decade introduced person-centred care and person-directed care principles that underpin the concepts of personal dignity, autonomy, and choice. These principles align well with the perspective *"pain is whatever the experiencing person says it is, existing whenever the experiencing person say it does"* [17 p. 8], and facilitate best-practice pain management (e.g., applying standardised and regular pain assessments). However, pain remains poorly documented, assessed, and managed in Australian RACHs [5,18–20].

Receipt of evidence-based pain care is essential for social, physical, and emotional wellbeing. Despite the importance of pain management to aged care recipients, pain-specific recommendations were omitted
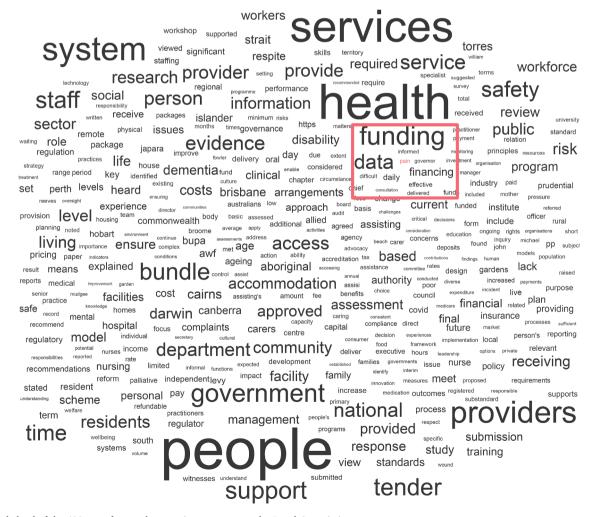

Fig. 2. Word cloud of the 400 most frequently occurring terms across the Royal Commission reports.
The frequency of words corresponds to their size in the word cloud. The word "pain" is coloured pink and highlighted with a pink rectangle.

Table 3
The top ten most frequent words appearing in each Royal Commission report.

Rank	Word	*n*	%	Cumulative percentile
Interim Report				
1	People	1025	2.57	100.00
2	Services	536	1.35	99.98
3	Health	375	0.94	99.97
4	System	297	0.75	99.95
5	Support	263	0.66	99.93
6	Community	242	0.61	99.92
7	Government	233	0.59	99.90
8	Providers	192	0.48	99.89
9	Time	192	0.48	99.89
10	Broome	191	0.48	99.85
Final Report				
1	People	6174	1.50	100.00
2	Health	5104	1.24	99.99
3	Services	4616	1.12	99.99
4	Providers	3046	0.74	99.98
5	System	2995	0.73	99.97
6	Government	2433	0.59	99.97
7	Funding	2342	0.57	99.96
8	Bundle	2074	0.50	99.95
9	Tender	2065	0.50	99.94
10	Support	1933	0.47	99.94
Recommendations				
1	Services	223	1.73	100.00
2	People	209	1.62	99.95
3	Health	198	1.53	99.91
4	Providers	139	1.08	99.86
5	Government	134	1.04	99.81
6	System	131	1.01	99.77
7	Provider	111	0.86	99.72
8	Receiving	99	0.77	99.67
9	Approved	95	0.74	99.62
10	Funding	95	0.74	99.62
Appendices				
1	Health	257	1.38	100.00
2	People	209	1.12	99.98
3	Covid	158	0.85	99.96
4	Residents	143	0.77	99.94
5	Services	142	0.76	99.91
6	Staff	123	0.66	99.89
7	Community	116	0.62	99.87
8	Family	79	0.42	99.85
9	Facility	77	0.41	99.83
10	National	74	0.40	99.81

from the Final Report of the RC. This is at odds with the 'rights-based' or egalitarian approach of the RC, that recommends a "*new system for aged care should be rooted in the protection and promotion of the rights of the people who require support and care.*" [8 p. 14] General recommendations for improving aged care are unlikely to sufficiently achieve adequate pain management for consumers, as effective pain management requires specialised knowledge, techniques, and care culture [21]. For example, effective and appropriate pain management is most likely in RACHs with pain-vigilant cultures, where staff suspect the presence of pain.

Additionally, pain management for individuals living in RACHs requires strategies and knowledge to identify pain in all residents including those who are unable to communicate verbally such as those with cognitive impairment (e.g., people living with dementia) or those with a language barrier (e.g., people from culturally and linguistically diverse backgrounds). This is evident in the former group (i.e., residents with cognitive impairments), for example, where fewer, weaker and lower-dose analgesics are often administered compared to cognitively intact individuals [22–24]. As such, in their submission to the RC, the Australian Pain Society provided the following recommendations: encourage evidence-based strategies of pain management, facilitate a government or publicly funded multidisciplinary care in RACHs, and restructure existing aged care funding towards evidence-based multidisciplinary pain management [21]. These best care practices, including the value of multidisciplinary pain management to deliver a comprehensive, expertise-driven, person-centred and effective pain care are supported not only in Australia, but also in other countries, such as Japan and the Netherlands [25–28].

In response to the RC's findings, the federal government pledged a historic financial support of 17.7 billion Australian dollars reform package in the 2021 budget. A judicious use of some of this support should be targeted towards implementing the best practice recommendations of the Australian Pain Society. Yet, as evidenced by the absence of the word "pain", no clear pathway to pain management-specific outcomes was mapped. This is despite the published RC reports highlighting the failure of the aged care system to meet the pain care needs and deliver safe and quality care to older Australians. The repudiation of mentioning or listing pain in any of the RC Recommendations perhaps result in compromising the focus on best practice pain management that the older population rightly deserves and awaits from aged care providers. By doing so, the human right of aged care recipients to access appropriate pain management may have been excluded or overlooked from the rights-based approach of the RC.

Finally, our findings suggest that government initiated public inquiries should consider the presented evidence to help formulate specific and targeted recommendations to enable subsequent legislations and policies that benefit the target population.

4.1. Strengths and limitations

Term frequency analysis is limited by the rigid operationalisation of the concept of interest. Pain was operationalised as a single term ("pain"), and therefore the text was examined through a narrow semantic lens which omits other phrases used to express or refer to pain, such as analgesia. We did not report any other clinically relevant words featuring in the final recommendations of the RC, as this was outside the scope of the paper. Absent from our approach was an attempt to describe the latent, rather than semantic, meaning of words. The emotional and conceptual differences that can underscore each instance of the word "pain" remains unexamined. Though, the automated detection of the word "pain" has advantages as an efficient process which can be easily replicated by other researchers. Further, blind independent analyses were completed as part of the study with the same results produced by two different researchers. Thus, our text mining technique offers a simple, rigorous, and systematic approach to text analysis of official documents such as reports published by the government and other stakeholders (e.g., peak body organisations).

Due to our operationalisation of pain as a single word, our analysis does not identify recommendations that holistically address the causes of poor pain management or foster environments that enhance pain management. For example, the RC recommended access to specialists via multidisciplinary outreach [8], congruent with the Australian Pain Society's recommendation for multidisciplinary pain management [21]. However, this specific recommendation by the RC has raised concerns, due to the lack of operational detail by the RC [29]. This supports our conclusion that the RC Recommendations do not sufficiently describe a roadmap for achieving satisfactory pain management outcomes for consumers of aged care services.

5. Conclusions

Pain *per se* characterises the suffering experience of aged care recipients, disrupting physical function, emotional wellbeing, and quality of life. Yet, the testimonial and submitted evidence on recipients' experience of pain obtained during the RC have not translated to clear, actionable recommendations. The sizable population of older adults in Australia remain vulnerable, with common pain experiences that are often under-recognised and under-treated. Policy makers must act now to incorporate the operational details and pain-specific changes to funding structures and health policies in order to restore the human right to adequate and appropriate pain management to some of

Australia's most vulnerable citizens.

Data availability statement

All data used in this article are extracted from the publicly available, published reports of the Australian Royal Commission into Aged Care Quality and Safety. The code for the text mining analysis is publicly available online on the Open Science Framework at: https://osf.io/6kst8/.

Author contributions

Conceptualisation and study design: M Atee. Data curation and formal analysis: M Atee, M Andreotta, R Lloyd and D Whiting. Methodology: M Atee, M Andreotta, R Lloyd and D Whiting. Project administration: M Atee. Writing original draft: M Atee and M Andreotta. Review and editing: all authors.

Consent to publish

All authors have provided the corresponding author with permission to be named in the manuscript and consented to submit this manuscript.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

M Atee is one of the originators of the PainChek® instrument, which is marketed by PainChek Ltd. (ASX: PCK). He is also a shareholder of PainChek Ltd. He previously held the position of a Senior Research Scientist (October 2018 - May 2020) at PainChek Ltd. and is currently serving the position of Research and Practice Lead at The Dementia Center. He had a granted patent titled "A pain assessment method and system; PCT/AU2015/000501" in Australia, China, Japan, and the U.S., which was assigned to PainChek Ltd. M Atee is also a member of the Australian Pain Society. Other authors declare no conflict of interest.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.ahr.2023.100126.

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