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Kaitiaki
Nursing Research

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Kaitiaki Nursing Research

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Papers in all areas of nursing are welcome. Authors should present original work, or new and original analysis of existing work. Letters to the editor are also published. All articles and manuscripts will be subjected to the same rigorous review process.

Kaitiaki
Nursing Research

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FROM THE EDITOR: **Patricia McClunie-Trust**

Nursing research: Allowing good practices to travel

Tēnā koutou, tēnā koutou, tēnā tatou katoa.

Welcome to the 2023 edition of *Kaitiaki Nursing Research*. As we publish the 14th edition of the journal, it is worth reflecting on the value of research in contributing to knowledge for contemporary nursing practice and in documenting the history of our role in healthcare for future generations of nurses. Nursing is a constantly evolving profession that is driven to seek new solutions for the contemporary challenges we experience in complex health care and tertiary education contexts. Our research documents the creative responses and innovations we have made to manage the challenges we face.

Nursing is a profession that is defined by its social relevance and ethical positions (Hoeck & Delmar, 2018). As Hoeck and Delmar suggest, it is a profession that is constantly re-evaluated in relation to its contribution to health care and the values that guide nurses as health professionals. Nursing is characterised by a distinct body of knowledge that underpins clinical decision-making, and by the ability to navigate complex client situations according to a set of shared values. Nursing research helps us negotiate and conceptualise the space between practice and scholarship, connecting the everyday work of nursing to formal knowledge and evidence for practice.

Ceci et al (2017) note that nursing knowledge should be derived from the contexts in which it occurs, taking account of the organisational influences that push and pull the thinking and reasoning of nurses in practice. Research is critical in this process of recording, analysing and synthesising observations and measurements of practice in specific contexts. It enables *"good practices to travel outside of the very particular circumstances where we find them to make practice better in other locations"* (Ceci et al, 2017, p. 51). Publishing research enables us to capture the essence of nursing in our place and time in ways that generate evidence for practice, and knowledge for policy and quality improvement. It also shapes the historical narratives of nursing in Aotearoa New Zealand by documenting how we have navigated the ethical, cultural, and political challenges of our time and made an impact on the delivery of health care.

This edition of *Kaitiaki Nursing Research* offers insights into some of the ideas that are unfolding in nursing scholarship in Aotearoa New Zealand. We offer these in the hope that the research documented in this edition will be useful to nurses in other contexts.

Care workers need support

Care and support workers make an important contribution to health care in Aotearoa New Zealand, particularly in assisting registered nurses (RNs) to provide holistic care for older adults. It is important that the needs of care and support workers are met, both in terms of financial reward and support from their employers (Garces-Ozanne & Carlos, 2022). Barry et al explored the impact of the Care and Support Worker (Pay Equity) Settlement Act (2017) on the work-related quality of life of homecare support workers. The findings of this study suggest that while the support workers they interviewed reported increases in their pay rate, their hours of guaranteed employment were reduced. They also experienced intense stress in the workplace due to understaffing, high workload, lack of coordination, and problems with scheduling. This study emphasises the need for more oversight in the homecare industry to ensure the safety and wellbeing of both support workers and clients. This oversight could also encompass nurses working in the sector.


Patricia McClunie-Trust

Clinical placements across a variety of settings provide essential learning opportunities for bachelor of nursing students, particularly in gaining real-world skills and experience to competently practise as RNs (Moroney et al, 2022). The research conducted by Thomson et al explored the experiences of nursing students who had clinical placements in managed isolation and quarantine facilities (MIQFs) during the COVID-19 pandemic. The findings of this research illuminate an innovative and responsive approach to providing community-based clinical experience under the restrictions of the pandemic. Using MIQFs as a community placement enabled nursing students to gain unique experiences for clinical learning, rather than resorting to clinical projects and simulation as an alternative. This research highlights how nurse educators used a challenging situation to create innovative opportunities for clinical learning, while providing a safe, student-centred experience.

> **Using MIQFs as a community placement enabled nursing students to gain unique experiences for clinical learning.**

Link-nurse programmes aid the prevention of pressure injuries by designating specific nurses as experts in this field of care, who can act as a resource for their colleagues (Moir et al, 2022). This further study by Moir et al asked link nurses to identify changes in their practice areas brought about by participation in a pressure injury prevention link nurse programme. They found that all of the nurse participants noticed an increase in their knowledge and awareness of pressure injury prevention. This research highlights how positive changes in care occur when nurses are supported to lead quality improvement processes. Leading by example and being seen to be able to make improvements, such as in new equipment purchases, increased link nurses' sense of autonomy. Recognising a need and leading their own change project was a positive process for nurses, management and colleagues in this study.

The daily struggle of psoriasis

Evidence synthesis provides summaries and interpretations of primary research and other published information that are essential to inform nursing practice and improve health care. We have included three qualitative reviews in this edition, including a meta-synthesis, an integrative review, and a qualitative systematic review. Greenwood and McClunie-Trust used meta-ethnography to synthesise qualitative research on the experiences of people who live with psoriasis. Participants in the primary studies illuminated the daily struggles they experience, including how psoriasis shapes the way they live their lives and how they work to make themselves and their bodies invisible as a coping strategy. These powerful narratives reveal important insights into how people live with psoriasis as a long-term condition. The findings of this synthesis show how important it is that health professionals understand the impact of psoriasis on the lives of those people who live with it as they play a pivotal role in helping people to successfully manage their condition.

Sibley and Mercer conducted an integrative review on the management of behavioural and psychological symptoms of dementia. The objective of this review was to determine the factors that created nurses' reliance on PRN antipsychotics in those with behavioural and psychological symptoms of dementia. The findings of this review show that using person-centred care plans, that focus on the individual, reduces use of PRN antipsychotics. However, the management of symptoms of dementia is complicated by a mix of low staffing, and/or inadequate training in aged-care facilities, leading to increased risk for both the individual client and staff, who are vulnerable to burnout. Appropriate education and training for nurses and care and support workers further reduces these risks, when paired with the use of non-pharmacological care plans.

Weber used a qualitative systematic review to explore how nurses decide on a safe site for intramuscular injections in an acute mental health setting. The risks and benefits of different intramuscular injection sites remain a subject for debate in the acute mental health literature. Although a few primary studies have investigated the issue of the safe site for intramuscular injections, the evidence remains varied and sometimes contradictory. This review reports on a synthesis of primary research that determined whether accessing the dorsogluteal site is safer in an inpatient acute mental health setting where there is the potential for violence and agitation, as well as during personal restraint. The overall goal of the review was to provide practical guidance for health-care providers to help ensure the safe and effective administration of intramuscular injections in acute inpatient mental health settings.

A protocol for research

Research protocols are important to publish to create a detailed account of a research topic and approach, because publication invites peer review and makes it possible for other researchers to replicate the study. It also avoids duplication of research and enables greater collaboration between researchers (Ohtake & Childs, 2014). In this edition, Oda et al share a protocol for their planned research on improving nursing oral care practice for care-dependent older adults through interprofessional collaboration. This research aims to develop a guideline for conducting a nurse-led oral care assessment and care plan for care-dependent older adults. It will involve the development of training and other resources to support the implementation of the guideline by enhancing nurses' knowledge and confidence and encouraging the normalisation of daily oral care in nursing practice.

The role of oral history

Oral history has an important role in preserving the lived experiences of nurses who have gone before us. The life stories of our nurse elders preserve knowledge about nursing practice and patient care in health systems over time. They also capture how these nurses have responded to the challenges they have encountered in their professional lives. Heather Woods, the NZNO librarian, has contributed an article for our methodology section in this edition emphasising the importance of oral traditions in recording and enriching our nursing culture.

References

Ceci, C., Pols, J., & Purkis, M. E. (2017). Privileging practices: Manifesto for "New Nursing Studies". In T. Foth, D. Holmes, M. Hülsken-Giesler, S. Kreutzer & H. Remmers (Eds.), *Critical approaches in nursing theory and nursing research. Implications for nursing practice* (pp. 51–67). V & R Univeritätsverlag Osnabrück.

Garces-Ozanne, A., & Carlos, M. R. (2022). An exploratory study of workers in the residential aged care sector of New Zealand: what drives them to stay or leave? *International Journal of Social Economics, 49*(6), 867-881. https://doi.org/10.1108/IJSE-09-2021-0544

Hoeck, B., & Delmar, C. (2018). Theoretical development in the context of nursing —the hidden epistemology of nursing theory. *Nursing Philosophy, 19*(1), e12196. https://doi.org/10.1111/nup.12196

Moir, C., Taylor, P., Seaton, P., & Snell, H. (2022). An Evaluation of Barriers and Facilitators for a Pressure Injury Prevention Link Nurse Role: A Mixed-Methods Study in New Zealand. *Journal of Wound, Ostomy and Continence Nursing, 49*(4), 314-321. https://doi.org/10.1097/WON.0000000000000888

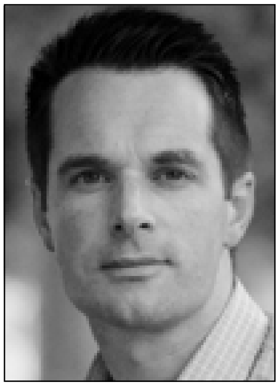
Moroney, T., Gerdtz, M., Brockenshire, N., Maude, P., Weller-Newton, J., Hatcher, D., Molly, L., Williamson, M., Woodward-Kron, R. & Molloy, E. (2022). Exploring the contribution of clinical placement to student learning: A sequential mixed methods study. *Nurse Education Today, 113,* 105379. https://doi.org/10.1016/j.nedt.2022.105379

Ohtake, P. & Childs, J. (2014). Why publish study protocols? *Physical Therapy, 94*(9), 1208-1209. https://doi.org/10.2522/ptj.2014.94.9.1208

Work-related quality of life for support workers and the Pay Equity Settlement Act 2017

Christine Barry

Christina Severinsen



Andy Towers

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ABSTRACT

Aim: This study aims to explore the impact of the Care and Support Worker (Pay Equity) Settlement Act (2017) on the work-related quality of life of homecare support workers.

Background: Previous research found negative consequences from the Act's implementation on care and support workers' quality of life; however work-related quality of life has not been addressed, providing an opportunity for further investigation.

Methodology: The study used a qualitative approach and conducted semi-structured interviews with eight female homecare support workers in 2021. The interviews were analysed thematically using Van Laar et al's (2007) Work-Related Quality of Life model.

Findings: The findings indicate that the Act's implementation has adversely affected participants' work-related quality of life. Five key themes were identified, including work re-organisation and intensification, undesirable collegial working relations, and a decline in managerial support and communication. Additionally, pay increments were identified as not keeping up with inflation.

Discussion: This study highlights the need for sector-specific guidelines for homecare support workers and standard regulations for providers. The implementation of future legislation should also undergo careful reassessment of how fiscal measures are used.

Conclusion: The Care and Support Worker (Pay Equity) Settlement Act (2017) has had a negative impact on participants' quality of life at work. The findings of this study contribute to the understanding of the unintended consequences of the Act's implementation on care and support workers and the need for improvements in the sector.

KEYWORDS

Homecare, care and support workers, Pay Equity Act 2017, work-related quality of life

INTRODUCTION

Care and support workers play an essential role in health and disability systems worldwide by providing direct care and support in the home, community and disability services (Ravalier et al, 2019; Vassos et al, 2019). They care for older adults and people with various chronic diseases, injuries, disabilities, and mental health and addiction issues (Ministry of Health, 2016; Ravenswood et al, 2015). However research has shown that care and support workers often face poor working conditions and are susceptible to unfavourable pay and marginalisation (Ravalier et al, 2019; Strandell, 2020). Additionally, care and support work is often considered undervalued and gendered as women's work (Hebson et al, 2015; Stranz & Szebehely, 2018). With the ageing global population, finding ways to support and improve conditions for this vital workforce is important.

Aotearoa New Zealand's care and support workforce is primarily female, culturally diverse, and ageing, with most workers between 45 and 65 years old (Meagher, 2016; Ravenswood & Douglas, 2017). They mostly work part-time and are not regulated by the Health Practitioners Competence Assurance Act (Ministry of Health, 2016). The demand for care and support services is increasing due to an ageing population and the prevalence of disability and non-communicable diseases (Home and Community Health Association & Lattice Consulting, 2018). However, the working conditions of care and support workers have been affected by class, gendered norms, and hierarchical working relations (Charlesworth & Heap, 2020; Ravenswood & Harris, 2016). Research shows that care work is often undervalued and subjected to gender discrimination (McGregor & Davies, 2019; New Zealand Human Rights Commission, 2012).

Previous research illustrates that financial restructuring of health systems and associated resource constraints have led to intensification of the work of care and support workers, resulting in more significant stress, role ambiguity, reduced staffing rates, and reduced time to complete duties (Strandell, 2020; Trydegård, 2012). Restructuring and resource constraints have further undermined key workplace factors for care and support workers, such as remuneration, employment hours and job security (Stranz & Szebehely, 2018). International research also shows that care and support workers often have low wages, and variable contracts and employment hours, with a high percentage of workers in some countries, such as the United Kingdom, employed under zero-hour contracts (Ravalier et al, 2019; Rubery et al, 2015). In Aotearoa New Zealand, many home and community care workers have limited guaranteed hours of employment and earn the minimum wage (Ravenswood & Douglas, 2017; Ravenswood et al, 2015).

The New Zealand Government enacted the Care and Support Worker (Pay Equity) Settlement Act of 2017 in response to fiscal and work pressures facing care and support workers (Douglas & Ravenswood, 2019; Treasury, 2017). The Act provided $2.048 billion over five years to ensure pay equity for carers in residential, home, community and disability sectors (Care and Support Workers (Pay Equity) Settlement Act, 2017; Ministry of Health, 2018). However, research by Douglas and Ravenswood (2019) found the Act had unintended negative consequences, including reduced hours of work, increased workloads, and heightened work-related stress for care and support workers. Additionally, the home and community care sector saw significant changes in working conditions affecting the job security of Levels 3 and 4 care and support workers, and many were left financially worse off. What was unclear from the Douglas and Ravenswood (2019) investigation was the different ramifications for care and support workers' wider work life, in particular their work-related quality of life. Recent research by McFadden et al (2021) highlights that support workers' work-related quality of life is fundamentally associated with their motivation and ongoing contentment at work**.** The study reported by this article aimed to explore how the Care and Support Worker (Pay Equity) Settlement Act (2017) has affected the work-related quality of life of home and community support workers.

METHOD

Van Laar et al's (2007) Work-Related Quality of Life model was applied as a framework for a deductive, feminist qualitative investigation into the impact of the Act on support workers' quality of life. The Work-Related Quality of Life model includes four components: working conditions, stress at work, work-life balance, and career and job satisfaction. This model has been widely used in research and aligns with the deductive approach. The feminist qualitative approach was chosen as the care and support workforce is predominantly female and has a history of gender discrimination.

Participants

The participants in this study were support workers primarily employed in the home and community sector, located in an urban city in the lower North Island of New Zealand. For the purposes of confidentiality, the specific location will remain undisclosed. To recruit participants, a study information sheet was distributed to an industry training organisation (ITO), home and community sector providers, unions, community health and social service organisations, and through word of mouth. Potential participants interested in this study contacted the researcher via phone or email, who checked whether they met the study's inclusion criteria. The criteria included that participants be English-speaking females, over 18 years of age, currently working as support workers, primarily in a homecare role and holding a Level 3 or 4 experience or qualification. The study's criteria that participants should be women was to enable women's voices pertaining to the Act to be heard. Eight participants meeting these criteria were accepted into the study and their identities protected through pseudonyms and participant numbers. The researcher conducted the interviews, which included each participant completing a brief questionnaire enabling the collection of background information (age, years of homecare experience etc), which helped to provide a contextualised understanding of the participants. Table 1 (below) provides key participant demographic information.

Data collection

This study used in-depth, semi-structured, face-to-face interviews for data collection. The interviews were conducted using a set of open-ended questions based on the Work-Related Quality of Life scale.

Table 1. Key participant demographics

Participant pseudonym	Age	Level 3 or 4	Full-time or part-time	Years of experience as support worker
Sharon	65	3	Part-time	7-10
Lorraine	47	3	Full-time	15-18
Jill	53	4	Full-time	15-18
Helen	56	3	Full-time	7-10
Molly	66	3	Full-time	7-10
Cathy	50	3	Full-time	11-14
Sarah	not stated	3	Full-time	19+
Tanya	51	4	Full-time	11-14

The study received ethical approval from the Massey University Human Ethics Committee, and all participants gave their consent before the interview. The researcher recorded and transcribed the interviews aided by a computerised software transcription service. Identifying information was removed, and the interviews were checked for accuracy by the researcher, and then by participants to ensure data quality.

Data analysis

This study employed Clarke and Braun's (2014) six-step process of thematic analysis to analyse the data collected from the interviews. Thematic analysis was selected due to the method's strength in capturing the complexities of meanings and use in exploring experiences from participant interviews (Gavin, 2008; Guest et al, 2012). The transcripts were imported into NVivo software and coded and analysed according to the theoretical concepts of Van Laar et al's (2007) framework of the four psycho-social subscale components: working conditions, stress at work, work-life balance, and career and job satisfaction. Aspects or concepts within the data perceived as important or significant were systematically assigned to codes under these components, forming coding trees relevant to the research question. Therefore, this study used a combination of deductive and inductive approaches, in which codes emerged from the data and were assigned to the components forming coding trees, and categories were created by addressing similarities and overlaps in codes and coded data. This process involved merging and re-defining codes and resulted in more extensive general codes, with some becoming promoted to potential prominent themes. The first researcher managed the process of code development, and researchers two and three facilitated in the review and refinement of the codes. The four sets of components and their thematic maps were compared to check the possible themes and their relationship to each other. This helped inform the story behind the data and in answering the research question.

RESULTS

The study's findings on the effects of the Settlement Act on support workers' work-related quality of life are presented using the four components identified as underlying work-related quality of life: working conditions, stress at work, work-life balance, and job and career satisfaction. These components were used as a framework to analyse and present the data collected from the interviews.

Working conditions

The study found that six support workers reported a significant increase in their pay rate since the Pay Equity Settlement Act was implemented. However half of the participants also reported declining employment hours. This decline was linked to a reduction in guaranteed hours, the hiring of cheaper staff, and less time allocated to clients for care. This suggests that while some workers benefited from the increased pay, they also experienced a reduction in the amount of work available to them. For example:

> *"Because our pay went up, they probably weren't quite willing to give us many more hours ..."*
>
> *"They also changed our working ... instead of giving an hour to shower, we have to do what we're doing in three-quarters of an hour, or half an hour. Plus, we were expected to do more in that time, which was less time than what we had then when the pay went up. They didn't do it so much for existing clients, but they did it for new clients."* (Helen)
>
> *"Once pay equity came in … what did they start doing? Us ones that knew what we were doing and had up to Level 3, we weren't getting the work. They were actually bringing on new ones that they could pay $2 or $3 cheaper."* (Molly)

Some participants also noted that the pay increments they received over the last four years had not kept pace with inflation and living costs, resulting in their wages being similar to the minimum wage. Participants also expressed concerns about the reorganisation and scheduling of their work. Some reported experiencing work intensification, which included pressure to accept extra shifts, working alone in situations meant to be handled by two people, and a lack of time off work. These factors may have negatively affected the overall quality of their working lives.

> *"You do, at times, feel pressured to fill those [extra] hours, even if you don't want to. You get the sob story of, 'But there's no one else to do the job, and this needs to be done.' And quite frequently, you do give in when you shouldn't … Two days off in three weeks is not good."*
> (Lorraine)

The study also found that the participants perceived a decline in management support and communication following the Act's implementation. Support was often limited to occasional feedback and emails, with only one provider offering regular staff meetings. This lack of support and communication from management may have added to the stress and dissatisfaction reported by the participants, negatively impacting their overall work-related quality of life.

> *"After pay equity came in, we didn't really have much to do with the company itself. For coordinators, it was hard to get through to them. We sat for ages on the phone. There were times when there was an urgent need to get them in, and we got, 'Just leave a message.' And so you deal with a problem yourself. And then, later on, you forget to call them back and tell them what happened."* (Sharon)

Participants did not receive adequate management guidance and support, which negatively affected their work. They also mentioned the lack of support forums, which decreased after the Act's implementation. Participants felt unimportant, unsupported and alone.

For example:

> *"We don't have enough contact. We're out here on our own, and we don't have office contact ..., you just get a text message on the phone. Nobody. They don't ring."* (Jill)

Changes in how work was organised and reduced communication and support from coordinators led to a decline in the workplace culture in terms of valuing and recognising their roles as support workers. The centralisation of a provider led to the loss of local and regional coordinators and was linked to a lack of concern for support workers, communication problems, and reduced support. Overall, support workers felt that the workplace culture had worsened and that there was less emphasis on their well-being.

Participants felt there was a lack of management support for training, despite the legal requirement under section 12 of the Care and Support Worker (Pay Equity) Settlement Act 2017 that employers must ensure that care and support workers can gain qualifications. They also reported that communication and provision of practical training opportunities were ineffective, often lacking, or absent and worse since the implementation of the Act.

> *"I think there needs to be ongoing training. They have sent girls in to do catheter bags who have never done a catheter bag in their life. Well, to me, that's wrong!"* (Molly)

> *"There's no training … we get taught by each other, not officially by anyone who should be."* (Sharon)

> *"Well, they say they give us training, but they never do. I've never been trained in using a hoist or any equipment ever. Although they will tell you that all girls are trained, they're not."* (Sarah)

Stress at work

All the study participants experienced intense stress in the workplace due to understaffing, high workload, lack of coordination, and problems with scheduling. They also described feeling pressure to cover extra shifts at the last minute and working for long periods without days off. The participants attributed these issues to the reorganisation of their work following the Act and they reported feeling fatigued and experiencing unsafe working conditions.

> *"The biggest pressure, again, you get pressured into doing extra hours when you shouldn't be. You just get too tired."* (Lorraine)

> *"I [hurt my hand] ... And it was because I was fatigued. I worked too much, slept too little. I did that at work. And it's fatigue, it's fatigue. Yeah, such a mess."* (Cathy)

Participants in the study reported stress related to worsening relationships between co-workers due to the reorganisation of work following the Act's implementation. This behaviour included some co-workers not showing up for shifts and high variability in their availability for shifts, performing care tasks poorly, performing care tasks quickly and leaving client visits as soon as possible, and unpleasant behaviour when communicating with other co-workers. Some of this behaviour resulted in other workers being landed with additional work. These issues compounded and negatively affected client care. One participant reported bullying by co-workers and competition for higher-paying shifts being more prevalent after the Act went into effect.

Work-life balance

Participants reported feeling that their welfare and work-life balance were not considered. This situation had worsened since the Act's implementation, as a result of work intensification and shortages of available staff. They strongly disagreed that their employers provided adequate facilities and flexibility to accommodate their family life.

> *"They don't ... Absolutely, they don't. They don't talk to you about your needs at all. To be honest with you, they're just worried about covering these clients."* (Molly)

> *"We have no coordinator or anybody that gives a toss ... so no, it's non-existent."* (Sarah)

Support workers linked management's lack of flexibility regarding their employment hours to staff shortages and the centralisation of work.

> *"Not ... so good. Really! No. They are happy if you want an extra shift [laugh], not so happy about time off … I had to do clients before I could go to a funeral because they didn't have anyone to cover."* (Helen)

> *"When we had a coordinator, you could ring her, and she would sort it. You know, just cover your shift. It was easy. However, now you don't do anything because no one will deal with anything. We tend not to now because we know our clients are not going to get covered. So, I think that's gone by the way, that whole flexibility."* (Sarah)

Five support workers reported that their hours did not suit their circumstances, and the organisation of work significantly affected their ability to achieve work-life balance.

> *"The split shifts are silly things ... I hate the split shift, and I'd like to not do the night shift. But to get enough hours [I've] got to. There's basically no work between one and four, so you've got to do the split shifts to get your hours, to get your 40 hours a week."* (Molly)

> *"No, they don't suit my personal circumstances. I used to finish work at 4 o'clock. And the hour and a half difference makes a huge difference when your partner goes to bed very early because of his hours. So, with the service review that's coming up, I'm hoping ... I'm hoping to see what changes I can make to bring my finish time down. I don't mind losing a few hours if I get to spend more time with my family."* (Lorraine)

Support workers felt that management was not considering their wellbeing and were dissatisfied with how management handled shift coverage. These issues indicate a broader workplace culture which prioritises work over personal life and shows little willingness to make changes.

Career and job satisfaction

The implementation of the Act has negatively impacted the job satisfaction of the support workers due to poor work organisation and communication. Additionally, the workers reported not receiving recognition or appreciation from management and feeling undervalued and disrespected. These issues can have a negative impact on employee morale and may contribute to high turnover.

> *"No appreciation whatsoever. You would ring, and they didn't want to know what your name was – they want to know what your number was."* (Molly)

> *"Being paid on the higher rate doesn't mean they value me!*

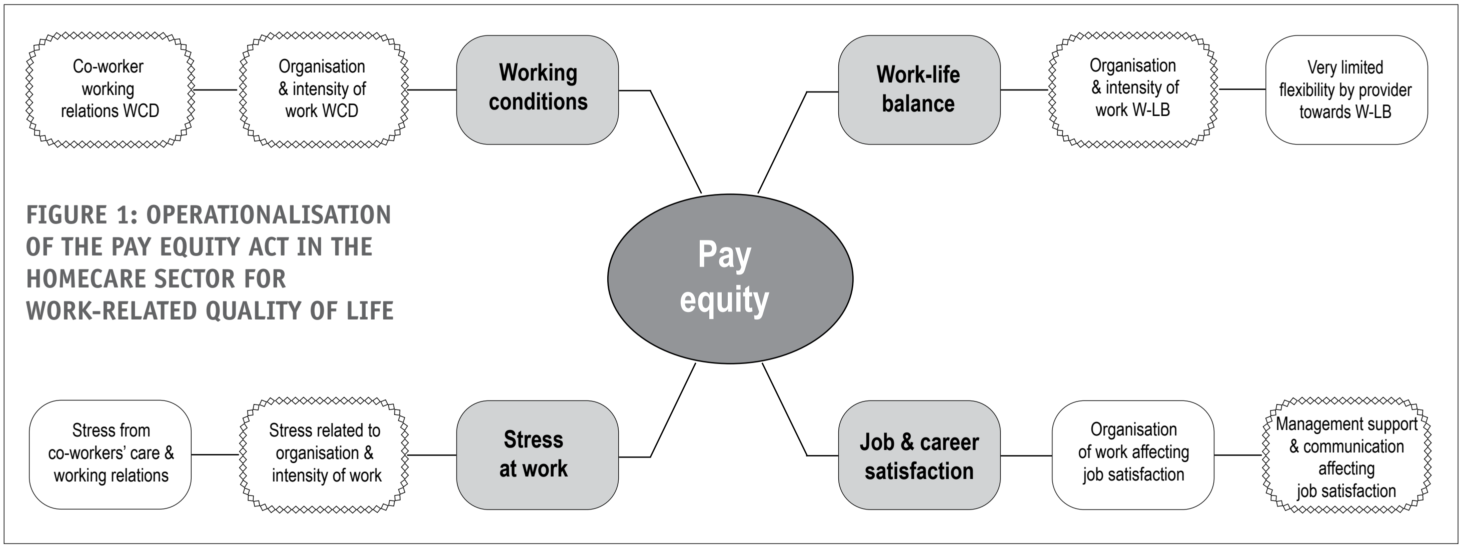

FIGURE 1: OPERATIONALISATION OF THE PAY EQUITY ACT IN THE HOMECARE SECTOR FOR WORK-RELATED QUALITY OF LIFE

This flow diagram illustrates the relationship between the four components of the Van Laar et al (2007) Work-Related Quality of Life model and the key themes identified by the researcher through deductive thematic analysis. The key themes are highlighted in the boxes with decorated borders and are associated with supporting sub-themes. The diagram provides a clear visual representation of how the implementation of the Pay Equity Act has negatively impacted the work-related quality of life of the homecare support worker participants in this study. It serves as a valuable tool to succinctly convey the findings of the research and the impact of pay equity on support workers.

> *It just means I'm paid on the higher rate. And that's all there is to it."* (Jill)

The participants' responses indicate that management does not seem to understand or appreciate fully the importance of their role and that they are not taking the views and feedback of the support workers regarding client care seriously. This lack of consideration and sincerity can lead to a lack of trust and engagement among support workers, which can negatively impact the quality of client care.

> *"I sent [so many] complaints to that person in the office, ... but they don't answer [my many] complaints. And in the end, I got told, 'Oh, sorry, they went to my junk file.' I mean, now ... that's our leadership! They are all legit ones, clients missing care, you know."* (Sarah)

The participants' responses clearly indicated they felt undervalued and unappreciated in their roles. They felt their contributions were not recognised, and management did not value their work. This lack of recognition can lead to a lack of job satisfaction, which can negatively affect the quality of life at work and the workers' perceptions of pay equity.

> *"And even now, the pay is terrible. We [are] only $1 more than the living wage. So, it's a bit of a joke now! It was great to start with because we're to go from $14 to $21 [which] was pretty cool. And then we've just had 50c increments each year; we just went up to $25. I've just gone up to $25."* (Molly)

Deductive thematic analysis identified five key themes in the provided information: organisation and intensity of work; stress related to organisation and intensity of work; organisation and intensity of work and work-life balance; co-worker working relations; and management support and communication affecting job satisfaction. These themes highlight the negative impact of the Care and Support Worker (Pay Equity) Settlement Act (2017) on the work-related quality of life for these homecare support workers. The themes are illustrated in a flow diagram (Figure 1, above) which shows how the implementation of the Act has led to these adverse effects.

DISCUSSION

This study was conducted to investigate the effects of the Pay Equity Settlement Act 2017 on support workers' work-related quality of life in Aotearoa New Zealand. The research builds on previous work by Douglas and Ravenswood (2019) on the unintended consequences of the Act's implementation on the quality of life of care and support workers. The study used the Van Laar et al (2007) Work-related Quality of Life model to identify five key themes related to working conditions, stress at work, work-life balance, and job satisfaction. This researcher's study found that the Act negatively impacted the work-related quality of life of these home and community support worker participants.

A significant finding of the study was the negative impact of the re-organisation and intensification of work on the participants' work-related quality of life. The employers' response to the Act caused changes in work schedules, workloads, and work expectations that offset the initial benefits of the increased pay rates. Participants had less time to perform tasks and felt rushed and pressured to complete them, which decreased the time allocated for client care. These findings were consistent with previous research from Nordic countries and Douglas and Ravenswood (2019). It is also important to note that although support workers' rates of pay were increased under this Act, nurses in this sector did not receive corresponding pay increases (Douglas & Ravenswood, 2019).

The findings of this study point to the need for more regulation of homecare services, including guidelines relating to time frames for the provision of care and nationally applied practice guidelines specific to support workers in the homecare sector. The study highlights the importance of effective communication and management support in the homecare industry to improve job satisfaction, training and the quality of care provided to clients. Additionally, it emphasises the need for more oversight in the homecare industry to ensure the safety and wellbeing of both support workers and clients. This oversight could also extend to nurses working in the homecare sector.

The findings of this study suggest the Act has negatively affected the work-related quality of life of homecare support workers employed in an urban lower North Island area of Aotearoa New Zealand. The re-organisation and intensification of work, lack of management support, and poor collegial working relations all contributed to a negative impact on the work-related quality of life of these workers. The findings of this study highlight the need for further examination of the effects of work intensification, standard regulations for homecare providers, and development of nationally applied sector-specific practice guidelines for support workers in the homecare sector. Finally, the study illustrates the need for more research into the effects of the Act on the homecare sector and the welfare of support workers and clients. There are implications for safe practice, including heightened potential for errors and accidents affecting client and support worker safety. Such negative circumstances impinge on the provision of care and affect the fundamental purpose of care and support work.

LIMITATIONS

The study has limitations, including a small sample size, and the potential for information provided to be affected by selective memory bias and telescoping. This researcher addressed four of Van Laar et al's (2007) six psycho-social scales to enable an appropriate scope and research time frame for this study.

CONCLUSION

This study found the implementation of the Care and Support Worker (Pay Equity) Settlement Act (2017) had a significant, negative impact on the work-related life of the participants. It found that the re-organisation and increased intensity of work, along with a decline in managerial support, had negatively affected the participants' working conditions and job satisfaction. The study supports earlier findings of unintended consequences of the Act's implementation. This study highlights the need for more regulation of service providers to address the shrinking time frames for providing care to clients, and the development of specific homecare support worker guidelines, to improve the work conditions and quality of life of homecare support workers.

REFERENCES

Care and Support Workers (Pay Equity) Settlement Act 2017. https://www.legislation.govt.nz/act/public/2017/0024/28.0/whole.html#DLM7269110

Charlesworth, S., & Heap, L. (2020). Redressing gendered undervaluation in New Zealand aged care: Institutions, activism and coalitions. *Journal of Industrial Relations, 62*(4), 608-629. https://doi.org/10.1177/0022185620925102

Clarke, V., & Braun, V. (2014). Thematic analysis. In T. Teo (Ed.), *Enyclopedia of Critical Psychology* (pp. 1947-1952). Springer New York. https://doi.org/10.1007/978-1-4614-5583-7_311

Douglas, J., & Ravenswood, K. (2019). *The value of care: Understanding the impact of the 2017 Pay Equity Settlement on the residential aged care, home and community care and disability support sectors*. New Zealand Work Research Institute. https://workresearch.aut.ac.nz/__data/assets/pdf_file/0003/350553/Pay-Equity-Report_Digital_final.pdf

Gavin, H. (2008). *Designing qualitative research*. Sage Publications.

Guest, G., MacQueen, K., M, & Namey, E., E. (2012). *Applied thematic analysis*. Sage Publications. https://doi.org/10.4135/9781483384436

Hebson, G., Rubery, J., & Grimshaw, D. (2015). Rethinking job satisfaction in care work: Looking beyond the care debates. *Work, Employment and Society, 29*(2), 314-330. https://doi.org/10.1177/0950017014556412

Home and Community Health Association & Lattice Consulting. (2018). *Spreading our wings*. https://hcha.org.nz/assets/Uploads/Spreading-our-wings-HCHA-Report.pdf

McFadden, P., Ross, J., Moriarty, J., Mallett, J., Schroder, H., Ravalier, J., Manthorpe, J., Currie, D., Harron, J., & Gillen, P. (2021). The role of coping in the wellbeing and work-related quality of life of UK health and social care workers during COVID-19. *International Journal of Environmental Research and Public Health, 18*(2), 815. https://doi.10.3390/ijerph18020815

McGregor, J., & Davies, S. G. (2019). Achieving pay equity: Strategic mobilization for substantive equality in Aotearoa New Zealand. *Gender, Work & Organization, 26*(5), 619-632. https://doi.org/10.1111/gwao.12253

Meagher, G. (2016). *Valuing care work and care workers: Workforce and equal pay issues in New Zealand aged residential care*. Macquarie University. https://researchers.mq.edu.au/en/publications/valuing-care-work-and-care-workers-workforce-and-equal-pay-issues

Ministry of Health. (2016). *Health of the Health Workforce 2015*. https://www.health.govt.nz/system/files/documents/publications/health-of-health-workforce-2015-feb16_0.pdf

Ministry of Health. (2018). *Summary of the pay equity for care and support workers: Overview and timeline*. https://www.tewhatuora.govt.nz/our-health-system/pay-equity-settlements/care-and-support-workers-pay-equity-settlement/summary-of-the-pay-equity-for-care-and-support-workers/

New Zealand Human Rights Commission. (2012). *Caring counts –Tauitiaki tika*. http://hdl.voced.edu.au/10707/345405

Ravalier, J., Morton, R., Russell, L., & Rei Fidalgo, A. (2019). Zero-hour contracts and stress in UK domiciliary care workers. *Health & Social Care in the Community, 27*(2), 348-355. https://doi.org/10.1111/hsc.12652

Ravenswood, K., & Douglas, J. (2017). *The New Zealand Aged Care Workforce Survey 2016*. New Zealand Work Research Institute. https://workresearch.aut.ac.nz/__data/assets/pdf_file/0005/77828/The-New-Zealand-Aged-Care-Workforce-Survey-2016.pdf

Ravenswood, K., Douglas, J., & Teo, S. (2015). *The New Zealand Aged Care Workforce Survey 2014*. https://www.hrc.co.nz/files/2614/3019/0144/NZ_Aged_Care_Workforce_Survey_report.pdf

Ravenswood, K., & Harris, C. (2016). Doing gender, paying low: Gender, class and work-life balance in aged care. *Gender, Work & Organization, 23*(6), 614-628. https://doi.org/10.1111/gwao.12149

Rubery, J., Grimshaw, D., Hebson, G., & Ugarte, S. M. (2015). 'It's all about time': Time as contested terrain in the management and experience of Domiciliary Care Work in England. *Human Resource Management, 54*(5), 753-772. https://doi.org/10.1002/hrm.21685

Strandell, R. (2020). Care workers under pressure – A comparison of the work situation in Swedish home care 2005 and 2015. *Health & Social Care in the Community, 28*(1), 137-147. https://doi.org/10.1111/hsc.12848

Stranz, A., & Szebehely, M. (2018). Organizational trends impacting on every-day realities: the case of Swedish eldercare. In K. Christensen & D. Pilling (Eds.), *The Routledge Handbook of Social Care Work Around the World* (pp. 45-57).

Treasury. (2017, July 28). *Budget 2017 Information Release*. New Zealand Government. https://www.treasury.govt.nz/sites/default/files/2017-11/b17-3704875.pdf

Trydegård, G.-B. (2012). Care work in changing welfare states: Nordic care workers' experiences. *European Journal of Ageing, 9*(2), 119. https://doi.org/10.1007/s10433-012-0219-7

Vassos, M., Nankervis, K., Skerry, T., & Lante, K. (2019). Can the job demand-control-(support) model predict disability support worker burnout and work engagement? *Journal of Intellectual & Developmental Disability, 44*(2), 139-149. http://doi.org/10.3109/13668250.2017.1310818

Van Laar, D., Edwards, J. A., & Easton, S. (2007). The Work-Related Quality of Life scale for healthcare workers. *Journal of Advanced Nursing, 60*(3), 325-333. https://doi.org/10.1111/j.1365-2648.2007.04409.x

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The placement experience of nursing students in managed isolation and quarantine facilities

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ABSTRACT

Aim: This research describes the experiences of New Zealand nursing students who were allocated to managed isolation and quarantine facilities (MIQFs) as a clinical placement during the COVID-19 pandemic.

Background: The nursing students were based in Christchurch, New Zealand, during the time the MIQFs were operating, between 2020 and 2022. They were in the third year of a bachelor of nursing programme (BN). Placement in MIQF was optional for these students. In the initial stages of this placement, concern about the students' safety, ie the risk of them being infected with COVID-19, was expressed by their families, the public and the media

Methods: A descriptive, qualitative design was used for this study. There were seven participants, and data were collected from focus group interviews. The online platform Zoom was used for focus group meetings, due to the complete lockdown during the initial data-gathering in 2020. The focus group interviews were recorded and transcribed, then analysed for themes.

Findings: The study found that the MIQF was a valid and unique placement for the nursing students, providing them with clinical skills and learning not found elsewhere. The students said they felt supported by clinical and academic staff and gained confidence in communication and critical thinking in an often-challenging environment. The nursing students all met competence according to Nursing Council requirements. Notably, the student nurses described feeling safe within these facilities, and none contracted COVID-19 during their placements.

Conclusion: Clinical placement of year-three BN students in MIQF during the COVID-19 pandemic was described by the participants as a well-grounded and innovative learning experience.

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KEYWORDS

COVID-19, nursing students, clinical placement, managed isolation quarantine facilities

INTRODUCTION

Coronaviruses are a diverse family of viruses that can cause infections in both humans and animals. They include the common cold and the viruses which caused previously large-scale infections such as severe acute respiratory syndrome (SARS) and Middle East respiratory syndrome (MERS) (Ministry of Health [MOH], 2020a). COVID-19, caused by the SARS-CoV-2 virus, is a highly infectious coronavirus, that quickly spread worldwide in late 2019 and early 2020. The World Health Organization declared it a pandemic in March 2020 (World Health Organization [WHO], 2023). In New Zealand, the first recorded case of COVID-19 was confirmed on February 28, 2020 (MOH, 2020a), after which border restrictions were put in place. The New Zealand Government's response was to implement a nation-wide lockdown, with all public places closed, and only those people considered essential able to continue working (MOH, 2020c). From this time until April 2021, all international arrivals, apart from very few exceptions, were required to complete a 14-day period of isolation in a managed isolation and quarantine facility (MIQF) before entering the country (Ministry of Business, Innovation and Employment [MBIE], 2021).

The Canterbury District Health Board (CDHB) employed a nursing workforce to work in MIQFs. These nurses were employed with the stipulation that they not work in any other clinical setting, to prevent potential spread of infection, and were also required to be tested for COVID-19 on a weekly basis (MBIE, 2021). There were six MIQFs in the South Island, all located in Christchurch (CDHB, 2021). These facilities were hotels that had been reassigned for quarantine purposes. This was regarded as a practical solution at the time but because the facilities were not purpose-built for quarantine, they were sometimes a challenging environment for managing infection control, with limited air-conditioning and air-flow conditions that could contribute to airborne infection.

One of the effects of the lockdown was to put an immediate halt to nursing students' clinical placements as the students were deemed non-essential workers (MOH, 2020b). Clinical placements in any form did not resume until early May 2020, when the New Zealand alert level was reduced. Clinical placement restrictions rapidly became a global issue, with concerns about placing students into clinical environments which were stressful and ever-changing due to the pandemic. High workloads for nursing staff affected their ability to supervise students and support that academic liaison staff were able to give was limited (Ulenaers, Grosemans, Schrooten & Bergs, 2021). Many nursing schools struggled to provide students with clinical experiences that were safe and relevant, increasingly replacing them with online and virtual technologies and simulation. However, regulations that stipulated the required number of clinical placement hours still needed to be upheld, although some provisions were made to accommodate the pandemic. This was a challenging time, with health-care facilities desperate for help on the one hand, and the need to keep students and academic staff safe on the other (Morin, 2020).

BACKGROUND

Year-three bachelor of nursing (BN) students were offered clinical placements in the Christchurch MIQFs starting in September 2020 and continuing until the facilities closed in April 2022. These placements related to the family and community nursing section of the BN course. The immediate reaction to this placement opportunity was one of anxiety on the part of students' families, the public and the media, that the MIQFs were an unsafe environment due to the risk of contracting COVID-19. However, the nursing students who chose to do clinical placement at the MIQFs, and the academic staff member allocated to support them, were given extensive training in the use of personal protective equipment (PPE) and were included in weekly swab testing offered to all staff at these facilities. Allocation to the MIQF placement was optional for both the nursing students and academic staff, due to it being an unconventional clinical learning environment and due to the level of anxiety in the community at the time. The placement fitted the criteria of community-based nursing, met the learning objectives for the course, and the students met the required competency for their scope of practice, as set by the Nursing Council (NCNZ, 2007). Once a student chose this placement, the inclusion criteria that were then applied were that neither they nor their family members were immunocompromised in any way, nor had any other risk factors.

Academic staff prepared the students for this placement with reviews of health assessment frameworks, clinical skills and safety measures, including use of personal protective equipment (PPE). As part of orientation at the MIQFs, they were fully fitted with PPE appropriate to the area. They were orientated and security-cleared to be on the premises by New Zealand Army personnel. The nursing students worked alongside registered nurses (RNs), monitoring guests' health and wellbeing and managing health concerns. They worked in a multidisciplinary team consisting of police, military, hospitality, medical and nursing personnel. The people quarantined at the facilities were referred to as "guests", rather than patients or clients, due to the novel hotel environment of MIQF.

There were personal and professional challenges for the students allocated to this placement. In the initial stages, these included the intrusion of the media, who questioned the wisdom of placing nursing students at these facilities, and also the perceptions and beliefs of the wider community. These concerns, which centred on the risk of students and staff contracting COVID-19, were predominantly negative and based on conjecture rather than fact. In terms of their safety, the students felt prepared by policies and procedures put in place to protect them. For the students, the key outcomes from the experience included learning to adapt and hone communication skills, working in collaboration with a diverse multidisciplinary team and learning to deal with the stigma – based on fear of infection – expressed by family, friends, the wider community and other health professionals. Of note, the students were in the third year of their BN degree and had considerable knowledge and skills to build on. Nonetheless, they gained valuable clinical experience working in this environment, not only with numerous acutely unwell COVID-19 patients, but also from working in an unknown and potentially unstable clinical environment.

The COVID-19 pandemic offered a unique opportunity to explore the experiences of the nursing students allocated to the MIQF clinical setting. Given that the Christchurch students were the only nursing students in the country who undertook MIQF clinical placements, this allowed the researchers to document an important milestone in the history of New Zealand nursing. To date, while many studies have identified novel opportunities for nursing student placement worldwide (Ahmed et al, 2022; Barisone et al, 2022; Berger, 2021; Cushen-Brewster et al, 2021; Jamieson et al, 2021; Kang & Yang, 2021; Norman & Meszaros, 2021; Popoola, 2021; Ulenaers et al, 2021), none have been published about nursing students being placed in an isolation quarantine facility during the 2020 pandemic.

METHODOLOGY

A descriptive, qualitative design was used because it was relevant to the aim of the study, which was to describe the experiences of BN students allocated to an MIQF. Data were collected from two focus groups, using the online platform Zoom as a tool for focus group meetings. Using Zoom was necessary due to the complete lockdown during the initial stages of data-gathering. Focus groups provide a forum for open discussion and can facilitate the exploration of the participants' own viewpoints. They are often used for qualitative data collection in health research and have the advantage of participants being able to listen to and develop a range of viewpoints (Stewart & Shamdasani, 2014). Holding the focus groups online allowed participants to choose a time to participate that was most convenient to them, provided an opportunity to participate from home and lessened the chance of cross-infection with COVID-19. This also helped overcome other potential problems with bringing the students together, such as students being in different geographical locations and working different shifts. With a small number of participants, the facilitators were readily able to manage group dynamics and keep the discussion on topic, which can be difficult in focus group meetings (Braun & Clarke, 2013).

Purposive sampling was used to recruit participants from the group of 24 potential participants who had attended placements in the Christchurch MIQFs. All 24 students were contacted by email, and 10 consents were obtained, with seven participants taking part in the focus group interviews. The participants consisted of five women and two men, whose ages ranged from 20 to 42 years; three identified as New Zealand European, two as Pacific and two as Māori. The number who consented was higher than the number who finally participated – the ability to participate was affected by the impact of workload during the pandemic.

Ethical approval was obtained from the Ara Research Knowledge Transfer Ethics Committee (no. 1890). Organisational locality approval was provided, and participants were invited via email by an intermediary. None of the participants were taught or assessed by members of the research team to avoid the potential for coercion. Informed consent was gained from all participants before data collection and anonymity and confidentiality of participant data was maintained by using pseudonyms in transcribing; the independent transcriber signed a confidentiality agreement.

Three of the research team were not used as interviewers as they were markers or moderators of theory or clinical assessments in year three, which would have created a potential conflict of interest. The two researchers who conducted the focus group interviews were not involved in this work. There was no academic advantage or disadvantage to the students for their participation in the research. In accordance with institutional policies, no financial reward was made for participation in the focus groups.

The two researchers who conducted the focus group sessions had expertise in group management, allowing all participants to have an equitable and fair opportunity to share their views. The focus group questions were provided to the participants on the day the hour-long sessions took place and participants were offered the opportunity to add or amend any responses afterwards. Questions were open-ended and varied according to participant responses. A full list of the focus group questions can be seen as Appendix 1, on p18.

For consistency of data collection, the same two researchers conducted both focus groups. Each session began with a karakia, an introduction and an explanation of the focus group process, including the aim of the research. Permission was sought from the participants to audiovisually record the session via Zoom. Notes were taken by one of the focus group facilitators. These were used predominantly to guide the session, clarify information and stimulate further conversation on issues that evolved during the discussion. One example was, when the participants talked about safety, the notetaker asked them, "Did you feel safe?"

All five researchers analysed the data, after the audiovisual recordings were transcribed verbatim by an independent transcriber. The researchers used the six phases of thematic analysis identified by Braun and Clarke (2013), which specifies that each step must be completed before the next is started. First, the researchers familiarised themselves with the data, each of them viewing the audiovisual Zoom recordings of the focus groups and reading the transcripts repetitively. Each researcher identified important patterns in the data, labelling them to create categories, and then comparing them with what the other researchers had produced. The emerging codes were reviewed to recognise overlaps and redundancies, and themes and concepts were identified. Each researcher was allocated a theme to explore further and synthesise. Subthemes emerged through this in-depth exploration of the raw data. Quotes from the participants ensured authenticity and correlation of data. In retrospect, the initial intention of the thematic analysis was too linear. Braun and Clarke (2022) advise seeking, developing, and checking to ensure the research team have captured the data. With repetitive analysis of the themes and subthemes, this process occurred naturally over time.

FINDINGS

Six themes were identified from the data which were ultimately synthesised to the following five:

- **Safety in the MIQF** – whether the nursing students felt they were safe from COVID-19 infection; and with guests who were often frustrated due to days of isolation;

- **Communication** – the challenges of communicating with clients under isolation conditions;
- **Working in the multi-disciplinary team** – the importance of teamwork within a unique and diverse workforce;
- **Stigma –** the impact on participants of discrimination from the community; and
- **Confidence and competence –** the valuable skills learnt in this unique environment.

Safety in the MIQF

The nursing students' safety was a key consideration when deciding to use MIQF as a placement opportunity. A key question students were asked in the focus group sessions was, "Did you feel safe?" The responses below show that the participants did feel safe from infection and prepared for their role, due to the processes put in place to protect them. But they did not always feel safe with frustrated and angry guests.

> *"I have never ever felt unsafe at all in any situation all the time that I was there, it is a safe and controlled environment. With PPE, I got extensively trained and felt confident donning and doffing. You had to have your own health checks which were done by other staff. I did everything by the book, and I didn't get COVID."*

However the students sometimes felt unsafe with guests, who were restricted to their rooms for prolonged periods, and at times became agitated and frustrated.

> *"The only thing that made me feel unsafe was that occasionally guests would get really angry with us, regarding not being able to go out of their rooms which was often for smokes once they had just landed, or a little bit frustrated with having to have their children swabbed and then them being swabbed."*

Communication

The students emphasised how important communication was in caring for guests in the MIQF. The impact of isolation on the guests could be addressed by making a commitment to spend time them. This enabled therapeutic relationships to develop and gave guests time to talk and interact socially. The students discussed the importance of communication skills that promoted mental health and the challenge of conversing with guests who did not speak English.

> *"If they were alone, you would be the only face-to-face interaction they would have, so you really needed to take time to talk to them and they really appreciated it. With full PPE on, they could only see our eyes, behind goggles, so they could not see our facial expressions. We had to really know body language. In addition, this preceptor taught me how to gauge a patient in terms of their verbal and nonverbal cues to assess their mental status and I found that helpful. We also had to organise interpreters and then we would have forms printed, so that the health checks could be performed accurately."*

Functioning in the multidisciplinary team

The importance of teamwork was evident and integral to the success of the MIQF. This was a unique experience for the nursing students, which required them to hone their communication skills and reflexive practice. The multidisciplinary team (MDT) included defence force personnel, police, hotel staff, health and education personnel, interpreters and a wellbeing team.

> *"There were challenges, but it was interesting to see how well we worked together and yes, it was enjoyable and a positive experience working alongside a diverse team. Being able to work with the NZDF, the police, hotel and the different health staff was unique and something that might never occur again."*

The challenges of the MDT included maintaining the confidentiality of guests' health information when working with personnel who were not health workers. Putting up those barriers to protect guests' privacy could be challenging at times, but the students also saw it as a learning experience, relevant to the professional responsibility of maintaining confidentiality.

> *"How to explain things to different team members, because they would have various levels of health literacy, was quite a different skill to learn. In the hospital, the team usually consists of other health practitioners, so as nurses we really had to think that personal information cannot just be given out and that permission is needed from the people themselves and we had to present this in a non-confronting, non-conflict sort of way."*

Stigma and discrimination outside the MIQF

Stigma and discrimination were issues that affected the students in their personal lives, especially those in the first cohort allocated to MIQF. Discrimination came from friends, family, and the public, who were fearful of infection. Some health professionals also expressed a lack of confidence in the isolation processes when the pandemic was in the initial stages.

An example was when a student allocated to MIQF had a family member admitted to hospital.

> *"Where I was living at the time, they were not comfortable with me being in the MIQF, so I moved to my mum's for the placement time. I remember talking to a lady saying I am going to work as a student [in a MIQF], and she visibly took a huge step away from me, so I would end up just not telling people that I was there."*

> *"Initially when my mum was admitted to hospital, they were not too happy for me to visit, but after a while I was allowed to talk to her. I decreased my visits and had another family member visit her instead of me."*

Building confidence and competence

Working in the MIQF provided a unique learning experience and an opportunity for the nursing students to use the skills they had already acquired, and learn new skills. They reported that at the end of the placement and their subsequent completion of the BN programme, they were confident in caring for any patient with an infectious disease and had gained valuable infection control skills.

> *"I am more confident and will happily swab anyone, even children, which was challenging initially. I am confident with PPE, this is not new, and I know the expectations and outcomes. It has been helpful for me; I taught my current clinical nurse manager how to do swabs because we had to get a rapid swab done. Other important things are reinforced especially with this new world with Covid. I feel confident with infection control which will help me throughout my career."*

The participants felt that the MIQF placement enabled them to meet the Nursing Council competencies for third-year students.

> *"Meeting competency is about a lot of thinking and talking to our nursing lecturers and nursing staff that everything does apply. I have done so many things on one shift and every single competency can be applied. It is different, you just look at learning in a unique way and think outside of the box, so having those discussions was helpful."*

DISCUSSION

Since the onset of the COVID-19 pandemic, the nursing workforce has had to pivot and adapt to the ever-changing clinical scene across Aotearoa. While nurses have been described as "invisible heroes" who have contributed to the vaccination, isolation and treatment of infected people, the impact of their contribution has often gone unrecognised (Popoola, 2021). As the pandemic entered New Zealand, there was understandable fear of COVID-19 amongst the public and also within the health professions who were seeking advice about infection prevention and control (Berger, 2021). While the MIQF environment no longer exists, several key lessons emerged from the nursing students' experience – these related to safety, communication skills, working in a multidisciplinary team, the learning experience and managing stigma. When the BN students entered the MIQF setting on September 7, 2020, a national nursing organisation suggested that this setting was unsafe for nursing students to practice. However this research highlights that students were able to protect their own safety by following infection control procedures. Preparing the students for this placement, and thus helping to protect their safety, included tutorial work and simulations, revision of PPE procedures and revising experience of illness prevention and infection control from previous placements. Safety concerns for nursing students and academic staff in the clinical setting were evident in literature reflecting on lessons from the COVID-19 pandemic (Rice et al, 2021; Rizzo Parse, 2020; Schuman, 2020). The student participants in this study said the media description of MIQFs as "unsafe" did not reflect their experiences and that they understood and adhered to safety procedures and policies. However their sense of safety was challenged by the needs and behaviours of some MIQF guests, which included aggression, fighting, and expression of exasperation and anger.

Communication has always been at the heart of nursing practice (Hutchinson, 2017). However it was recognised that communication with guests in the MIQF was less than optimal due to the necessity for social isolation and because staff had to wear PPE which hinders communication and can distort the message (Spillane, 2020).The nursing students knew that guests could only see their eyes, behind goggles, which made communication particularly challenging for non-English speakers. With PPE restricting the ability of staff to communicate, and the need to keep social contact to a minimum, it is understandable why some guests felt isolated and anxious while in the MIQF. However, the students enjoyed communicating with guests from different countries and backgrounds, and recognised that their skills in assessment and promoting mental health were enhanced by the experience. The literature says that COVID-19 created new opportunities for learning; however, nursing students in some parts of the world were placed in clinical settings they were not ready for (Rizzo Parse, 2020). However these year three nursing students, due to their seniority, were able to demonstrate well-honed communication skills in practice.

The students found communication with the MDT interesting. They noted that the team at MIQF – defence staff, police, hotel staff, nurses, interpreters and wellbeing teams – was unique and they might never work in such a group again. They emphasised the need to collaborate, and gained insight into interprofessional practice. Roth (2020) stated the initial chaos of COVID-19 worldwide settled into a new phenomenon of "unexpected innovation" – the collaboration the nursing students experienced in the MIQF could be seen as an example of this. Barriers were broken down between health, police, defence, hospitality, and education personnel, to enable a seamless experience in the MIQF environment. Collaboration had some barriers, in particular that of guest privacy – students knew they were not able to share personal health information with non-health professionals.

Prosen (2020) said that while nursing professionals should be celebrated for their efforts, there had been negative reactions such as stigmatisation of and discrimination against people diagnosed with COVID-19 and those caring for them. This research highlighted the nursing students' personal experience of stigma associated with the MIQF placement. Some of their families expressed reservations about their taking up placements at MIQF without full understanding of the pandemic and the environment. It is important to avoid labels that stigmatise people who have an infectious disease such as COVID-19, and the health professionals who care for them (WHO, 2020). Health professionals outside the MIQF setting were cautious with the students on this placement, with one student prevented from visiting family in hospital. The students spoke about not perpetuating the stigma and how the guests were not dangerous to the public. However, they refrained from informing people in the community they were on placement in MIQF to protect themselves from discrimination.

This research highlighted media intrusion, with accounts of media trying to photograph guests in the MIQFs, particularly in the initial stages. The media have a role in pandemics, but do not always communicate the science effectively, creating further misinformation, stigma, fear and inappropriate responses (Généreux et al, 2020). The students reported that they had applied critical thinking to practice while placed in the MIQFs and had learned to "think outside the box". Overseas literature said students felt supported in their practice during the pandemic, with partnerships formed between tertiary providers and health agencies (Bliss, 2021, Rodriguez et al, 2021). The Christchurch students reported being well supported by clinical and academic staff. Aided by that support, the students developed confidence in communication and nursing skills, contributing to their preparation for graduation and employment. Some of the students expressed pride for their contribution in the MIQFs, and the lessons learnt will assist in their future careers.

The MIQF clinical placement was a unique and valid learning experience for these nursing students, providing a different learning experience to that of any other nursing students in the country at the time. They felt supported and met competence requirements, none contracted COVID-19 while on placement, and all subsequently were able to complete their degree. Clinical placements in community nursing are often hard to find, and this research has shown that thinking broadly can provide students with valid and varied placement options. Further, this model of alternative placement could inform future clinical practice learning and support the nursing workforce in any future pandemic. Several authors have described the COVID-19 era as being uncertain and shifting rapidly, with lessons to be learnt for the future planning of student clinical experience (Aurentz & Layman, 2020; Bitton & Buck, 2020; Schuman, 2020), with an emphasis on new collaborations, partnerships and workforce changes.

LIMITATIONS

This research explored a unique clinical placement opportunity for year-three nursing students during the COVID-19 pandemic. A limitation of this study is that there were a small number of participants; however their voices describe an innovative and safe learning opportunity for students, which could be repeated in any future pandemic.

CONCLUSION

This research has highlighted an innovative and responsive approach to the COVID-19 pandemic, which provided nursing students with a clinical learning experience in a community setting. Despite its challenging and unfamiliar environment, the benefit of the MIQF placement was that it was safe for nursing students, RNs, guests and the multidisciplinary personnel. It was courageous of the students to take up the opportunity to undertake clinical learning in the MIQFs, rather than resorting to clinical projects and simulation. This research has highlighted an opportunity to "think outside the box" for clinical learning, while providing a student-centred learning experience.

REFERENCES

Ahmed, W. A. M., Abdulla, Y. H. A., Alkhadher, M. A., & Alshameri, F. A. (2022). Perceived Stress and Coping Strategies among Nursing Students during the COVID-19 Pandemic: A Systematic Review. *Saudi Journal of Health Systems Research, 2*(3), 85-93. https://doi.org/10.1159/000526061

Aurentz, C., & Layman, J. (2020). Reflections on nursing education during a pandemic and lessons learned. *The Missouri Nurse, Summer 2020*, 28-30.

Barisone, M., Ghirotto, L., Busca, E., Diaz Crescitelli, M. E., Casalino, M., Chilin, G., Milani, S., Sanvito, P., Suardi, B., Follenzi, A., & Dal Molin, A. (2022). Nursing students' clinical placement experiences during the Covid-19 pandemic: A phenomenological study. *Nurse Education in Practice, 59*, 103297–103297. https://doi.org/10.1016/j.nepr.2022.103297

Berger, S. (2021). Encounters with uncertainty and complexity: Reflecting on infection prevention and control nursing in Aotearoa during the COVID-19 pandemic. *Nursing Praxis in Aotearoa New Zealand, 37*(3), 15-19. https://doi.org/10.36951/27034542.2021.027

Bitton, J. R., & Buck, D. K. (2020). The impact of the pandemic on Oregon nursing education. *Oregon State Board of Nursing Sentinel, 39*(4), 20-21.

Bliss, J. (2021). The impact of Covid-19 on practice learning in nurse education. *British Journal of Community Nursing, 26*(12), 576-580. https://doi.10.12968/bjcn.2021.26.12.576

Braun, V., & Clarke, V. (2013). *Successful qualitative research: a practical guide for beginners.* Sage.

Braun, V., & Clarke, V. (2022). *Thematic Analysis: a practical guide.* Sage.

Canterbury District Health Board. (2021, December 17). *Canterbury's government agencies team up to support COVID-19 Care in the Community Quarantine Facilities.* https://www.cdhb.health.nz/te-whatu-ora-waitaha-canterbury-news/canterbury-government-agencies-team-up-to-support-covid-19-care-in-the-community/

Cushen-Brewster, N., Barker, A., Driscoll-Evans, P., Wigens, L., & Langton, H. (2021). The experiences of adult nursing students completing a placement during the COVID-19 pandemic. *British Journal of Nursing, 30*(21), 1250–1255. doi: 10.12968/bjon.2021.30.21.1250

Généreux, M., Schluter, P. J., Hung, K. K., Wong, C. S., Pui Yin Mok, C., O'Sullivan, T., David, M. D., Carignan, M.-E., Blouin-Genest, G., Champagne-Poirier, O., Champagne, É., Burlone, N., Qadar, Z., Herbosa, T., Ribeiro-Alves, G., Law, R., Murray, V., Chan, E.Y.Y., Pignard-Cheynel, N.,... Roy, M. (2020). One virus, four continents, eight countries: An interdisciplinary and international study on the psychosocial impacts of the Covid-19 pandemic among adults. *International Journal of Environmental Research and Public Health, 17*(22), Article 8390. https://doi.org/10.3390/ijerph17228390

Hutchinson, D. (2017). Consultation skills: are yours up to scratch? *Practice Nurse, 47*(2), 10-14.

Jamieson, I., Andrew, C., & King, J. (2021). Keeping our borders safe. The social stigma of nursing in managed isolation and quarantine border facilities during the COVID-19 pandemic. *Nursing Praxis in Aotearoa New Zealand, 37*(3), 53-61. https://doi.org.10.36951/270352.2021.035

Kang, D.-H.-S., & Yang, J. (2021). Clinical Practice Experience of Nursing Students During the COVID-19 Pandemic. *Korean Journal of Adult Nursing, 33*(5), 509-521. https://doi.org/10.7475/kjan.2021.33.5.509

Ministry of Business, Innovation and Employment. (2021). *MIQ timeline.* https://www.mbie.govt.nz/immigration-and-tourism/isolation-and-quarantine/managed-isolation-and-quarantine/about-miq/miq-timeline/

Ministry of Health. (2020a). *Single case of Covid-19 confirmed in New Zealand.* https://www.health.govt.nz/news-media/media-releases/single-case-covid-19-confirmed-new-zealand

Ministry of Health. (2020b). *Chief nursing officer letter to nurses across Aotearoa.* https://www.health.govt.nz/system/files/documents/pages/cno-letter-nurses-across-aotearoa-5jun20.pdf

Ministry of Health. (2020c). *History of the COVID-19 alert system.* https://covid19.govt.nz/about-our-covid-19-response/history-of-the-covid-19-alert-system/

Norman, K., & Meszaros, K. (2021). Community nursing placements: student learning experiences during a pandemic and beyond. *British Journal of Community Nursing, 26*(5), 214–217. https://doi.org/10.12968/bjcn.2021.26.5.214

Nursing Council of New Zealand. (2007). *Competencies for RNs.* https://www.nursingcouncil.org.nz/Public/Nursing/Standards_and_guidelines/NCNZ/nursing-section/Standards_and_guidelines_for_nurses.aspx

Popoola, T. (2021). COVID-19's missing heroes: Nurses' contribution and visibility in Aotearoa New Zealand. *Nursing Praxis in Aotearoa New Zealand, 37*(3), 8-11. https://doi.org/10.36951/27034542.2021.026

Prosen, M. (2020). Social stigma in the time of coronavirus (COVID-19): an epidemic we must not remain silent about. *Slovenian Nursing Review, 54*(2), 100-103. https://www.researchgate.net/publication/342395565_Social_stigma_in_the_time_of_coronavirus_COVID-19_an_epidemic_we_must_not_remain_silent_about

Rice, M. E., Shank, B., Clark, T., Robertson, M., Hamlin, A. S., Ruffin, T., & Wilson, D. R. (2021). Caring During COVID-19: Nursing Education. *Tennessee Nurse, 84*(2), 18-19.

Rizzo Parse, R. (2020). Nurse education: You can't go home again. *Nursing Science Quarterly, 33*(3), 197. doi: 10.1177/0894318420922211

Rodriguez, A. M. M. M., Cardoso, T. Z., Abrahão-Curvo, P., Gerin, L., Palha, P. F., & Segura-Muñoz, S. I. (2020). Vaccination against influenza in the face of COVID-19: teaching-service integration for training in nursing and health. *Vaccination Against Influenza in Primary Care, 25*(SPE), 1-6. https://doi.org/10.1590/2177-9465-EAN-2020-0379

Roth, E. (2020). Epidemic temporalities: A concise literature review. *Anthropology Today, 36*(4), 13-16. https://doi.org/10.1111/1467-8322.12590

Schuman, R. (2020). Transitions in nursing clinical education due to Covid-19. How Houston Baptist University transformed its nursing programme. *Texas Nursing Magazine, 4,* 14-15.

Spillane, E. (2020). COVID-19 and the impact it has on communication in maternity. *Midwifery Matters, 165,* 8-11.

Stewart, D. & Shamdasani, P. (2014). *Focus groups: Theory and practice* (3rd ed.). Sage.

Ulenaers, D., Grosemans, J., Schrooten, W., & Bergs, J. (2021). Clinical placement experience of nursing students during the COVID-19 pandemic: A cross-sectional study. *Nurse Education Today, 99*, 104746–104746. https://doi.org/10.1016/j.nedt.2021.104746

World Health Organization. (2020). *Social stigma associated with COVID-19*. https://www.who.int/publications/i/item/social-stigma-associated-with-covid-19

World Health Organization. (2023). *Coronavirus disease (COVID-19)*. https://www.who.int/health-topics/coronavirus#tab=tab_1

APPENDIX 1

Focus group questions

- Can you tell me how you were orientated and prepared for the placement in the MIQF? For example, what preparation/education did you receive?
- What was the clinical day you experienced in practice, working under the direction and delegation of the registered nurse?
- What did you enjoy most about the work in the MIQF?
- What were the most significant learning experiences for you as a student nurse in the MIQF?
- What were the biggest challenges for you as a student nurse in the MIQF?
- How did the experience in the MIQF draw on your knowledge and experience in the bachelor of nursing programme?
- How did the clinical portfolio support your learning while on placement in the MIQF?
- How did the experience in the MIQF facility draw on your personal and life experiences?
- Thinking beyond your clinical placement in the MIQF, how did the experience impact on your life – thinking about relationships, community, and social activities?
- Thinking beyond your clinical placement in the MIQF facility, how did the experience impact on your preparation in transitioning to a registered nurse?
- What advice would you give to bachelor of nursing students behind you going on placement in the MIQF?
- Anything that you would like to add or thought you would be asked about that has been omitted?

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Changes noticed following a pressure injury link nurse programme

ABSTRACT

Health quality and safety improvement is every health worker's responsibility. Nurses have the knowledge and skills to take leadership roles in this field. Link nurses are an example of nurses filling practice-specific quality management roles. In this research, where a pressure injury prevention link nurse programme was instituted, nurses embraced the quality improvement project.

Aim: The aim of this study was to identify changes link nurses noticed in their practice areas as a result of participation in a pressure injury prevention link nurse programme.

Design: Qualitative results from a mixed methods study are reported here.

Methods: Data were collected in three nurse focus groups. The technique used to collect data was Aspinal's (2005) Nominal Group Technique. Twenty-two participants answered a question on the changes they had noticed in pressure injury prevention in their area following a link nurse programme.

Findings: All nurses noted an increase in their colleagues' knowledge and awareness of pressure injury prevention; patients were reported as now being part of the care team; assessment tool use and documentation/reporting was noted to have improved in all areas; a policy created in the aged residential care and rural groups led to the acquisition of new pressure injury prevention equipment; blame culture was reported to be reduced in aged residential care.

Conclusion: Following the link nurse programme, nurses were encouraged and empowered by the changes they were able to institute in their workplaces. Such nurse-led programmes fulfill a need in quality improvement action and further inception of such programmes should be encouraged for nurses and practice colleagues.

Relevance to clinical practice: This research has highlighted that many positive changes in care can come about when nurses are supported to lead quality improvement processes.

What does this research contribute to the wider global community?

- A highlighted outcome was that link nurses educated and empowered colleagues across the health-care team, following the mantra "quality is everyone's business".
- The link nurse project led to increased consumer education and involvement in their own care. This is vital in a person-centred care model.

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KEYWORDS

Pressure injury, link nurse, resource nurse, quality improvement, change, patient safety, pressure injury prevention

INTRODUCTION

There is increased international awareness that health quality and safety depends on all health-care workers (Altmiller & Hopkins-Pepe, 2019). However, a recent review found nurses' attitudes to pressure injury prevention were substandard, at around 75 per cent of the expected level, and concluded that nurses required further education to be effective in preventing and treating pressure injuries (Rostamvand et al, 2022). This finding is important because health-care associated pressure injuries are a nurse-sensitive outcome measure, used as an indicator of health-care performance (Needleman et al, 2002). Nurses report being hindered in their efforts to provide optimum prevention and care for pressure injuries (Barakat-Johnson et al, 2019). In New Zealand this also appears to be an issue. In 2015, a report on pressure injuries in New Zealand was completed by KPMG for the Health Quality & Safety Commission, the Accident Compensation Corporation (ACC), and the Ministry of Health. That report found staff responsible for caring for pressure injuries felt they lacked the authority to make decisions about care. Consequently, a quality improvement programme to reduce pressure injuries was suggested by the authors (KPMG, 2015).

There is an obvious need for change in practice to ensure quality care, and this is occurring. Following the 2015 KPMG report, nurses have been actively addressing the issue. As a member of the Pan-Pacific Pressure Injury Alliance (PPPIA), the New Zealand Wound Care Society hosted the online launch of the 2019 Clinical Practice Guideline for Prevention and Treatment of Pressure Ulcers/ Injuries (Kottner et al, 2019). The mission of the PPPIA is to improve outcomes for people with pressure areas by increasing knowledge and research (https://pppia.org/). Also, as a result of the KPMG report, a link nurse programme was introduced in one district health board (DHB) in New Zealand.

BACKGROUND

A Canadian-based paper encourages nurses to take the lead in improvement science, by initiating and directing quality improvement projects (Flynn et al, 2017). Resource or link nurses can take up this leadership role. A link nurse can be involved in all aspects of quality improvement such as inception and leading of projects, monitoring and auditing, education of colleagues, purchase and maintenance of equipment, reporting to the quality and safety team, and potentially setting up a topic-specific community of practice (Pyrko et al, 2017) . Such positions have been used successfully to increase knowledge and skillful care in a range of areas, including pressure injury prevention and infection control (Quinn-O'Neil et al, 2011; Rowe et al, 2018). Evidence suggests that when link nurses were given specific roles in pressure injury prevention, there was reduction in pressure injuries from 10/1000 patient days to 2.17/1000 patient days. In part this was achieved by link nurses feeling more autonomous in initiating work to reduce pressure injuries (Quinn-O'Neil et al, 2011). Evidence of nursing leadership, and consequently autonomy in nursing care, must be recognised and emulated, and should add to the evidence on which nursing practice is based.

The research reported here involved a New Zealand link nurse programme starting in 2018 and funded by ACC to reduce pressure injury harm. Link nurses were educated and supported in quality improvement practice and pressure injury prevention through a DHB quality improvement service, and a local education provider. Link nurses were, in turn, to educate their practice colleagues and initiate a quality improvement project in their workplace. This report aims to fill a gap in research as there are no evident reports which specifically outline the changes pressure injury prevention (PIP) link nurses observed from their endeavours. The unique and positive outcomes reported are important to nursing practice because they have the potential to reduce the extensive cost of pressure injury care with a comparatively small financial outlay, and more broadly, because they enhance the initiation and ongoing support of autonomous evidence-based nursing practice.

The link nurse programme process is explained here before the study procedure.

Table 1. Link nurse project objectives

1) Develop and implement a quality improvement education programme, enabling PIP link nurses to improve their understanding of pressure injury prevention and management, while equipping them to lead and foster change specifically related to pressure injury issues.

2) Enhance the clinical staff's knowledge of evidence-based strategies to prevent the occurrence of pressure injuries, and to assess this knowledge, before, and one year after, the introduction of the PIP link nurse role.

3) Assess pressure injury outcomes across the clinical sites involved in this project, before, and one year after, the implementation of the PIP link nurse role.

4) Assess the feasibility and value of having a PIP link nurse resource by exploring the experiences of the PIP link nurse and key stakeholders with whom they work.

5) Determine critical factors needed to make a PIP link nurse role successful.

6) Establish a PIP link nurse community of practice to enable networking and share information to support and enhance their role.

PIP link nurse project

The PIP link nurse programme is outlined to provide a context for the data collection that occurred during this study. The objectives of the link nurse programme are listed in Table 1 (see p20).

PIP link nurse programme participants and setting

The PIP link nurse project was offered in two areas in the region, an urban area with a population of 380,000, and the largest town in the rural area with a population of approximately 30,000. The urban group included nurses working in an 800-bed public hospital, community home visiting, and aged residential care (ARC). The rural area included nurses working in the 120-bed local base hospital and ARC facilities.

Fifty-eight registered nurses (RNs) were initially recruited into PIP link nurse roles across the region in hospital sites and community settings. Recruitment to the PIP link nurse role occurred via advertising in staff update web notifications, appointment by nurse leaders, and staff self-nomination. Candidates were then appointed via a competitive process in which nurses made an application to participate in the project against specified selection criteria, which required them to have at least three years of clinical nursing experience and be working in the delivery of direct patient care at the time of application. Prerequisites included the completion of an online pressure injury prevention course, having a current professional portfolio, prior training in preceptorship/clinical teaching, computer literacy skills and demonstrable clinical leadership skills that would enable them to be a change agent in their practice area. The nurse was required to have their application signed by their nurse manager, affirming the nurse met the selection criteria and had appropriate qualities to fulfil the role and that they would support them in the programme. Only nurses who both met the selection criteria and were formally approved by their nurse manager were successful with their application. Funding was provided for backfill staff to release the nurses once a month and for the time for the pressure injury academic education.

During 2019, a bespoke pressure injury prevention course was delivered to recruited link nurses. A local education institution provided graduate-certificate level education on pressure injury identification and management. The PIP link nurses were provided with detailed education on a range of quality improvement tools to enable them to identify gaps in care or care processes, and to develop change ideas alongside a plan for change implementation. The course consisted of 110 hours that combined face-to-face and self-directed learning, along with time to complete assessments and implement change ideas for pressure injury prevention in practice. Time release was assured for PIP link nurse activities, with their shifts being filled by other nurses. This was paid for by project funds, as research has identified issues such as limited organisational commitment, and lack of release time for the nurse, affecting the success of such projects (Shepherd et al, 2005; Barr et al, 2021) . Education sessions were held in local DHB education facilities in both city and rural areas.

Link nurses were required to complete at least one pressure injury prevention quality improvement project in their clinical area during the 12-month period. Link nurses used a locally developed maturity matrix of management and work systems to assess their workplace to determine where improvement was needed. Once completed, quick projects were identified and actioned, while the CDHB Process for Improvement (2015) was used for longer project work. In June 2019, nurses developed the scope of their local project, outlined in a specific driver diagram (Provost & Bennett, 2015). The driver diagram was a visual display of factors that helped achieve the project aim. These factors included leadership, improvement data, education and training, equipment and resources, individual care and assessment, and continuity of care. PIP link nurses then each focused on one change idea. Using Deming's "Plan, Do, Study, Act" cycle, nurses tested, refined and implemented changes, supported by the project manager, nurse educator and quality facilitator to make use of the quality tools provided for them at project briefings (Deming, 2018). Thirty-two PIP link nurses completed change ideas and implemented them in their practice settings.

Of the 32 PIP link nurses who completed the programme, seven were from ARC, 15 from DHB medical/surgical nursing, two were from older person's health community service, one was from women and children's health, and seven from other unspecified areas. Twenty-six nurses withdrew from the PIP link nurse programme. Reasons for withdrawal were that they did not attend the first project briefing (n=5), personal circumstances (n=5), overcommitted/no resource to cover (n=5), left their workplace or change of position (n=5), role was not as expected (n=5), and other – not specified (n=1).

The aim of this study was to identify changes that link nurses noticed in their practice areas as a result of participation in a PIP link nurse programme.

METHODS

Design

A mixed-methods exploratory sequential design guided data collection and analysis. In this design, qualitative data was collected from focus groups which explored the experience of the PIP link nurses. The results of the focus groups informed the questions for subsequent surveys sent to all PIP link nurses, their managers, and colleagues, that then provided quantitative data. Results on the barriers and facilitators experienced in the PIP link nurse programme, with both qualitative and quantitative data, have been reported elsewhere (Moir et al, 2022). This paper focuses on qualitative results from the focus group interviews regarding changes noticed by the PIP link nurses in their areas of practice. Only aspects of the methodology relevant to the focus groups will be included here.

Study procedures were reviewed and approved by the University of Otago Ethics Committee (number 19/123). As research was carried out in association with a DHB, locality consent was gained internally by the DHB. All participants were informed of the focus group process, signed consent forms, and completed a short demographic questionnaire.

Data collection – focus groups

Three focus groups were held on the same day in September 2019; two in one city and one in a rural area. Of the 32 nurses who could be included, 22 attended while 10 decided not to participate. One group had nine participants and was hospital-based; the second group had eight participants and comprised community care and ARC nurses; the third group had five participants from the rural setting who were a mix of ARC and hospital nurses.

Nominal group technique (NGT) technique was used as the procedure for the focus groups. This technique allows for open discussion and consultation on the research questions. Data are collected at the time of the focus group, with the themes understood and voted on by the participants (Aspinal et al, 2006). The facilitators of all focus groups were experienced PhD-qualified academics who had experience with focus group methodology, agreed on the questions, and were not known to the PIP link nurses. The key question asked in the focus group relevant to this report was: *What changes have you noticed as a result of the link nurse role in your area?*

Data analysis

All focus groups followed the four-step NGT process, for which outcomes are reported as priorities, voted on by the group. This process began with participants identifying factors they saw as facilitators of, or barriers to, the PIP link role, and any changes they had noticed as a result of the link nurse project. The first step in the focus group was for participants to individually record their ideas on the research questions. In the second step, participants' ideas were recorded, one at a time, on a whiteboard in an open discussion session. During the third clarification step, the meaning of each idea was explored to ensure participants could make informed decisions when ranking their priorities. During the final ranking step, participants ranked each idea in order of importance, and a consensus among participants was reached on priorities. Priorities for the barriers and facilitators questions have been reported elsewhere (Moir et al, 2022). In the case of the key question reported here regarding changes the link nurses noticed, answers were not prioritised as the changes were all evident; so all were recorded once a common theme was agreed on (see Table 3, opposite page). The focus groups took approximately 90 minutes to complete.

RESULTS

The three focus groups were comprised of 22 of the 32 PIP link nurses (66 per cent) actively working in the role at the time of data collection. All participants were registered nurses (RN) working in New Zealand.

Table 2 (right) shows the demographics of the three focus groups. One male participated in one focus group; the rest were female. Consistent with the demographics of the RN workforce in New Zealand, the ARC nurses were predominantly of Asian ethnicity with fewer years of experience than the DHB group, who were predominantly New Zealand European; the rural group was of relatively evenly mixed ethnicity.

Table 3 (see p23) shows the changes in pressure injury prevention observed by the three focus groups in their work areas.

Outcomes nurses noticed from the PIP link nurse programme related to change were wholly positive. Table 3 shows nurses in all areas noticed an increase in colleagues' knowledge and awareness of pressure injury prevention. Not only was there an increase in awareness however, but also the active dissemination of skills on pressure injury prevention and care to the staff, leading to more responsive and efficient care. In all focus groups, patients were reported as now being part of the team working to prevent PI. Use of assessment tools and documentation/reporting was noted to have improved in all areas. Also, a policy created in the ARC and rural groups led to the acquisition of new PIP equipment. In ARC the blame culture was reported to be reduced.

Table 2. Demographics of focus group participants for three groups

DHB n=9	ARC/community n=8	Rural mixed n=5
Ethnicity		
NZ European 8 Asian other 1	NZ European 1 Indian 4 Asian other 3	NZ European 3 Indian 2
Years as RN		
1-5 1 6-10 2 16-20 3 21-25 1	1-5 3 6-10 4 35-40 1	1-5 3 6-10 2

DISCUSSION

The aim of this aspect of the research was to elucidate the changes the PIP link nurses had noticed in their workplaces as a result of the link nurse project. The link nurses said they learnt a raft of new knowledge and skills that they were able to carry forward to their practice areas and colleagues, not only about pressure injury but also about how to plan and implement quality improvement processes. The latter was not necessarily what they had expected; however they rose to the challenge of carrying out their own quality improvement project. The focus group responses also indicated that their work had fostered involvement of the whole health-care team, which has been previously identified as an important factor in the success of quality improvement projects (Altmiller & Hopkins-Pepe, 2019; Moir et al, 2022). The more familiar the concept of "QI as everyone's business" becomes in practice, the greater ease with which it will be part of every health professionals' work, and their own and their employer's expectation of their work.

The notion of "blame culture" was taught in the link nurse course and emphasised as not enhancing quality improvement activity. One of our focus groups (city ARC/community) mentioned that the culture of blame had decreased as a result of the PIP link nurse programme. Nurses discussed this as meaning that responsibility for the development of pressure injuries was previously regarded as being due to neglect, and therefore someone was to blame. In a review of papers on barriers to incident reporting, Hamed and Konstantinidis

Table 3. Changes in pressure injury prevention observed by the three focus groups in their work areas

City hospital	City ARC/community	Rural hospital/ARC/community
Better care and improved outcomes	Increased education and staff knowledge and use of PIP link nurse as support	Generating support for equipment
Increased staff awareness of pressure injuries and information-seeking	Increased awareness, and inclusion in orientation of new staff	Policy on pressure injuries updated
Improved assessment tool	Blame culture awareness taught in course has helped reduce this	Increased awareness among clinical staff and patients
Improved patient knowledge	Able to buy new equipment	Education from ARC supported staff who had struggled with skills required
	Staff making PI their business and documenting more	Safety first form for pressure injuries Increased ease of reporting
	Didn't have a policy before and do now	Community support workers owned responsibility for PI care, leading to earlier recognition of problems
	Community nursing now have information for clients in the pack	Wards with TrendCare now have all the assessment information in one place, which increases efficiency

(2022) noted that nurses were afraid of reporting adverse events due to the punitive and blaming reaction of co-workers and managers. They suggested a "culture of learning" replace the "culture of blame" so that all health-care workers could report errors without fear. In the case of the PIP link nurse project in the ARC sector, it seems a culture of learning emerged and was noticed as a positive change in the work culture. This could be seen as the start of a community of practice – one of the goals of the link nurse programme.

According to the focus group nurses, awareness, assessment tool use, documentation and development of policies had all increased following the PIP link nurse project. While this is a positive outcome, research in Australia implies discretion is needed in the use of such processes. Lovegrove et al (2020) assessed 200 case notes for the pressure injury action reported. While there were 14 cases, including four at-risk and three high-risk patients, in which no preventative interventions were prescribed, 88.7 per cent of not at-risk patients had (unnecessary) preventative interventions prescribed. This surprising result indicates that documentation and actions should be appropriate to the situation, and the work of link nurses could ensure this.

All focus groups noticed that patients/residents were more informed of prevention of pressure injuries than before the PIP link nurse project. The nurses said this increased knowledge fostered patients' involvement in their own care. Consumer involvement in policy-making on pressure injury prevention was addressed in the protocol for the International Clinical Practice Guidelines; the authors acknowledged the lack of consultation with consumers that has previously taken place in this area (Kottner et al, 2019). Latimer et al (2014) noted that patient preferences for involvement in pressure injury prevention are unknown. Their research into the topic found that patients experienced barriers to pressure injury prevention in the health-care environment that impeded their participation. A strategy of including "patients as partners in care" is recommended to involve both health-care providers and consumers in the prevention of pressure injuries. This current project has encouraged more "patients as partners" in the areas where the link nurses worked.

STRENGTHS AND LIMITATIONS

The strengths of this study lie in the range of nursing roles that were represented in the focus groups. The mix of hospital-based, ARC/community and rurally-based nurses allowed a range of views – however, for the most part, the similarity of their experiences is noteworthy. When planning such programmes, health quality and safety organisations would be advised to note these results and the results of the other aspects of this study (Moir et al, 2022). However, this research was limited to one link nurse programme in one relatively small area and would benefit from the support of other similarly designed studies. Limitations also include the lack of follow-up of nurses who left the programme, as it is possible changes occurred in their workplaces that may have differed from those reported here. Also, there was no objective measurement of change, or pressure area reduction. Pressure injuries can increase following such a project before levelling out and eventually reducing (Beinlich & Meehan, 2014). Further research on the sustainability and outcomes of the project is required.

RELEVANCE TO CLINICAL PRACTICE

Nurses and other health workers have previously mentioned they felt a lack of autonomy when working to prevent pressure injuries (Barakat-Johnson et al, 2019; KPMG, 2015). This may have contributed to the poor attitude to pressure injury care expressed by nurses in the study by Rostamvand et al (2022). Following the PIP link nurse programme reported here, nurses were encouraged and empowered by the changes they were able to institute in their workplaces. Support of employers and managers and engagement of colleagues encouraged the link nurses (Moir et al, 2022). Leading by example and being seen to be able make improvements, such as in new equipment purchases, increased link nurses' autonomy. Recognising a need and leading their own change project was a positive process for the nurse, management and colleagues. Such nurse-led programmes fill a gap in quality improvement action and further inception of such programmes should be encouraged by nurses for nurses and their colleagues. While follow-up has been started on pressure injury incidence since the link nurse programme, these results are not yet available, which is a limitation to this report. Also valuable to follow up is the movement of the link nurses from their areas of practice, and whether they carried their skills to new areas. All these factors should be considered when assessing the outcomes of the programme.

REFERENCES

Altmiller, G., & Hopkins-Pepe, L. (2019). Why quality and safety education for nurses (QSEN) matters in practice. *Journal of Continuing Education in Nursing, 50*(5), 199-200. https://doi.org/10.3928/00220124-20190416-04

Aspinal, F., Hughes, R., Dunckley, M., & Addington-Hall, J. (2006). What is important to measure in the last months and weeks of life?: A modified nominal group study. *International Journal of Nursing Studies, 43*(4), 393-403. https://doi.org/10.1016/j.ijnurstu.2005.06.005

Barakat-Johnson, M., Lai, M., Wand, T., & White, K. (2019). A qualitative study of the thoughts and experiences of hospital nurses providing pressure injury prevention and management. *Collegian, 26*(1), 95-102. https://doi.org/10.1016/j.colegn.2018.04.005

Barr, T. L., Malloch, K., Ackerman, M. H., Raderstorf, T., & Melnyk, B. M. (2021). A blueprint for nursing innovation centers. *Nursing Outlook, 69*(6), 969-981. https://doi.org/10.1016/j.outlook.2021.05.006

Beinlich, N., & Meehan, A. (2014). Resource Nurse Programme. *Journal of Wound, Ostomy and Continence Nursing, 41*(2), 136-141. https://doi.org/10.1097/won.0000000000000001

Canterbury District Health Board. (2015). Process for Improvement. In *Clinical Governance Policy*. https://edu.cdhb.health.nz/Hospitals-Services/Health-Professionals/CDHB-Policies/Clinical-Manual/Documents/Clinical-Governance-Policy.pdf

Deming, W. E. (2018). *Out of the Crisis* (reissue). MIT Press.

Flynn, R., Scott, S. D., Rotter, T., & Hartfield, D. (2017). The potential for nurses to contribute to and lead improvement science in health care. *Journal of Advanced Nursing, 73*(1), 97-107. https://doi.org/10.1111/jan.13164

Hamed, M. M. M., & Konstantinidis, S. (2022). Barriers to incident reporting among nurses: a qualitative systematic review. *Western Journal of Nursing Research, 44*(5), 506-523. https://doi.org/10.1177/0193945921999449

Kottner, J., Cuddigan, J., Carville, K., Balzer, K., Berlowitz, D., Law, S., Litchford, M., Mitchell, P., Moore, Z., Pittman, J., Sigaudo-Roussel, D., Yee, C. Y., & Haesler, E. (2019). Prevention and treatment of pressure ulcers/injuries: The protocol for the second update of the International Clinical Practice Guideline 2019. *Journal of Tissue Viability, 28*(2), 51-58. https://doi.org/10.1016/j.jtv.2019.01.001

KPMG. (2015). *The case for investment in: A quality improvement programme to reduce pressure injuries in New Zealand.* Report prepared for the Health Quality & Safety Commission, Ministry of Health and Accident Compensation Corporation. https://www.hqsc.govt.nz/resources/resource-library/the-case-for-investment-in-a-quality-improvement-programme-to-reduce-pressure-injuries-in-new-zealand/

Latimer, S., Chaboyer, W., & Gillespie, B. (2014). Patient participation in pressure injury prevention: giving patients a voice. *Scandinavian Journal of Caring Sciences, 28*(4), 648-656. https://doi.org/10.1111/scs.12088

Lovegrove, J., Fulbrook, P., & Miles, S. (2020). Relationship between prescription and documentation of pressure injury prevention interventions and their implementation: An exploratory, descriptive study. *Worldviews on Evidence-Based Nursing, 17*(6), 465-475. https://doi.org/10.1111/wvn.12473

Moir, C., Taylor, P., Seaton, P., & Snell, H. (2022). An Evaluation of Barriers and Facilitators for a Pressure Injury Prevention Link Nurse Role: A Mixed-Methods Study in New Zealand. *Journal of Wound, Ostomy and Continence Nursing, 49*(4), 314-321. https://doi.org/10.1097/WON.0000000000000888

Needleman, J., Buerhaus, P., Mattke, S., Stewart, M., & Zelevinsky, K. (2002). Nurse-staffing levels and the quality of care in hospitals. *New England Journal of Medicine, 346*(22), 1715-1722. https://DOI: 10.1056/NEJMsa012247

Provost, L., & Bennett, B. (2015). What's your theory? Driver diagram serves as tool for building and testing theories for improvement. *Quality Progress, 7, 36-43.* http://www.apiweb.org/QP_whats-your-theory_201507.pdf

Pyrko, I., Dörfler, V., & Eden, C. (2017). Thinking together: What makes communities of practice work? *Human Relations, 70*(4), 389-409. https://doi.org/10.1177/0018726716661040

Quinn-O'Neil, B., Kilgallen, M. E., & Terlizzi, J. A. (2011). Cultivating quality: Creating a unit-based resource nurse program. *American Journal of Nursing, 111*(9), 46-51. https://doi: 10.1097/01.NAJ.0000405062.20646.b7

Rostamvand, M., Abdi, K., Gheshlagh, R. G., Khaki, S., Dehvan, F., & Barzgaran, R. (2022). Nurses' attitude on pressure injury prevention: A systematic review and meta-analysis based on the pressure ulcer prevention instrument (APuP). *Journal of Tissue Viability, 31*(2), 346-352. https://DOI: 10.1016/j.jtv.2021.12.004

Rowe, A. D., McCarty, K., & Huett, A. (2018). Implementation of a nurse driven pathway to reduce incidence of hospital acquired pressure injuries in the pediatric intensive care setting. *Journal of Pediatric Nursing, 41,* 104-109. https://doi.org/10.1016/j.pedn.2018.03.001

Shepherd, M., Hattersley, A., & Ellard, S. (2005). Integration of the MODY link nurse project: 20-month evaluation. *Journal of Diabetes Nursing, 9*(2), 47-52. https://www.diabetesonthenet.com/wp-content/uploads/jdn9-2-47-52-1.pdf

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The lived experience of people with psoriasis: A qualitative meta-synthesis

ABSTRACT

Background: This review explores the lived experience of people through the lens of their journey with psoriasis. Most of the efforts to understand the impact of psoriasis on a person's life have been quantitative studies focusing on quality of life. There is a need to understand more about what it is like living with psoriasis. This understanding may provide insight into the wellbeing and health priorities of those living with psoriasis and help health professionals provide them with more holistic care.

Objective: To explore the lived experiences of adults with psoriasis.

Methods: A qualitative meta-synthesis was undertaken using meta-ethnography. Databases searched included CINAHL, PubMed, MedNar, Gale and Sociology Source. Qualitative studies published in English and reporting primary data analysis including the experiences of people with psoriasis were considered for inclusion.

Findings: Nineteen studies were included. Three themes emerged from the synthesis about the lived experience of psoriasis, including the impact on participants' self-identity, wellbeing and culture. Participant voices underline the daily struggles they experience, including how psoriasis is all-consuming, shaping their being, and how people with psoriasis use isolation as a coping mechanism, making themselves and their bodies invisible.

Conclusion: Psoriasis affects all aspects of a person's life. The level of understanding a health professional has of what it is like to live with psoriasis underpins and informs their therapeutic approaches and can play a pivotal role in helping a person with psoriasis successfully manage their condition.

KEYWORDS

Psoriasis, lived experience, self-identity, isolation, culture, wellbeing

INTRODUCTION

The aim of this review was to explore the lived experiences of people with psoriasis. Psoriasis is a common chronic debilitating long-term condition that affects millions of adults worldwide. It is estimated that approximately 90,000 people in New Zealand have been diagnosed with this condition (Health Navigator, 2023). Due to the skin being the largest and most visible organ of the human body, having blemished skin affects all aspects of a person's quality of life and has further implications as it predisposes them to many other comorbidities. For these reasons, individuals with psoriasis experience unique psychosocial effects and encounter day-to-day challenges. Exploring the lived experiences of adults with psoriasis is an evolving area of research that has the potential to inform current clinical practice and direct population health initiatives.

BACKGROUND

World Health Organization (WHO) (2016) data suggests that the prevalence of psoriasis in all countries ranges from 0.09 per cent to 11.43 per cent of the population. Studies show that psoriasis is prevalent in adults, affecting approximately 2 per cent to 4 per cent of both males and females equally (Alzeer et al, 2022; Demir &

Aksoy, 2019; Nicolescu et al, 2021). Recent literature has shown that psoriasis is a cutaneous disease linked to comorbidities like inflammatory bowel disease, cardiovascular disease, mental health disorders, diabetes mellitus, metabolic syndrome, psoriatic arthritis, hypertension and hyperlipidaemia (Daniel, 2020). Being a chronic, incurable condition, psoriasis can stretch from childhood through to old age, leading to missed opportunities in education, work, and personal life (WHO, 2016). Psoriasis burdens individuals with stigma and discrimination, undermining self-confidence and self-image.

Treatment for psoriasis is based on the severity, body surface area it covers and the clinician. Kalb (2019) suggests that with a limited surface area of <3 per cent, treatment should be topical therapy. Another option available for treatment is phototherapy, which involves using "narrowband" ultraviolet (UVB) light (Oakley, 2001). For larger affected areas, covering more than 10 per cent of the body, systematic therapy using medications such as methotrexate, ciclosporin, acitretin or apremilast (not subsidised in New Zealand) may be indicated. Biologic systematic therapy is the subsequent line of treatment, but its usage in clinical practice is limited due to its high cost (Vather, 2020). Complementary or alternative medicines (CAM) are also commonly used by people with psoriasis, including herbal therapies, dietary supplements, mind/body interventions, climatotherapy (bathing in the Dead Sea and sunbathing for several weeks) and traditional Chinese medicines (Talbott & Duffy, 2015).

People with psoriasis tend to score lower in studies on subjective health status and psychological well-being (Reimus et al, 2007). Subjective wellbeing is defined as how people feel about their lives and their overall satisfaction with life (Cummins et al, 2009). A high level of disease severity is strongly associated with lower subjective wellbeing and depression, while improvement in skin condition was found to improve wellbeing (Schuster et al, 2022). Therefore, it is essential to evaluate the mental burden of this disease to weigh the impact of psoriasis on people's lives (Dogan et el, 2022) and include measures of wellbeing in therapeutic approaches (Schuster et al, 2022).

Given the prevalence and long-term nature of psoriasis, along with its complex management, the objective of this meta-synthesis was to report on the lived experiences of people with psoriasis. This review will enable us to make recommendations to inform decision-making in current health practices and policies. The review question was: *"What are the lived experiences of adults with psoriasis?"*

METHODS

Study design

The methodological process followed in this review was informed by the meta-ethnography phases outlined by Noblit and Hare (1988). There are seven phases to completing a meta-ethnography, as shown in Table 1 (above) (France et al, 2019, p. 2).

Table 1. Meta-ethnography – seven phases

Phase 1	Identifying a phenomenon of interest that qualitative research might inform
Phase 2	A systematic review of the literature
Phase 3	Reading the studies
Phase 4	Determining how the studies are related
Phase 5	Translating the studies into one another
Phase 6	Synthesising translations
Phase 7	Expressing the synthesis

Phase 1 – Identifying a phenomenon: A phenomenon of interest was identified, and a review question was developed. Elements of the PICo (population, phenomenon of interest, context) were identified as adults, lived experiences and psoriasis during the systematic literature review. The population was viewed as human adults; the phenomenon of interest was lived experiences and the context mechanism cause-and-effect relationship, psoriasis. The PICo is presented in Table 2 (below).

Phase 2 – Systematic review of the literature: A systematic search was carried out using five databases in August 2022. The search used the terms derived from the PICo. The entire PubMed search string used is shown in Appendix 1 (see p37) and was adapted for CINAHL, MedNar, Gale and Sociology Source.

Table 2. PICo table

	Key words	Synonym and other terms
P - Population	Adults	Adults
I - Interest Phenomenon of	Lived experiences	Attitudes, perceptions, views, feelings emotions, life experiences
Co - Context	Psoriasis	Psoriasis

Table 3. Inclusion/exclusion criteria

Inclusion	Exclusion
Adults > 18 years	Children
Psoriasis	Eczema and other skin conditions
"Lived experiences"	Quantitative
Qualitative	Non-English language
English language	Grey literature
Within 10 years (2012-2022)	
Peer-reviewed primary research	

Study selection

Phase 3 – Reading the studies: Inclusion and exclusion criteria were applied to the selection of studies (see Table 3, p26). Primary research studies published in the last 10 years were included. Articles found to be exclusive to infants, children, adolescents or other skin conditions were excluded, along with articles not published in English unless an English translation was available. Additional relevant articles were handpicked from the reference lists of secondary research studies to add completeness and rigour. The PRISMA process diagram (Figure 1, below) shows the identification of the studies selected at each stage. Each study was critically appraised for methodological quality using the Joanna Briggs Institute (JBI, 2020) critical appraisal tool for qualitative research studies (see Appendix 2, p38-39).

Data analysis framework

The data analysis for this meta-ethnography took place in stages four, five and six.

Phase 4 – Determining how the studies are related: The reviewers examined each study in detail, colour highlighting quotes to place the quotes from each study into sub-categories; along with metaphors, concepts or themes. Then each sub-category was synthesised, and common concepts or themes were identified. This process identified whether the accounts were directly comparable (reciprocal translations), in opposition to each other (refutational), or related studies but dissimilar, which, when taken together, represented a narrative storyline.

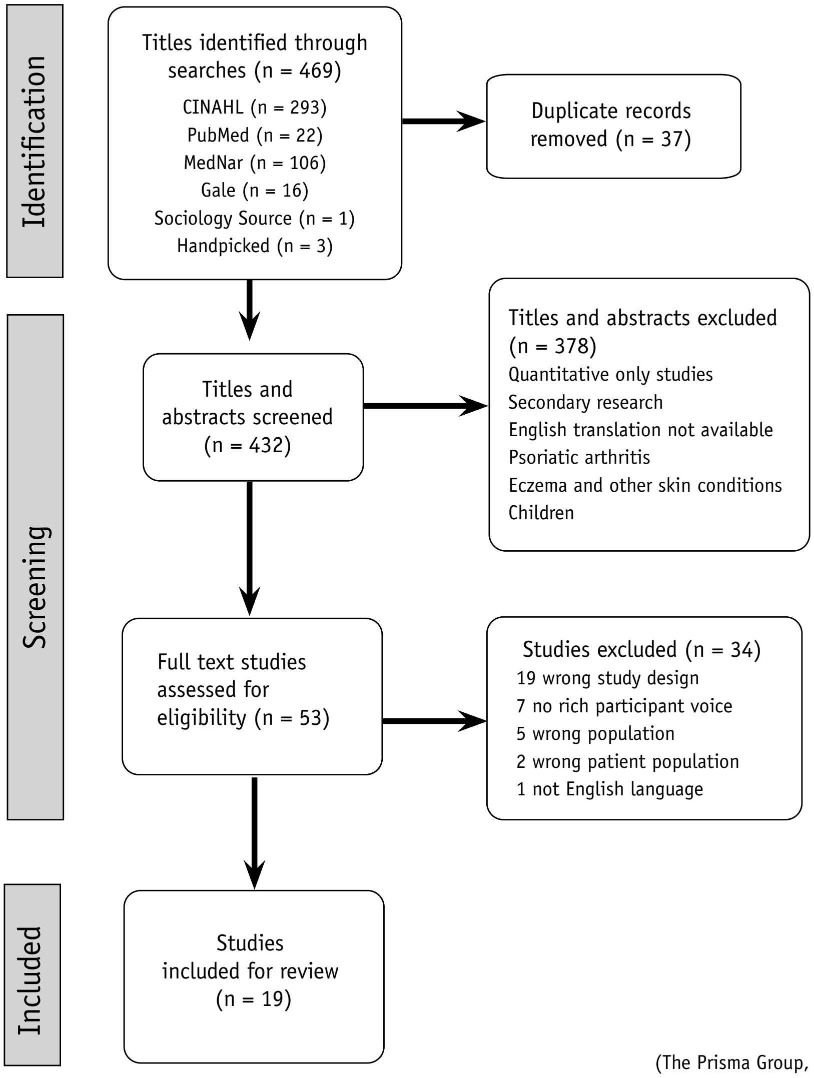
Phase 5 – Translating the studies into one another: The translating process entailed appraising the key concepts amid and across the studies. The reviewers examined the key concepts amid and across each study, and each concept was, in turn, juxtaposed to all the other studies to determine similarities or variances. Similarities and variances of key concepts between studies were identified, and the concepts were arranged into categories, encompassing the themes across the studies (third-order constructs) (Connery et al, 2020).

Phase 6 – Synthesising translations: The synthesis was achieved by preserving each study's central metaphors and concepts and comparing them with the key metaphors and concepts from other studies. The synthesising of the translations produced overarching metaphors and themes from the concepts of the original studies.

Characteristics of selected studies

The characteristics of the 19 studies selected for inclusion in the meta-synthesis are set out in Table 4 (see p28-30). The 19 studies were published between 2013 and 2022. All studies were in English and were from differing qualitative designs consisting of: three phenomenology, two exploratory descriptive, two grounded theory, one ethnography, one mixed method, and 10 interpretive qualitative. The settings of the studies ranged from hospital inpatient and outpatient clinics, health clinics, and their own patient or home environment. Studies were done in China, Israel, Denmark, the United States, the United Kingdom, Norway, Brazil, Germany, Iran, France, Italy, Spain and Canada. No New Zealand- or Australian-based studies were found.

FIGURE 1. PRISMA FLOW DIAGRAM – Identification of studies via research databases



(The Prisma Group, 2009)

Table 4. Study characteristics

Author/s	Title	Publication year	Journal	Country	Setting	Study design	Aim of study/objectives
1. Fisher, S., Ellen, M., Cohen, A. D., & Kagan, I.	Coping with psoriasis or hidradenitis suppurativa: A qualitative study	2020	Advances in Skin & Wound Care	Israel	Dermatology outpatient department	Phenomenology	To examine how patients with psoriasis or HS cope with their conditions on a personal and psychosocial level during times of exacerbation and symptom deterioration.
2. Gambles, B.	A phenomenological study of the psoriasis patient receiving home phototherapy	2016	Dermatological Nursing	United Kingdom (UK)	University hospital	Phenomenology	To obtain an understanding of the lived experiences of a group of patients receiving phototherapy treatments in their own homes.
3. Khoury, L. R., Danielsen, P. L., & Skiveren, J.	Body image altered by psoriasis: A study based on individual interviews and a model for body image	2014	Journal of Dermatological Treatment	Denmark	Bispebjerg University Hospital, Dermatology Department	In-depth semi-structured interviews	To investigate the influence of psoriasis on patients' body image.
4. Ljosaa, T. M., Bondevik, H., Halvorsen, J. A., Carr, E., & Wahl, A. K.	The complex experience of psoriasis-related skin pain: A qualitative study	2020	Scandinavian Journal of Pain	Norway	Dermatology ward and outpatient clinic in a university hospital in Oslo	In-depth semi-structured interviews, framed in a qualitative and interpretive paradigm	To explore in depth how patients experience psoriasis-related skin pain and how they deal with it.
5. Martin, M. L., Gordon, K., Pinto, L., Bushnell, D. M., Chau, D., & Viswanathan, H. N.	The experience of pain and redness in patients with moderate to severe plaque psoriasis	2015	Journal of Dermatological Treatment	United States of America (US)	Four US sites in Washington, Colorado, Georgia and California	Concept elicitation and cognitive interviews	To better understand the relevance and consistency of the symptomatic experience of pain and redness in moderate to severe psoriasis patients, and to evaluate the content validity of the Psoriasis Symptom Inventory.
6. Meneguin, S., Aparecida de Godoy, N., Pollo, C. F., Miot H. A., & de Oliveria, C.	Quality of life of patients living with psoriasis: A qualitative study	2020	BMC Dermatology	Brazil	Dermatology outpatient clinic Sao Paulo State University Medical School	Descriptive exploratory study	To understand the perceptions of patients living with psoriasis in relation to their quality of life and to identify aspects to improve it.
7. Narayanan, S., Guyatt, V., Franceschetti, A., & Hautamaki, E. L.	Disease burden and patient-reported outcomes among patients with moderate to severe psoriasis: An ethnography study	2014	Psoriasis: Targets and Therapy	US, France, Germany, Italy, Spain, UK, Brazil and Canada	Own patient environment in the US, France, Germany, Italy, Spain, Uk, Brazil and Canada	Ethnography	To explore patients' views on treatment and the impact of psoriasis on health-related quality of life.

Table 4. Study characteristics

Author/s	Title	Publication year	Journal	Country	Setting	Study design	Aim of study/objectives
8. Nelson, P. A., Kane, K., Pearce, C. J., Bundy, C., Chisholm, A., Hilton, R., Thorneloe, R., Young, H., Griffiths, C. E. M., & Cordingley, L.	'New to me': Changing patient understanding of psoriasis and identifying mechanisms of change. The Pso Well patient materials mixed-methods feasibility study.	2017	British Journal of Dermatology	UK	Community-based sample of primary-care patients from a previous study (University of Manchester)	Mixed method	To investigate whether Pso Well materials (i) broaden understanding of psoriasis without increasing anxiety; (ii) are acceptable; and (iii) comprise features that appear to affect change. Qualitative interviews explore acceptability and perceived active ingredients.
9. Nelson, P. A., Barker, Z., Griffiths, C. E. M., Cordingley, L., & Chew-Graham, C. A.	'On the surface': A qualitative study of GPs' and patients' perspectives on psoriasis	2013	BMC Family Practice	UK	GPs' and community sample from North West of England	In-depth semi-structured interviews	To compare and contrast the perspectives of people with psoriasis and of GPs on the challenges of managing psoriasis in primary care.
10. Newi, A. L., Tsianakas, A., von Martial, S., Sommer, R., & Blome, C.	How important is subjective wellbeing for patients? A qualitative interview study of people with psoriasis	2022	Quality of Life Research	Germany	Inpatient dermatology rehabilitation clinic	Semi-structured one-on-one telephone interviews	To investigate the importance of subjective wellbeing as an outcome of psoriasis treatment from patients' perspective.
11. Parkhouse, A. R.	Experiences of stigma-stress among people living with psoriasis in the United States	2019	American Journal of Health Behaviour	US	Flyer's advertising study; interested people contacted researcher via telephone/email	Grounded theory approach; semi-structured interviews via telephone and in person	To explore and describe experiences of stigma as a stressor among people living with psoriasis.
12. Taliercio, V. L., Snyder, A. M., Webber, L. B., Langner, A. U., Rich, B. E., Beshay, A. P., Ose, D., Biber, J. E., Hess, R. H., Rhoads, J. L. W., & Secrest, A. M.	The disruptiveness of itchiness from psoriasis: A qualitative study of the impact of a single symptom on quality of life	2021	Journal of Clinical Aesthetic Dermatology	US	University of Utah Health Psoriasis Clinic	Semi-structured interviews	To understand the far-reaching impacts of itchiness on the lives of those with psoriasis and their families.
13. Yaghoubinia, F., Saeedinezhad, F., Keikhaei, A., & Piri, F.	Experiences of young girls with psoriasis: A descriptive phenomenological study	2020	Medical Surgical Nursing Journal	Iran	Dermatology clinics of Zhedan hospitals	Phenomenological study	To explain the experiences of young girls with psoriasis.

Table 4. Study characteristics

Author/s	Title	Publication year	Journal	Country	Setting	Study design	Aim of study/objectives
14. Zhong, H., Yang, H., Mao, Z., Chai, X., & Li, S.	Impact of moderate- to-severe psoriasis on quality of life in China: A qualitative study.	2021	Health and Quality of Life Outcomes	China	Two dermatology inpatient clinics in Shandong province, eastern China	In-depth semi-structured one-to-one interviews	To investigate and explore the impact of psoriasis on the quality of life of patients with moderate-to-severe psoriasis.
15. George, C., Sutcliffe, S., Scheinmann, D., Mizara, A., & McBride, S. R.	Psoriasis: The Skin I'm In. Development of a behaviour change tool to improve the care and lives of people with psoriasis	2021	Clinical and Experimental Dermatology	UK	Adult tertiary referral psoriasis service	One-to-one interviews using a semi-structured questionnaire	To explore and communicate the experiences of living with psoriasis and interacting with health-care professionals.
16. Khoury, L. R., Skov, L., and Moller, T.	Facing the dilemma of patient-centred psoriasis care: A qualitative study identifying patient needs in dermatological outpatient clinics	2017	British Journal of Dermatology	Denmark	Department of Dermatology and Allergy, Herlev and Gentofte Hospital	Individual semi-structured interviews	To explore the unmet needs and health perspectives of people with psoriasis, regarding interaction with clinicians and the structure inherent to consultations in a hospital outpatient dermatological clinic.
17. Fordham, B. A., Nelson, P., Griffiths, C. E. M., & Bundy, C.	The acceptability and usefulness of mindfulness-based cognitive therapy for people living with psoriasis: A qualitative study	2015	British Journal of Dermatology	UK	Mindfulness-based cognitive therapy intervention programme	In-depth semi-structured interviews	A pilot study exploring the effect of mindfulness-based cognitive therapy to reduce physiological arousal and psychological distress for people with psoriasis.
18. Kouwenhoven, T. A., van der Ploeg, J. A. M., & van de Kerkhof, C. M.	Treatment goals in psoriasis from a patient perspective: A qualitative study	2019	Journal of Dermatological Treatment	Netherlands	Radboud University Medical Center	In-depth semi-structured interviews	To explore treatment goals in patients with psoriasis that originate entirely from the patient perspective.
19. Bundy, C., Borthwick, M., McAteer, H., Cordingley, L., Howells, L., Bristow, P., & McBride, S.	Psoriasis– snapshots of the unspoken: Using novel methods to explore patients' personal models of psoriasis and the impact on well-being.	2014	British Journal of Dermatology	UK	Members of the Psoriasis Association and a dermatology centre outpatient clinic	"Dear psoriasais..." postcards only instruction: 'Write a letter to your psoriasis describing how it makes you feel and think, and how it has impacted your life'	To offer people with psoriasis a novel way of expressing their personal models of psoriasis in order to better understand their experiences of living with the condition.

Phase 7 – Expressing the synthesis

FINDINGS

Three primary themes emerged from the synthesis, including psoriasis is all-consuming, hiding my body and psoriasis shapes your being (see Figure 2, below).

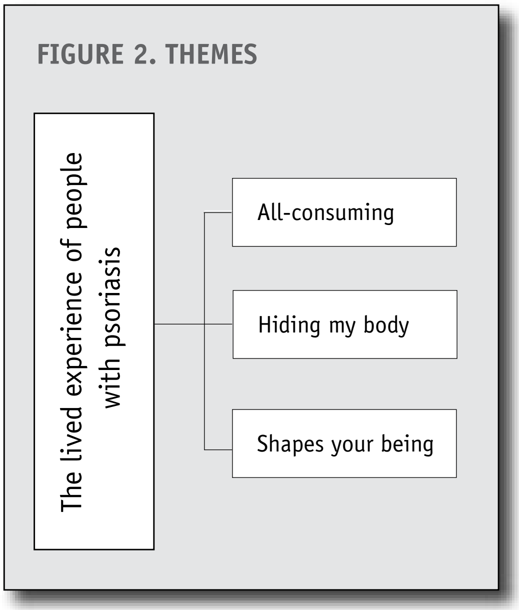


FIGURE 2. THEMES

Theme 1 – All-consuming

Narrative storyline – psoriasis is uncomfortable

Psoriasis is all-consuming because it affects every aspect of a person's life. Participants in the studies relate stories of the experience of itching, pain and the shedding of scales, all of which are constant (Fisher et al, 2020; Gambles, 2016). This intense itch can be painful and distracting, coupled with the overproduction of flaky scales that leave a trail wherever one goes, resulting in stress and anxiety for those with psoriasis (Khoury et al, 2014; Ljosaa et al, 2020).

> *"There's never a moment my scalp doesn't itch"*
> (Taliercio et al, 2021, participant FG P5 294, p. 47).

The sensation of constantly being itchy affects their concentration and disrupts their ability to work effectively. Participants' stories articulate the ever-present sensation of being itchy, which makes it difficult to focus on anything else except to scratch that itch until relief is obtained (Fisher et al, 2020). The bleeding caused by scratching distracts the person, undermining their ability to concentrate effectively at work (Taliercio et al, 2021; Zhong et al, 2021).

> *"When I am scratching myself all day, I can't concentrate on something else. It keeps my mind busy most of the day"*
> (Fisher et al, 2020, participant M8pso, p. 663)
>
> *"It affects work efficiency. Let's say if I'm working on something and touched my hair accidentally. Dandruff would fall a lot and I would feel dirty and itchy and couldn't resist scratching. If it bleeds, my concentration on work would be directly lowered"*
> (Zhong et al, 2021, participant Male 2, p. 7)

Participants' stories depict a vicious cycle of intense itching, the sort of itching that cannot be controlled, and that drives them to distraction (Fisher et al, 2020; George et al, 2021). It leaves a trail of destruction in its wake, including blood, skin, and feelings of despair and frustration. As one participant's partner noted:

> *"When he needs to scratch, he will start bleeding, and he will say, 'Oh, that's better.' And, within minutes, he is trying to scratch it even more while he is bleeding, and it itches so bad"*
> (Taliercio et al, 2021, participant FG4 FM1214-215, p. 45)
>
> *"S**t gets everywhere, like armchairs. It's worse than a dog shedding. [My wife] asks me why I itch it, but it's because it f***ing itches … Why can't you just understand? I'm sorry I'm making a mess. She asks, 'Why don't you go to the doctor?' I have! Nothing works"*
> (Taliercio et al., 2021, participant FG3 P5 225-228, p. 46)

The following studies observe feelings of revulsion and embarrassment about the trail of skin that people with psoriasis leave in their wake (George et al, 2021; Packhouse, 2019; Zhong et al, 2021).

> *"Everyone kept saying, 'Oh my God will you stop itching, it's terrible, there's bits of your psoriasis all over the house' "*
> (George, et al, 2021, participant 16, p. 4).
>
> *"[It is] extremely itchy and always has flakes falling off. In the worst time, the fallen flakes from my legs would add up to 50g. A dreadful scene"*
> (Zhong et al., 2021, participant Male13, p. 4)

People with psoriasis realise that their skin shedding affects not only them but also their loved ones. Participants' stories relate their extreme awareness of their skin flaking off, and the dreadful mess they leave in their wake, including the extra cleaning involved (Fisher et al, 2020; Packhouse, 2019).

> *"When I rise from a chair, I quickly check if there are scales on it and whip them away quickly. It makes me so ashamed"*
> (Fisher et al, 2020, participant M8pso, p. 664).
>
> *"My poor wife she has a lot to put up with, all the extra cleaning and things. The bed gets covered in blood and mess; I drop scale everywhere"*
> (Gambles, 2016, participant Peter, p. 45).

Participants identified heat and sweat as contributing to an increased itch (Khoury et al, 2014; Taliercio et al, 2021). They have found that wearing inappropriate clothing for the weather conditions, to hide their psoriasis, leads to discomfort and increased itch.

> *"I have to wrap myself up in a lot of clothes, which is uncomfortable. The psoriasis flares up and starts itching"*
> (Khoury et al., 2014, participant M4, p. 4)
>
> *"It is more itchy throughout the day if I start sweating […] or*

> *like if you are going out to exercise or something, it is more itchy to me"*
> (Taliercio et al., 2021, participant IT4 40-42, p. 45).

People with psoriasis tell of sleepless nights, up itching all night, unable to curtail the uncontrollable desire to scratch, and the impact of little sleep on their functioning (Fisher et al, 2020; Taliercio et al, 2021; Zhong et al, 2021).

> *"Even if I'm sleepy at night, I can't fall asleep because it's too itchy. Sometimes I wake up in the middle of the night. It's so uncomfortable and I don't know how to make it better"*
> (Zhong et al, 2021, participant Male 10, p. 4)

> *"It seems like I can't remember the last time I slept eight hours in a row. So, it definitely [...] affects my sleep"*
> (Taliercio et al., 2021, participant FG2 P3 243-245, p. 46)

> *"The itch from my psoriasis prevents me from sleeping. It makes me be agitated most of the time"*
> (Fisher et al, 2020, participant F3pso, p. 664).

Some participants feel that psoriasis-associated pain is easier to deal with than itch, as pain can be controlled, whereas they have found no way to stop the incessant itch (Martin et al, 2015; Taliercio et al, 2021). Others find that pain distracts them from the itch; however, psoriasis-related pain also prevents them from doing things they did in the past (Taliercio et al, 2021; Zhong et al, 2021).

> *"But I would much rather hurt than itch, and so I do scratch until it hurts and then it doesn't itch anymore. [...] it's easier to deal with the pain"*
> (Taliercio et al., 2021, participant FG1 P1 508-509, p. 47)

> *"There [are] a lot of things we used to do [that now] we just can't because she is having pain and itching and she is not comfortable going out with all of the sores and plaques all over her body and bleeding all over everything"*
> (Taliercio et al., 2021, participant FG4 FM2 36-39 41-44, p. 46)

Theme 2 – Hiding my body

Narrative storyline – The notion of visibility

People living with psoriasis struggle with the visibility of their bodies in the world. The theme "hiding my body" characterises ideas about making the body invisible, encompassing the feelings and fears about being visible.

> *"Living with psoriasis is horrible because it is so visible"*
> (Kouwenhoven et al, 2019, participant F5, p. 16)

> *"You can't hide psoriasis; it is like a sign on your face and hands"*
> (Fisher et al, 2020, participant M10pso, p. 665)

People with psoriasis hide their bodies because being visible attracts unwanted attention and rejection, making them feel ugly, ashamed, stigmatised and like a leper.

> *"I don't want to display myself. I have seen how other people with psoriasis appear. They are white and disgusting."*
> (Khoury et al, 2014, participant W2, p. 4)

They tell stories about hiding their bodies in various ways: covering up with clothing, controlling how much they expose their body, or withdrawing from social interactions and activities and isolating themselves (Fisher et al, 2020; Gambles, 2016). Even the simple natural movement of an arm is restricted (Gambles, 2016; Khoury et al, 2014).

> *"I have rashes on the underside of my arm, so I try not to raise my arm..."*
> (Khoury et al, 2014, participant W3, p. 4)

> *"I have been hiding myself for a year, from anyone and from the outside world. I didn't invite people over either because I thought I would have to clean up all the flakes. So nobody visited me. My home didn't feel like home, it was just the place where I slept, like a den."*
> (Kouwenhoven et al, 2019, participant M3, p. 16)

People with psoriasis expressed anxiety at being seen as a person covered in a red, scaly, flaky unpleasant rash:

> *"You're desperate for people not to notice. So, I took my socks off, and all the kids went 'Aaah' … too late by then. I had been seen."*
> (Gambles, 2016, participant Rose, p. 45)

People with psoriasis feel unable to wear the clothes they want, as they feel that people are looking at them.

> *"You can't wear what you want; you become embarrassed about going swimming or to the gym, and you feel that people are looking at you."*
> (Gambles, 2016, participant Lisa, p. 45)

Participants reported that other people stare and comment about their unpleasant appearance of psoriasis, intimating that they are afraid they may catch something, so they distance themselves from the person with psoriasis (George et al, 2021; Yaghoubinia et al, 2019; Zhong et al, 2021). Participants said that because of the misconceptions associated with this skin condition, people are revolted and afraid (Newi et al, 2022; Parkhouse, 2019). A participant told of the experience at a gas station paying for the petrol, handing over the money.

> *"She saw my hand, which was covered full-blown in psoriasis scales, and she looked at my hand, looked at me, and put my change on the counter."*
> (Parkhouse, 2019, participant Beth, p. 250)

Other people's adverse reactions reinforce the internal struggles people with psoriasis face about their self-image and worth. This leads to self-preservation actions, such as hiding their body and isolating themselves, to avoid further attacks on an already fragile body image and self-esteem (Gambles, 2016; Narayanan et al, 2015).

> *"You feel like you should have a bell ringing as you're walking … like a leper."*
> (Gambles, 2016, participant Jim, p. 46)

> *"... I would never shower in a public changing room ... I won't give people the opportunity to think: 'Yuk, what's that?'."*
> (Khoury et al, 2014, participant W1, p. 5).

For some, looking at themselves in the mirror is a daily struggle, even if it is sometimes necessary to ensure they are not bleeding or the psoriasis patches are not exposed (Khoury et al, 2017; Narayanan et al, 2015). They hide their bodies as they feel ugly, ashamed and unattractive.

> *"I am too embarrassed to be naked, even in the dark."*
> (Fisher et al, 2020, participant M11pso, p. 664)
>
> *"I don't want to look at my body … My eyes focus on my face, and I control my eyes, so they don't slide down."*
> (Khoury et al, 2014, participant W1, p. 6)

Participants say they crave feeling and being normal, not being abnormal and different (Fisher et al, 2020; Meneguin et al, 2020). They say that looking "normal" means healthy and that the presence of psoriasis somehow makes them unhealthy. A participant said that after taking a shower,

> *"For a short time, my skin looks normal, without the ugly scales, and for a few minutes, I look healthy. I really like this feeling."*
> (Fisher et al, 2020, participant F7pso, p. 665)

They express feelings of sorrow and of wanting to vanish – vanish so that they are alone and do not need to pretend that they are alright. Alone, they do not need to feel shame as no one can see them; they can cry and feel sorry for themselves (Fisher et al, 2020; Parkhouse, 2019).

> *"You constantly feel like a part of you is broken or different, nobody wants to feel different."*
> (Parkhouse, 2019, participant Alan, p. 248)

Participants paint a picture of psoriasis being a *"very hidden condition"* (Parkhouse, 2019), hidden by the participants themselves and not publicised in the media to promote public understanding. Participants wish for an understanding they liken to how the media has facilitated a worldwide understanding of cancer.

> *"Quality of life could be improved by making other people aware that a person with psoriasis on their skin does not have a disease transmitted by sight, by clothing, by soap, in any way ... Because people stare and are disgusted and scared, but that is a problem that person has. I think that is the reason why a lot of people suffer ... to see the prejudice of others."*
> (Meneguin et al, 2020, participant DCS, p. 3)

Theme 3 – Shapes your being

Narrative storyline – Psoriasis has an emotional impact

These stories tell how a person's being is shaped by the emotional impact of psoriasis. Withdrawal from social circles commonly occurs, exacerbated by the reactions and reception of others and the inward struggles with changes to body image (Fisher et al, 2020; Gambles, 2016).

> *"It really connects to your being, and then how you evolve as a human being is with the psoriasis dictating it. It shapes you."*
> (Gambles, 2016, participant Rose, p. 45)

Participants describe how psoriasis shapes their social interactions with other people in ways that have implications for the whole breadth and scope of life (Khoury et al, 2017; Meneguin et al, 2020). They are embarrassed by the appearance of their skin condition and are subjected to stigmatism because of it. The anxiety they feel when socialising, defines and shapes them as a person. Participants express a profound sense of self – this is who I am now, because I have psoriasis.

> *"I don't go to friends' gatherings anymore. Sometimes it shows even on my face and I feel embarrassed to go out. If I go have lunch with my friends, and the skin flakes keep falling off, I couldn't be at ease. Even if there were no flakes, there would be white patches on the skin. I fear it would disgust others."*
> (Zhong et al, 2021, participant Female 17, p. 6).

Socialisation through employment can provide a sense of accomplishment, identity, and connection with people. Participants expressed a sense of loss of their former self and their identity within the community and workplace, and felt a reluctant acceptance that life would never be the same, that they would never be the same (Fisher et al, 2020; Narayanan et al, 2015).

> *"That's how I used to look [points at picture on mantelpiece], it's like I miss myself. Running things, being in charge, being in the office, being up in management and now I'm just like this now."*
> (Narayanan et al, 2015, participant Female US, p. 3).
>
> "Can I go to a job interview with face full of scales? Can I represent myself as a dignified academic person without shaking hands? Wearing a long sleeve shirt in summertime?"
> (Fisher et al, 2020, participant M10pso, p. 666).

Their appearance had changed and with it their sense of self.

> *"I wish my body was as before, without psoriasis. My body was clean and perfect ... I used to be a handsome guy, and then all of a sudden, I became a completely different person. I hate my psoriasis."*
> (Khoury et al, 2014, participant M1, p. 5)

Psoriasis affects the relationships people with psoriasis have with others. Participants in the studies reflected on the difficulties of: putting themselves out there with a prospective partner; telling their prospective partner that they have psoriasis; showing them their body; involving them in "life" with psoriasis; or just maintaining an existing relationship that started before developing psoriasis (Yaghoubinia et al, 2020; Zhong et al, 2021). They also talked about internal struggles with body image and self-loathing. As participants noted:

> *"… people's reactions, girls' reactions … it's your self-consciousness of it. That could be quite overwhelming at points."*
> (Nelson et al, 2013, participant P1, p. 5)

> *"I don't sleep on the same bed with my wife. I sleep in another room. I have my own bed with sheets and blankets of my own. I isolate myself from my family. There's no other way. I loathe myself."*
> (Zhong et al, 2021, participant Male 22, p. 6)

Participants reported their partners' responses to the manifestation of psoriasis.

> *"I have a kind husband, who tells me I look pretty, but it's difficult to believe ... I definitely prefer the light to be switched off, and if not, I avoid looking at myself."*
> (Khoury et al, 2014, participant W3, p. 4)

Participants highlighted the emotional remodelling and reshaping that takes place through the reactions of others to their skin condition. Those reactions help shape how they perceive that society views them and also in how they view themselves, changing and reshaping their being (George et al, 2021; Khoury et al, 2017).

> *"They get uncomfortable and afraid that it might be contagious. A girl in a fitness centre shouted out loud that I was disgusting."*
> (Khoury et al, 2014, participant W1, p. 5)

> *"It is quite isolating, it's hard to just deal with the skin disease and then also dealing with your emotions ... it's a bit like a split personality."*
> (George et al, 2021, participant 10, p. 5)

Participants also said that psoriasis alters their appearance, and in learning to cope with their "new" appearance, their being is reshaped.

> *"I once had a session with a psychologist, because I needed help to accept my body."*
> (Khoury et al, 2014, participant W3, p. 5)

Participants have pointed out that help is needed. Education about psoriasis and the psychological aspects that impact a person with the condition may be vital in removing some of the stigma around body image, helping to remove the social isolation they experience daily.

> *"They need to teach people that have this illness, what this illness does to you, and what to look out for so that you can mentally cope with this illness."*
> (George et al, 2021, participant 7, p. 6)

> *"Physically, today, I can say that I am rid of it. But psychologically I think I am not rid of it. If I really started thinking about all of this, I think I'd fall into depression. I can't say that today my psoriasis is in the past – even if it's no longer visible."*
> (Narayanan et al, 2015, participant Female France, p. 3).

DISCUSSION

This meta-synthesis sought to explore the lived experiences of adults with psoriasis. We identified 19 studies exploring the impact of psoriasis on participants' lives. The findings of this synthesis reveal how psoriasis impacts every aspect of a person's life and wellbeing. There is no universally accepted definition of wellbeing, due to different cultures valuing different concepts and perspectives (Mayberry et al, 2022). However, the World Health Organization (2020) defines wellbeing as "a state of complete physical, mental and social wellbeing, and not merely the absence of disease or infirmity" (para. 5). How we know ourselves is through our human interconnectedness and our position within society.

Wellbeing can be linked to a sense of purpose and belonging. Everyone wants to belong, in society, as part of a family, in social circles, and within a work environment. However, having psoriasis can lead to being socially displaced, excluded or marginalised and can cause existential health-related ruptures in people's lives. Psoriasis influences people's physical health as well as their psychological and psychosocial wellbeing. People with psoriasis often feel like lepers, displaced from where they belong and they struggle for re/emplacement and re/integration into their places of belonging (Mattes & Lang, 2021).

Douglas (1966) refers to this social displacement as creating a marginal state for people with psoriasis, who are perceived as dangerous. Social displacement results in a loss of belonging, and self-stigmatisation. This social displacement comes from the perception that people with psoriasis are dangerous, in terms of being infectious, contagious or unclean. Self-stigmatisation is the outcome of negative self-talk. It can lead to feelings of unworthiness, to the person self-isolating for fear of rejection and to an altered body image, all of which are associated with depression (Weinberger et al, 2021). People with psoriasis experience a transition in identity from their old self without psoriasis to the new self with psoriasis. This transition positions them outside their previous place of belonging and security, and into a marginal state, with society declaring their new status as unacceptable and to be feared.

Wellbeing can be affected through diminished identity and self-esteem. This diminished identity often leads to negative emotions like shame and self-loathing that lead to withdrawal from leisure and social activities, which then further diminishes self-esteem, creating a vicious cycle (Synard & Gazzola, 2018). It can be argued that the interconnected characteristics of identity, including culture, community, work, and belonging, are fundamental to wellbeing and that any disruption to any of these characteristics can be detrimental (Gall et al, 2021). Therefore, the balance of one's mental, physical, emotional and spiritual aspects of life is essential to one's wellbeing.

Psoriatic skin lesions can appear threatening because they can be interpreted as being contagious or infectious and therefore unsafe in proximity (Almeida et al, 2017). Consequently, people with psoriasis find themselves in what anthropologists call a liminal space. Liminality is derived from an inability to classify people as one thing or the other, or to position them in the cultural or social space in which they are normally located (Douglas, 1966). Multiple factors contribute to liminality, including the struggle about where self-identity and psoriasis overlap. The removal of a person from their identified cultural space has implications for their wellbeing (Gall et al, 2021).

Wellbeing measures are often underpinned by Western philosophical concepts and do not consider indigenous concepts of wellbeing (Gall et al, 2021). People with psoriasis have their own concepts of health and wellbeing, drawn from their own experiences and shaped by socialisation and social interactions. Their values and beliefs are shaped by the environment and worldwide views about image, and about being clean and touchable. Being healthy means being seen as "normal", with normal skin, even if this is an illusion brought about by a shower or through longer-lasting treatment options.

People with psoriasis rapidly become aware of others' aversion to the sight of their skin rash, and they attempt to hide it. They hide to normalise themselves, so they do not stand out as a "person out of place" in their interactions with others (Douglas, 1966). As a cultural and social concept, stigma is associated with the skin's appearance. The visible rash on the skin acts as a mark of something seen by others as repulsive, and creates feelings of disgust. This is a form of deep-seated social control constantly reinforced by social media (Magin et al, 2010). Social media portrays images of beautiful clear skin as the socially accepted norm, an image that those with psoriasis fail to meet. Social exposure, and consequent rejection based on skin appearance, create apprehension, anxiety and fear of intimacy in people with psoriasis (Lahousen et al, 2016). Having visible skin lesions causes psychological trauma, as the person realises they are no longer socially acceptable and feel out of place, leading to the self-isolating behaviour exhibited by those with psoriasis (Kowalewska et al, 2019).

Douglas (1966) describes the idea of "matter out of place", which is thought-provoking when applied to the shedding of skin experienced by those with psoriasis. Matter out of place is often perceived to be unclean in a cultural sense. Socially and culturally, skin shedding produces feelings of revulsion and a sense of uncleanliness, of the individual themselves, but also the environment they function in. The feelings of revulsion and uncleanliness lead to less-than-ideal situations at work and home where the person with psoriasis experiences aversion to the skin scale they leave in their wake. This aversion produces a connection between the marked body and danger, creating an anxious state of being, as they try to conceal or get rid of the evidence of uncleanliness which is socially and culturally unacceptable. The inability to control the visible symptoms of their skin condition drives people with psoriasis to remove themselves from situations where they may be stigmatised further, again generating isolating behaviour (Bundy et al, 2014).

A priority for people with psoriasis may be to try and make the appearance of the skin look more normal and reduce physical symptoms like flaking and itching. Health professionals need to understand what it is like to live with psoriasis daily. If they do, it will help them understand the priorities of people with psoriasis and the burdens they face daily. Insights into the lived experience of psoriasis could lead to improvements in the provision of care, treatment and support (Nash et al, 2015). If people with psoriasis can access therapeutic intervention (such as biologic medications) to control the visible symptoms of psoriasis, creating the appearance of normal skin, will this then enable them to move out of the liminal space, as they are no longer a "matter out of place", a leper in society, but a "normal person"?

Education is fundamental to the wellbeing of people with psoriasis and should be seen as a therapeutic intervention to help them understand and manage their condition. However, education should not just support the physical condition (Aldeen & Basra, 2011). The findings of this synthesis highlight that people with psoriasis need education and support with the psychological and psychosocial impacts of psoriasis. They need support to enable them to shift from the liminal and "matter out of place" space. Nurses are positioned to play a pivotal role in delivering ongoing education and support for people with psoriasis. Just as psoriasis is multifaceted, so is the understanding needed to treat and promote wellbeing for people with psoriasis.

RECOMMENDATIONS

- Primary New Zealand research is needed to further explore the cultural meanings and implications of psoriasis.
- Research should also explore health professionals' understanding of what it is like to live with psoriasis and how that understanding informs therapeutic approaches.
- Education for nurses is also essential to develop and widen their knowledge and understanding of skin conditions and the impact they have on wellbeing. This knowledge could help develop and inform current clinical practice.
- Health literacy education should be offered to people with psoriasis, to help them understand the therapeutic purpose of interventions.
- Health professionals need to be informed about what support groups are available for people with psoriasis in their region.

LIMITATIONS

This review offers interpretations of the meaning of living with psoriasis. A limitation may be that only qualitative studies were included in this synthesis. There may be findings from quantitative studies that provide different perspectives about living with psoriasis, including quality of life and wellbeing measures. While psoriasis is more dominant in people of European descent, it is present in all ethnicities. The cultural meanings and implications of psoriasis were not identified in the studies included in this synthesis.

CONCLUSION

This meta-ethnography identified and synthesised primary qualitative research literature on people's experiences with psoriasis. The findings from 19 studies spanning 10 years were synthesised and developed into storylines. In these stories, participants described a complex picture with a rich narrative of being all-consumed by psoriasis, wanting to hide their body and the fact that psoriasis shaped their being. These powerful narratives reveal important insights into how people live with psoriasis as a long-term condition.

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REFERENCES

Aldeen, T., & Basra, M. (2011). Management of psoriasis and its comorbidities in primary care. *British Journal of Nursing, 20*(18), 1186-1192. https://doi:10.12968/bjon.2011.20.18.1186

Almeida, V., Taveira, S., Teixeira, M., Almeida, I., Rocha, J., & Teixeira, A. (2017). Emotion regulation in patients with psoriasis: Correlates of disability, clinical dimensions, and psychopathology symptoms. *International Journal of Behavioural Medicine, 24*, 563-570. https://doi:10.1007/s12529-016-9617-0

Alzeer, F., AlOtair, H., & Aleisa, A. (2022). Epidemiology and cutaneous manifestations of psoriasis in Saudi Arabia: A narrative review. *Clinical, Cosmetic and Investigational Dermatology, 15*, 347-355. https://doi.org/10.2147/CCID.S352654

Bundy, C., Borthwick, M., McAteer, H., Cordingly, L., Howells, L., Bristow, P., & McBride, S. (2014). Psoriasis – snapshots of the unspoken: Using novel methods to explore patients' personal models of psoriasis and the impact on well-being. *British Journal of Dermatology, 171*(4), 825-831. https://doi.org/doi:10.1111/bjd.13101

Connery, A., McCurtin, A., & Robinson, K. (2020). The lived experience of stuttering: A synthesis of qualitative studies with implications for rehabilitation. *Disability and Rehabilitation, 42*(16), 2232-2242. https://doi.org/10.1080/09638288.2018.1555623

Cummins, R. A., Mellor, D., Stokes, M., & Lau, A. L. (2009). Measures of subjective well-being. In E. Mpofu & T. Oakland (Eds.), *Rehabilitation and health assessment: Applying ICF guidelines* (pp. 409-426). Springer Publishing Company.

Daniel, B. (2020). The multiple comorbidities of psoriasis: The importance of a holistic approach. *Australian Journal of General Practice, 49*(7), 433–437. https://doi.org/10.31128/AJGP-08-19-5035

Demir, M., & Aksoy, M. (2019). The retrospective evaluation of clinical and demographic features of children with psoriasis. *Journal of Harran University Medical Faculty, 16*(2), 321-325. https://doi.org/10.35440/hufd.491500

Dogan, Y., Killic, F. A., & Ozcelik, S. (2022). Anxiety, Depression, and Sexual Dysfunction in Patients with Psoriasis. *Turkish Society of Dermatology, 16*, 62-69. https://doi.org/10.4103/tjd.tjd_146_21

Douglas, M. (1966). *Purity and danger: An analysis of concepts of pollution and taboo*. Routledge. https://ebookcentral.proquest.com/lib/wintec/detail.action?docID=1223047

Fisher, S., Ellen, M., Cohen, A. D., & Kagan, I. (2020). Coping with psoriasis or hidradenitis suppurativa: A qualitative study. *Advances in Skin and Wound Care,* 33, 662-668. https://doi.1097/01.ASW.0000720260.58886.08

France, E. F., Cunningham, M., Ring, N., Uny, I., Duncan, E. A. S., Jepson, R. G., Maxwell, M., Roberts, R. J., Turley, R. L., Booth, A., Britten, N., Flemming, K., Gallagher, I., Garside, R., Hannes, K., Lewin, S., Noblit, G. W., Pope, C., Thomas, J., Vanstone, M., Higginbottom, G. M. A., & Noyes, J. (2019). Improving reporting of meta-ethnography: The eMERGe reporting guidance. *Psycho-Oncology, 28*, 447–458. https://doi.org/doi:10.1002/pon.4915

Fordham, B. A., Nelson, P., Griffiths, C. E. M., & Bundy, C. (2015). The accessibility and usefulness of mindfulness-based cognitive therapy for people living with psoriasis: A qualitative study. *British Journal of Dermatology, 172*, 805-840. https://doi.1:10.1111/bjd.13333

Gall, A., Anderson, K., Howard, K., Diaz, A., King, A., Willing, E., Connolly, M., Lindsay, D., & Garvey, G. (2021). Wellbeing of Indigenous peoples in Canada, Aotearoa (New Zealand) and the United States: A systematic review. *International Journal of Environmental Research and Public Health, 18*(5832), 1-31. https://doi.org/doi.org/10.3390/ijerph18115832

Gambles, B. (2016). A phenomenological study of the psoriasis patient receiving home phototherapy. *Dermatological Nursing, 15*(2), 42-47. https://web-p-ebscohost-com.wintec.idm.oclc.org/ehost/pdfviewer/pdfviewer?vid=6&sid=716f9e5e-816d-4118-8e00-cfa81154728b%40redis

George, C., Sutcliffe, S., Scheinmann, D., Mizara, A., & McBride, S. R. (2021). Psoriasis: The skin I'm in. Development of a behaviour change tool to improve the care and lives of people with psoriasis. *Clinical and Experimental Dermatology, 46*(5), 1-8. https://doi:10.1111/ced.14594

Health Navigator. (2023). *Psoriasis – Mate tongatonga uri.* https://healthify.nz/health-a-z/p/psoriasis/#:~:text=Psoriasis%20(mate%20tongatonga%20uri)%20is,New%20Zealanders%20have%20this%20condition.

Joanna Briggs Institute. (2020). Checklist for qualitative research: Critical appraisal tools for use in JBI systematic reviews. *JBI Global.* https://jbi.global/critical-appraisal-tools

Kalb, R. E. (2019). Overcoming challenges in the management of psoriasis: Treatment advances to improve standard of care. *Journal of Managed Care Medicine, 22*(4), 63-66.

Khoury, L. R., Danielsen, P. L., & Skiveren, J. (2014). Body image altered by psoriasis. A study based on individual interviews and a model for body image. *Journal of Dermatology Treatment, 25*, 2-7. https://doi:10.3109/09546634.2012.739278

Khoury, L. R., Skov, L., & Moller, T. (2017). Facing the dilemma of patient-centred psoriasis care: A qualitative study identifying patient needs in dermatological outpatient clinics. *British Journal of Dermatology, 177*(2), 436-444. https://doi:10.1111/bjd.15292

Kouwenhoven, T. A., van der Ploeg, J. A. M., & van de Kerkhof, C. M. (2019). Treatment goals in psoriasis from a patient perspective: A qualitative study. *Journal of Dermatological Treatment, 31*(1), 13-17. https://doi.org/10.1080/09546634.2018.1544408

Kowalewska, B., Gawek, N., & Kowalewska, J. (2019). Quality of life and stigmatisation of people with psoriasis. *Progress in Health Sciences, 9*(1), 132-136.

Lahousen, T., Kupfer, J., Gieler, U., Hofer, A., Linder, M. D., & Schut, C. (2016). Differences between psoriasis patients and skin-healthy controls concerning appraisal of touching, shame and disgust. *Acta Dermato-Venereologica,* 217, 78-82. https://doi.org/doi:10.2340/00015555-2373

Ljosaa, T. M., Bondevik, H., Halvorsen, J. A., Carr, E., & Wahl, A. K. (2020). The complex experience of psoriasis-related skin pain: A qualitative study. *Scandinavian Journal of Pain, 20*(3), 491-498. https://doi.org/doi.org/10.1515/sjpain-2019-0158

Magin, P., Heading, G., Adams, J., & Pond, D. (2010). Sex and the skin: A qualitative study of patients with acne, psoriasis and atopic eczema. *Psychology, Health & Medicine, 15*(4), 454-462. https://doi.org/doi:10.1080/13548506.2010.484463

Martin, M. L., Gordon, K., Pinto, L., Bushnell, D. M., Chau, D., & Viswanathan, H. N. (2015). The experience of pain and redness in patients with moderate to severe plaque psoriasis. *Journal of Dermatological Treatment, 26*(5), 401-405. https://doi.org/10.3109/09546634.2014.996514

Mattes, D., & Lang, C. (2021). Embodied belonging: In/exclusion, health care, and well-being in a world in motion. *Culture, Medicine and Psychiatry, 45*(1), 2-21. https://doi:10.1007/s11013-020-09693-3

Mayberry, K., Zapata, L. V., Byers, M., & Thurston, M. M. (2022). A scoping review of well-being assessment and interventions in student pharmacists. *American Journal of Pharmaceutical Education, 86*(6), 743-758. https://doi:10.5688/ajpe8793

Meneguin, S., de Godoy, N. A., Pollo, C. F., Miot, H. A., & de Oliveira, C. (2020). Quality of life of patients living with psoriasis: A qualitative study. *BMC Dermatology, 20*(22), 1-6. https://doi.org/10.1186/s12895-020-00116-9

Narayanan, S., Guyatt, V., Franceschetti, A., & Hautamaki, E. L. (2014). Disease burden and patient reported outcomes among patients with moderate to severe psoriasis: An ethnography study. *Psoriasis: Targets and Therapy, 5,* 1-7. https://doi.org/10.2147/PTT.S74906

Nash, A. S., McAter, H., Schofield, J., Penzer, R., & Gilbert, A. K. (2015). Psoriasis today: Experiences of the healthcare and impact on quality of life in a major UK cohort. *Primary Health Care Research & Development, 16,* 415-423. https://doi.org/doi:10.1017/S1463423614000450

Nelson, P. A., Barker, Z., Griffiths, C. E. M., Cordingley, L., & Chew-Graham, C. A. (2013). 'On the surface': A qualitative study of GPs' and patients' perspectives on psoriasis. *BMC Family Practice, 14*(158), 1-10. https://doi:10.1186/1471-2296-14-158

Nelson, P. A., Kane, K., Pearce, C. J., Bundy, C., Chrisholm, A., Hilton, R., Thorneloe, R., Young, H., Griffiths, C. E. M., & Cordingley, L. (2017). 'New to me': Changing patient understanding of psoriasis and identifying mechanisms of change. The Pso Well patient materials mixed-methods feasibility study. *British Journal of Dermatology, 177*, 616-617. https://doi:10.1111/bjd.15574

Newi, A. L., Tsianakas, A., von Martial, S., Sommer, R., & Blome, C. (2022). How important is subjective well-being for patients? A qualitative interview study of people with psoriasis. *Quality of Life Research*, 1-9. https://doi.org/10.1007/s11136-022-03189-w

Nicolescu, A. C., Bucur, S., Giurcaneanu, C., Gheuca-Solovastru, L., Constantin, T., Furtunescu, F., Ancuta, I., & Constantin, M. M. (2021). Prevalence and characteristics of psoriasis in Romania – First study in overall population. *Journal of Personalized Medicine, 11*(523), 1-12. https://doi.org/org/10.3390/jpm11060523

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing qualitative studies*. Sage.

Oakley, A. (2001). *Narrowband UVB phototherapy*. [Dermnet NZ]. https://dermnetnz.org/topics/narrowband-uvb-phototherapy

Parkhouse, A. R. (2019). Experiences of stigma-stress among people living with psoriasis in the United States. *American Journal of Health Behaviour, 43*(2), 243-257. https://doi.org/10.5993/AJHB.43.2.2

Reimus, J. L. M., Vingerhoets, A. J. J. M., Soons, P. H. G. M., & Korstanje, M. J. (2007). Suffering in psoriasis patients: Its relation with illness severity and subjective well-being. *International Journal of Dermatology, 46*(10), 1042-1045.

Schuster, B., Peifer, C., Ziehfreund, S., Tizek, L., Biedermann, T., Zink, A., & Schielein, M. C. (2022). Happiness and depression in psoriasis: A cross-sectional study in Germany. *Quality of Life Research,* 31(6), 1-13. doi: 10.1007/s11136-021-02991-2

Synard, J., & Gazzola, N. (2018). Moving towards positive well-being in the face of adversity: What explains individual variations in well-being following job loss? *International Journal for the Advancement of Counselling, 41*, 415-435. https://doi:10.1007/S10447-018-9359-6

Talbott, W., & Duffy, N. (2015). Complementary and alternative medicine for psoriasis: What the dermatologist needs to know. *American Journal of Clinical Dermatology, 16*, 147-165. https://doi.org/10.1007/s40257-015-0128-6

Taliercio, V. L., Snyder, A. M., Webber, L. B., Langner, A. U., Rich, B. E., Beshay, A. P., Ose, D., Biber, J. E., Hess, R., Rhoads, J. L. W., & Secrest, A. M. (2021). The disruptiveness of itchiness from psoriasis: A qualitative study of the impact of a single symptom on quality of life. *Journal of Clinical and Aesthetic Dermatology, 14*(6), 42-48. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8594538/pdf/jcad_14_6_42.pdf

The PRISMA Group. (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*. https://www.prisma-statement.org//documents/PRISMA%202009%20flow%20diagram.pdf

Vather, D. (2020). Guidelines for the management of psoriasis. *Dermnet NZ*. https://dermnetnz.org/topics/guidelines-for-the-treatment-of-psoriasis

Weinberger, N. A., Mrowietz, S., Luck-Sikorski, C., von Spreckelsen, R., John, S. M., Sommer, R., Augustin, M., & Mrowietz, U. (2021). Effectiveness of a structured short intervention against stigmatisation in chronic visible skin diseases: Results of a controlled trial in future educators. *Health Expectations, 24*(5), 1790-1800. https://doi.org/10.1111/hex.13319

World Health Organization. (2016). *Global report on psoriasis*. https://apps.who.int/iris/bitstream/handle/10665/204417/9789241565189_eng.pdf.psoriasis?sequence=1

World Health Organization. (2020, November 24). *Assembly of parties of the International Development Law Organization*. https://www.who.int/director-general/speeches/detail/assembly-of-parties-of-the-international-development-law-organization

Yaghoubinia, F., Saeedinezhad, F., Keikhaei, A., & Piri, F. (2020). Experiences of young girls with psoriasis: A descriptive phenomenological study. *Medical- Surgical Nursing Journal, 8*(4), 1-10. https://doi:10.5812/msnj.100994

Zhong, H., Yang, H., Mao, Z., Chai, X., & Li, S. (2021). Impact of moderate-to-severe psoriasis on quality of life in China: A qualitative study. *Health and Quality of Life Outcomes, 19*(1), 1-9. https://doi:org/10.1186/s12955-021-01902-w

APPENDIX 1

Box 1. PubMed search

Search#	**17/08/22**	
1	**Title/abstract**	Adult
2	**MeSH Terms**	Adult
3		S1 OR S2
4	**Title/abstract**	Experiences OR “lived experiences” OR attitudes OR perceptions OR views OR feelings OR emotions OR “life experiences”
5	**MeSH Terms**	(“experiences” [MeSH Terms]) OR (“attitude” [MeSH Terms]) OR (“emotions” [MeSH Terms])
6		S4 OR S5
7	**Title/abstract**	Psoriasis
8	**MeSH**	Psoriasis
9		S7 OR S8
10		S3 AND S6 AND S9
	Add filters	**2012-2022**

APPENDIX 2

Quality appraisal of studies using JBI Checklist for Qualitative Research

Author (year)	Title	Qu 1	Qu 2	Qu 3	Qu 4	Qu 5	Qu 6	Qu 7	Qu 8	Qu 9	Qu 10	Dependability
Fisher et al (2020)	Coping with psoriasis or hidradenitis suppurativa: A qualitative study	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	High
Gambles (2016)	A phenomenological study of the psoriasis patient receiving home phototherapy	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Moderate
Khoury et al (2013)	Body image altered by psoriasis: a study based on individual interviews and a model for body image	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Moderate
Ljosaa et al (2020)	The complex experience of psoriasis related skin pain: A qualitative study	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Moderate
Martin et al (2015)	The experience of pain and redness in patients with moderate to severe plaque psoriasis	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	No	Yes	Moderate
Meneguin et al (2020)	Quality of life of patients living with psoriasis: A qualitative study	Yes	Yes	Yes	Yes	Yes	Yes	Yes[1]	No	Yes	Unclear	Moderate
Narayanan et al (2015)	Disease burden and patient reported outcomes among patients with moderate to severe psoriasis: An ethnography study	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Moderate
Nelson et al (2017)	'New to me': Changing patient understanding of psoriasis and identifying mechanisms of change. The Pso Well patients materials mixed-methods study	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Moderate
Nelson et al (2013)	'On the surface': A qualitative study of GPs' and patients' perspectives on psoriasis	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Moderate

Author (year)	Title	Qu 1	Qu 2	Qu 3	Qu 4	Qu 5	Qu 6	Qu 7	Qu 8	Qu 9	Qu 10	Dependability
Newi et al (2022)	How important is subjective well-being for patients? A qualitative interview study of people with psoriasis	Yes	Yes	Yes	No	Yes	Yes	Yes	No$_2$	Yes	Yes	Low
Parkhouse (2019)	Experiences of stigma-stress among people living with psoriasis in the United States	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Moderate
Taliercio et al (2021)	The disruptiveness of itchiness from psoriasis: A qualitative study of the impact of a single symptom on quality of life	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	High
Yaghoubinia et al (2019)	Experiences of young girls with psoriasis: A descriptive phenomenological study	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Low
Zhong et al (2021)	Impact of moderate-to-severe psoriasis on quality of life in China: A qualitative study	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	High
George et al (2021)	Psoriasis: The skin I'm in. Development of a behaviour change tool to improve the care and lives of people with psoriasis	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	High
Khoury et al (2016)	Facing the dilemma of patient-centered psoriasis care: A qualitative study identifying patient needs in dermatological outpatient clinics	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Moderate
Fordham et al (2014)	The acceptability and usefulness of mindfulness-based cognitive therapy for people living with psoriasis: A qualitative study	Yes	Yes	Yes	Unclear	Unclear	No	No	No	No	Yes	Low
Kouwenhoven et al (2020)	Treatment goals in psoriasis from a patient perspective: a qualitative study	Yes	Yes	Yes	Yes	Yes	Unclear	No	Yes	Yes	Yes	Moderate

Author (year)	Title	Qu 1	Qu 2	Qu 3	Qu 4	Qu 5	Qu 6	Qu 7	Qu 8	Qu 9	Qu 10	Dependability
Bundy et al (2014)	Psoriasis – snapshots of the unspoken: Using novel methods to explore patients' personal models of psoriasis and the impact on well-being	Yes	Yes	Yes	Yes	Yes	Unclear	No	Yes	Yes	Yes	High

NOTES

Quality appraisal tool questions:

1) Congruity between the stated philosophical perspective and the research methodology.
2) Congruity between the research methodology and the research question or objectives.
3) Congruity between the research methodology and the methods used to collect data.
4) Congruity between the research methodology and the representation and analysis of data.
5) There is congruence between the research methodology and the interpretation of results.
6) Locating the researcher culturally or theoretically.
7) Influence of the researcher on the research, and vice-versa, is addressed.
8) Representation of participants and their voices.
9) Ethical approval by an appropriate body.
10) Relationship of conclusions to analysis, or interpretation of the data.

Subscript notes:

1. Individual participants are not clearly identified.
2. Minimal reporting of participant voices.

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Management of behavioural and psychological symptoms of dementia (BPSD): An integrative review

ABSTRACT

Background: Behavioural and psychological symptoms of dementia (BPSD) describes any agitation, aggression or escalated behaviours in a person with dementia. Recommended best practice for managing challenging BPSD is the use of nonpharmacological interventions in the first instance. Antipsychotic PRN medication is not recommended as a first-line intervention, and yet it is often used in this way.

Aim: In this study, we used an integrative review to investigate why it may be challenging for staff to use nonpharmacological interventions for managing BPSD, leading them to rely on antipsychotics.

Methods: The review process was based on Whittemore and Knafl's (2005) steps for conducting an integrative review. Articles that studied the use of PRN anti-psychotics, or non-pharmacological interventions, were accessed and analysed. Inclusion criteria were a focus on older adults, with a diagnosis of BPSD who were prescribed PRN anti-psychotic medication as well as non-pharmacological interventions and were hospitalised in aged residential care/acute settings. Excluded from the study were references to younger patients, those with dementia but not BPSD, and those living at home.

Results: Three themes emerged from the review: Low staff-to-patient ratios increased instances of problems with BPSD; numbers of staff with specialised training were low; and there was a need to educate staff further about the manifestation of BPSD and the implementation of person-centred care plans. Overall, use of care plans, focused on the individual, reduced use of PRN antipsychotics.

Conclusions: The management of BPSD is complicated by a mix of low staffing, and/or inadequate training opportunities, leading to increased risk for both the individual and possible staff burnout. The research has shown an increase in education/training reduces these risks when paired with implementation of non-pharmacological care plans.

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KEYWORDS

Behavioural and psychological symptoms of dementia, non-pharmacological interventions, behaviour management plans, aged residential care, acute psychotic older adult, nursing care

INTRODUCTION

Dementia is a term used to describe groups from more than 100 irreversible degenerative brain diseases with no cure. Each individual disease has its own symptoms; however, some are grouped together (Cloak & Al Khalili, 2022). The group that is the subject of this study is referred to as behavioural and psychological symptoms of dementia (BPSD); this describes any agitation, aggression, altered perception/thought content or escalated behaviours along with a diagnosis of dementia. Symptoms of BPSD can include disrupted thoughts, low mood/depression, altered perceptions or behaviours (such as agitation), psychosis, hallucinations, delusions and apathy (Dodd, et al., 2018). Each of the different symptoms is dependent on disease progression, and etiological factors, which manifest in biological, psychological and social ways (Byrne, et al., 2005). Of importance is the recognition that psychosis is no longer just related to schizophrenia. However, the profile of psychosis in dementia is significantly different from that seen in schizophrenia diagnosis (Leroi et al, 2003). As Zakrzewka-Sito and Kuczyńska (2021) point out, the reason psychosis is different in the elderly is that it is associated with dysregulation of the serotonergic system.

BPSD is commonly accompanied by a variety of difficult and sometimes challenging symptoms, including disturbed behaviour, thought, mood and perception, and poor impulse control (Buhagiar, et al., 2011). This results in health professionals or caregivers being challenged, and at times frustrated, when it comes to planning therapeutic interventions for their care. Consequently, when a patient with BPSD is labelled as aggressive, agitated and/or unmanageable, PRN antipsychotic medication is often administered without trying to implement nonpharmacological interventions such as redirection, or distraction. PRN antipsychotic medication is not recommended as a first-line intervention for managing challenging BPSD, and yet it is often used in this way. Overprescribing of PRN antipsychotics can result in over-sedation of patients, which creates greater risk of falls. According to Moniz-Cook et al (2001), although there is evidence to suggest that nonpharmacological interventions are best for individuals, using this as a first point of action for the treatment of BPSD is only occurring in limited areas of aged care. There is also the risk that personalised treatment plans and other nonpharmacological therapies will only work on occasion, as each patient presents differently and responds in different ways to treatment (Moniz-Cook et al). Due to the differences even within BPSD, one patient presenting with hallucinations/delusion will require completely different treatment from a patient presenting with agitation and sleep disturbance (Imtiaz et al, 2018).

This integrative review is a critique of research to determine the factors that make it challenging to use nonpharmacological interventions, thus leading to a reliance on PRN antipsychotics, in the care of individuals who have a diagnosis of dementia and present with BPSD.

Table 1. PICO

Population of interest	Older adults with dementia (45+ years) A diagnosis of dementia with behavioural and psychological symptoms of dementia (BPSD)
Phenomenon of interest (intervention)	Use of PRN and the influencing factors in BPSD Nonpharmocological approaches to BPSD
Context	People with dementia in aged residential care/ acute settings requiring PRN medication

Table 2. Study inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
• Older adults	• Adolescents, children, young adults
• Behaviour and psychological symptoms of dementia, BPSD • Behaviour management plans	• Behaviour plans • Dementia without BPSD • Dementia diagnosis living at home
• Acute care, aged residential care, ARC • Non-pharmacological interventions	
Date limits: 2009-2012, 2012-2022	1989-2009

METHOD

In 2005, Whittemore and Knafl developed the process of integrative review as a research methodology. It includes five stages: identify the problem of interest; search literature; evaluate literature; synthesise data; and finally, present data in a comprehensive and succinct way. An integrative review allows for a holistic approach by using various data sources for the research; in doing so, it enables a broader perspective of research that has been conducted on a specific topic (Whittemore & Knafl, 2005). Although this process may be structured in different ways, depending on the topic/review question and content, all integrative reviews are expected to follow a structured template (Melillo, 2020). Drawing on the principles of meta-analysis (Goldberg et al., 2022), a researcher creating an integrative review can synthesise data from multiple pieces of research, thus delivering a precise evaluation of the effectiveness of a single intervention (Conner, 2014).

The mnemonic PICO is a tool researchers can use to examine the phenomenon of interest; it is formulated as follows: population, intervention, comparison and outcomes (Cochrane Library, 2001). Using PICO ensures the data search remains focused and specific, which is important when completing the systematic portion of the review. The parameters for the search are detailed in Table 1 (above).

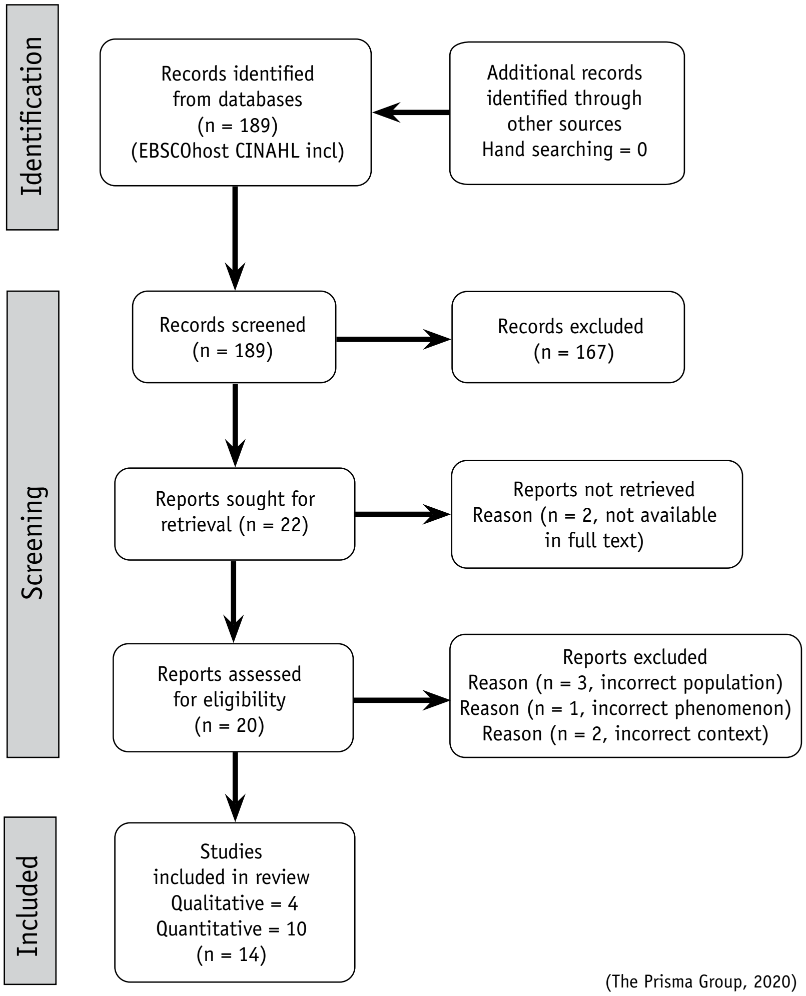
However, for this study, rather than trying to "compare" (as specified in the PICO framework), the idea of "context" was used instead, as comparisons would not address the research question and were only apparent in some of the included articles. Search terms included (and were limited to): "older adults", "behavioural and psychological symptoms of dementia", "BPSD", "behaviour management plans", "acute care" and "aged residential care". A 10-year date range was specified for articles to be accepted into the review. The only exception was the article by Crombie et al (2008), as its findings were particularly relevant to this review. The inclusion and exclusion criteria are summarised in Table 2 (above).

Using the specified search terms and inclusion/exclusion criteria, searches of databases revealed 189 potential articles for screening. The searches were recorded in a table, with the search strategy and study selection described using a Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) flow diagram (see right). This process resulted in 14 studies being selected for the review – four of them qualitative and 10 quantitative.

Data analysis is the essential process of an integrative review, synthesising diverse sources and facilitating better understanding of the issue being studied (Conner, 2014). For our analysis, each of the 14 articles was scrutinised and dissected to find its basic foundations, then evaluated and tabulated into structured form. In some literature, this process is called a "review matrix", which is described as a way of extracting data from the relevant published research (Garrard, 2017). Table 3 (below) summarises how each article was assessed using the Joanna Briggs Institute (JBI) (Joanna Briggs Institute, 2020)appraisal for qualitative research, and also assessed for the strength of the evidence in accordance with guidelines developed by Ackley et al (2008).

The Ackley guidelines enable each article to be assessed in terms of how of the study design minimises the impact

FIGURE 1. IDENTIFICATION OF STUDIES VIA DATABASES AND REGISTERS



(The Prisma Group, 2020)

Table 3. Level of evidence rating system

Level of evidence (LOE)	Description
Level I	Evidence from a systematic review or meta-analysis of all relevant randomised controlled trials (RCTs) or evidence-based clinical practice guidelines based on systematic reviews of RCTs or three or more RCTs of good quality that have similar results.
Level II	Evidence obtained from at least one well-designed RCT (eg large multi-site RCT).
Level III	Evidence obtained from well-designed controlled trials without randomisation (ie quasi-experimental).
Level IV	Evidence from well-designed case-control or cohort studies.
Level V	Evidence from systematic reviews of descriptive and qualitative studies (meta-synthesis).
Level VI	Evidence from a single descriptive or qualitative study.
Level VII	Evidence from the opinion of authorities and/or reports of expert committees.

Based on Ackley et al (2008)

Table 4. Study characteristics and key elements

STAFF SHORTAGE

Authors	Type of study	Level of evidence	Risk of bias score	Participants	Core elements	Outcomes
Backhouse et al, 2014	Postal study to determine the prevalence of antipsychotic use in care homes, explore which behaviours care home staff find difficult to manage and which non-pharmacological interventions are currently used within care homes.	VI	JBI Y = 6/9 U = 3/9	Facility managers of care homes with specialist dementia care in four counties of east England.	• 73% of dementia facilities utilise antipsychotics as a means of managing aggressive behaviour. • Facilities with more qualified staff had a higher use of antipsychotic prescriptions but not documented between PRN and regular. • Greater emphasis on implementation of person-centred care plans required. • The use of antipsychotic (as required) medication was based on the judgment of staff (qualified and unqualified). • Importance of qualified staff to make appropriate judgment on medication use.	Further education required for staff on both the use of antipsychotic medication and the proper implementation of individualised care plans.
Backhouse et al, 2016	Ethnographic to explore the use of nonpharmacological interventions used to manage BPSD in care homes.	IV	CASP Y = 8/10 U = 2/10	Sample included registered and nonregistered staff, from four separate care homes.	• Antipsychotic medication prescribed frequently in BPSD with minimal efficacy. NICE suggests medication as a last resort; instead, utilising person-centred care. • Organisational factors in care homes influence practice. • Daily activities not utilised as interventions, however should be.	More research required with further staff education on use of nonpharmacological interventions.
Manso-Calderón et al, 2020	Prospective study to explore whether the BEVASDE Assessment profile of BPSD differs between dementia types and the effects of medication on severity.	III	JBI Y = 5/9 N = 1/9 U = 3/9	806 patients exhibiting BPSD enrolled with outpatient clinics.	• Almost 75% of patients included received some type of psychotropic drug as a first-line response to BPSD. • BPSD increased carer stress/burden, increased chances of admission to institutions with severity dependant on subtype of diagnosis. Nonpharmacological interventions more effective in vascular dementia than Alzheimer's dementia.	Increased staffing required to implement nonpharmacological care plan interventions. Improved instances for nonpharmacological interventions.
Ozaki et al, 2017	Cross-sectional survey to examine the use of psychotropic drugs related to the prevalence, numbers of symptoms, severity and care burden in BPSD.	VI	JBI Y = 5/9 N = 4/9	Dementia patients treated with psychotropic medication exhibiting BPSD in specialised cognitive and behavioural unit for dementia and cognitive impairment.	• BPSD are often treated with psychotropic medications. Over-prescription remains common and an important issue to continue to discuss. • Facilities with more access to nonpharmacological interventions had less use for medication to manage BPSD. • Prescription of antipsychotics were more influenced by staff's perceptions of psychiatric conditions and co-severity of symptoms rather than the standardised clinical criteria. • Nonpharmacological treatments are seen as a promising way to address BPSD, however requires more research to do so.	Increased staffing to ensure safer 'staff to patient' ratio. Education on nonpharmacological interventions rather than medication to reduce over-prescribing/sedating as a management plan.
Richter et al, 2019	Cluster-randomised controlled trial to investigate if a person-centred care approach in reduction of BPSD which had been successful in the United Kingdom could be adapted to German conditions.	III	JBI Y = 7/9 N = 2/9	37 nursing homes in the east, west and north of Germany; all with a control group and intervention group.	• To duplicate successful person-centred care plans from the United Kingdom to Germany. Regular medication reviews were completed to ensure robust amount of data collected. • When duplicated, in the first three months the control group rather than the intervention group was found to have reduced antipsychotic use. • After 12-month follow-up, intervention group was found to have significant reduction in medication.	Low staffing hinders use of nonpharmacological intervention, as not enough time or appropriately trained staff. When increased staff and training was documented, nonpharmacological interventions were more successful.

Table 4. Study characteristics and key elements, continued

SKILL MIX

Authors	Type of study	Level of evidence	Risk of bias score	Participants	Core elements	Outcomes
Crombie et al, 2008	Survey to determine environment, policies, staffing, staff education/training, and behaviour management for staff caring for residents with BPSD.	IV	JBI Y = 6/9 N = 1/9 U = 2/9	Management staff in acute aged care facilities in rural regions and acute psychiatric wards in an urban area.	• 95% of patients in long-term acute care are diagnosed with dementia, with BPSD being a major cause of reduced quality of life, and carer stress. • Environment, behaviour management programmes and trained staff important. • Staff were found to have a lack of knowledge on disease progression/process, therefore unable to adequately manage inappropriate environment. • Reduced staff numbers negatively affected the use of nonpharmacological interventions.	Further education for staff required on BPSD and dementia disease progression as well as how to implement person-centred care plans.
Mallon et al, 2019	Cross-sectional survey to determine the views of care home staff in relation to experiencing and managing BPSD and if specialised training enhances person-centred care.	IV	JBI Y = 4/9 N = 5/9	54 dementia specialised long-term care homes.	• Guidelines for managing BPSD state patients should have comprehensive assessments completed on admission to establish factors influencing their symptoms. • Staff emphasised the importance of giving individuals time to understand their needs.	Staff agreeable to the implementation of person-centred care plans and using information gained from comprehensive assessments. Reduction in medication administration due to decreased BPSD symptoms.
Roe et al, 2020	Cross-sectional survey to explore the attitudes of direct-care staff in residential aged care when interacting with, and responding to, residents exhibiting BPSD.	IV	JBI Y = 5/9 N = 4/9	Caregivers (unregulated) and nurses working in aged residential facilities with BPSD; both registered and non-registered staff.	• 60% of dementia patients are placed in permanent care. • 80% of those diagnosed with dementia experience BPSD. • Routine administration of psychiatric medications, specifically antipsychotics or anti-anxiety agents, to treat BPSD is common practice in Australia and other western countries, with up to 78% of residents on some forms of psychotropic drugs. • Staff may need further education to be aware of potential risks of psychotropic medication and to be able to provide evidence-based care and appropriate medication administration.	Further education required for staff to increase use of person-centred care plans and reduce antipsychotic medication as a first response.
Saidlitz et al, 2016	Prospective study with systematic analysis to examine management of psycho-behavioural disorders in specialised units.	IV	JBI Y = 7/9 N = 2/9	General data was collected by reviewing patient files prior to staying in specialised cognitive behaviour units in hospital exhibiting BPSD and administered antipsychotic medication as a first response to management.	• More than half hospitalised patients receive psychotropic treatment during initial admission. • Staff tolerance towards behavioural diagnosis lower than those working in cognitive behaviour unit (CBU) teams. • Staff tolerance/patience was found to increase patient independence and decrease behaviours. • MDT collaboration along with nonpharmacological approach enables better care. • Inclusion of all disciplines within a hospital environment increased education about the individual, ensuring a holistic approach was taken.	Person-centred care is paramount in reduction of antipsychotic medication use. Further education for staff on BPSD increases staff tolerance, thus reducing difficult instances of behaviour.

Table 4. Study characteristics and key elements, continued

EDUCATION						
Authors	**Type of study**	**Level of evidence**	**Risk of bias score**	**Participants**	**Core elements**	**Outcomes**
Carnahan et al, 2017	Quasi-experimental longitudinal study to evaluate the effectiveness of specialised training programmes on BPSD with a focus on reduction of antipsychotic medication use.	III	JBI Y = 5/9 N = 1/9 U = 3/9	Residents (aged 65 years +) of 426 specialised dementia care units exhibiting BPSD.	• Pharmacotherapy options for behavioural and psychological symptoms of dementia include antipsychotics, anticonvulsants, antidepressants and anxiolytics. Olanzapine IMI utilised frequently as a first response to BPSD. • Increased incidence of sedation found with the use of the antipsychotic. • Little documented research on nonpharmacological interventions available within the facility.	Further education required for staff on adverse effects of using antipsychotics as a first response. Within the education, discussion on implementation of person-centred care plans to reduce symptoms, therefore reduce PRN use.
Duong et al, 2015	Retrospective observational study to examine the use of short-acting intramuscular olanzapine and the efficiency of reduced symptoms.	IV	CASP Y = 8/10	Staff caring for dementia inpatients 65 years and older prescribed intramuscular olanzapine for acute agitation in BPSD. Medical records were reviewed retrospectively.	• Specialised training for staff in programmes on BPSD and the risks of antipsychotic medication. • Focus on reduction of antipsychotic medication use as a first line of treatment in reduction of BPSD symptoms. Training associated with reduction in antipsychotic use for BPSD.	Specialised training in person-centred care plans required. Use of person-centred care plans required to reduce antipsychotic medication use.
Honda et al, 2016	Multimodal comprehensive care to assess the use of the Humanitude care model as a reduction to BPSD.	IV	CASP Y = 3/10 N = 4/10 U = 3/10	Vulnerable dementia patients exhibiting BPSD in acute care wards in hospital, cared for by one of four nurses with specialist knowledge in Humanitude care model.	• People with dementia are frequently admitted to the acute care hospital; BPSD results in poor care quality and provides barriers for staff interventions. • Four out of 40 nurses in a medical ward were trained in Humanitude methodology. Utilisation of this method showed a greater response from the residents, decreased symptoms.	The use of person-centred care has shown to reduce behaviours. Educating and increasing staff numbers is a large part of this implementation being successful.
Lertkratoke et al, 2021	Quasi-experimental, to determine the effects of Thai Integrated Care Program for Older Adults with Dementia (TICPD) and explore the difference in function of those with BPSD and caregiver burden before and after implementation.	III	JBI Y = 7/9 U = 2/9	Two hospitals in north-east Thailand, both specialising in dementia care, utilising a holistic approach, including nonpharmacological interventions. Two outpatient departments of hospitals focused on holistic care. Participants were over 60 years, diagnosed with dementia, exhibiting BPSD and had a family caregiver.	• Caregiver stress/burden high in dementia care facilities. • Case management important post-discharge for continuation of care. • Non-pharmacological interventions limited in community setting. • BPSD and caregiver burden increase chances of institutionalisation and hospitalisation. Care programmes effective, with patients exhibiting mild BPSD, however less effective with severe cases.	Further education and skill training for staff necessary for severe cases of BPSD. Reduced caregiver stress linked to increased education of staff.
Resnick et al, 2018	To objectively evaluate the effectiveness of person-centred care plans in reducing BPSD symptoms and use of antipsychotics.	II	JBI Y = 7/9 N = 2/9	Long-term aged-care facilities, 100+ beds, and allowed a registered staff member to work with the research team. Individuals with a diagnosis of BPSD and on one or more antipsychotic medications.	• Pathophysiological, psychological, and environmental mechanisms which underlie symptoms of BPSD. 90% of residents in care homes experience these symptoms which are seen as "unmet needs". • BPSD contributing factor to poor quality of life and increased cognitive then functional decline. Staff included changes to environment where appropriate (utilising gardens etc). • Time given to residents to allow for expression of needs. Care plans created using information gained about each individual.	Person-centred care plan linked to reduction in BPSD symptoms and antipsychotic use. Further education and training on care plans imperative to successful use and reduction of antipsychotic use.

of bias on results. A Level I study (systematic review of randomised control trials) is considered the strongest level of evidence. Based on their study designs, the 14 studies chosen for this review were rated as follows: Level II, n = 1; Level III, n= 4; Level IV, n = 7; Level V, n=0, Level VI, n = 2.

The review matrix is presented in Table 4 (see pages 44-46).

FINDINGS

Three themes emerged from the review. The first finding was that low staff-to-patient ratios increased instances of challenging BPSD. The second finding was that the numbers of staff with specialised training were low suggesting the need to educate staff about the progression of dementia and/or the manifestation of BPSD, as well as the implementation of person-centred care plans. Lastly, it was found that using person-centred care plans reduced instances of BPSD.

Low staff-to-patient ratio

Studies from the UK (Backhouse et al, 2014), Germany (Richter et al, 2019) and Thailand (Lertkratoke et al, 2021) suggest that with populations ageing and more people being diagnosed with dementia and BPSD, there is pressure on aged residential care (ARC) facilities, which are already under strain. According to the Australian Institute of Health and Welfare (2015), 60 per cent of those diagnosed with dementia will be placed in ARC at some stage during their disease process. This is a concern because there are not enough beds, the staff-to-patient ratio is low, and the number of individuals entering ARC at high-level needs has been increasing since 2008 (New Zealand Nurses Organisation, 2012). It is not just a matter of low staff numbers, but low numbers of qualified/higher trained staff that the research has highlighted as a concern. Without adequate staff numbers to facilitate basic care for their patients, there is even less of a chance they can take extra time to implement a personalised plan to manage BPSD, therefore reducing PRN antipsychotic use (Brodaty & Low, 2003). Crombie et al. (2008) support this finding, reporting that staff shortages and an inability to manage BPSD effectively is a difficult situation to remedy as dementia facilities rely on additional funding and specific reviews to enable any change.

Skill set and the use of antipsychotic medications

In addition to low staffing levels, another issue in relation to overuse of anti-psychotics is a lack of appropriately trained staff (Roe et al, 2020). Roe et al pointed out that insufficiently skilled staff are unaware of the potential risks of frequently using (or overusing) psychotropic medication. Or they may lack the ability to distinguish the severity of the episode of BPSD they are faced with. Instead, the staff stated the individual was just “being difficult” or “not behaving“. What drives use of psychotropic medication may be the quantity of residents presenting with BPSD rather than the severity of the BPSD. For example, Carnahan et al (2017) report the use of antipsychotic drugs increased when the area was staffed more by nurse aides than when there was a registered nurse (RN) supervising care.

In some cases, while staff were willing to trial nonpharmacological interventions, there were gaps between their theoretical knowledge and their ability to put it into practice (Backhouse et al, 2016). Further education would be beneficial to encourage use of techniques such as de-escalation or distraction, which staff may be unaware of. To ensure the effectiveness of care plans, it is important staff are aware of the reasons behind nonpharmacological interventions, which requires further training. The principal author of this study notes from practice experience that just implementing such a document and expecting the staff to understand the desired outcome is short-sighted. Education becomes an essential aspect of this care and gives staff/caregivers the confidence to use person-centred care to help reduce the use of antipsychotic PRN medication.

Further training for staff

Training about the adverse effects of antipsychotic medication is imperative to reduce its use and encourage more nonpharmacological interventions. Understanding these medications, their mechanisms of action and their adverse effects are important aspects of care. Limiting their use also reduces the risk of over-sedation and falls. If this is not understood first, it is hard to expect staff to implement nonpharmacological interventions which are more work and take longer to show results (Roe et al, 2020).

Backhouse et al (2014) used postal surveys to obtain information about the management of BPSD, and concluded further staff training was imperative. They highlighted nonpharmacological interventions which aimed to both improve the individual’s quality of life by reducing their symptoms, and to ensure staff were less burdened. An example of the importance of the training can be found in the work of Lertkratoke et al (2021), who conducted research comparing two hospitals which promoted holistic care in areas with high prevalence of BPSD. They reported that nonpharmacological interventions were only available where staff were specialised in managing BPSD. However such specialised units had only limited capacity, meaning only 25 per cent of patients had access to this level of care. Following a 12-week programme of specialised training for staff caring for patients with BPSD, as in Ozakia et al (2017), the intervention group presented with significantly less caregiver burden than those in the comparison group.

Staff with the skills required for individualised assessment and intervention are infrequently found in care homes where multiple approaches are required to manage the complexity of care (Backhouse et al, 2016).

DISCUSSION

Nonpharmacological interventions such as person-centred care are recommended as a first-line intervention. However, this is rarely the case in practice (NICE and SCIE, 2006). The use of antipsychotic medication to reduce BPSD is still required at times. However, according to Saidlitz et al (2016), antipsychotic medication should only be used in the most severe cases and never as a first response to management. The use of person-centred care (Backhouse et al, 2016; Backhouse et al, 2014)) where facilities had put in place programmes that focused on the individual’s likes and dislikes was shown to be effective if the conditions were right. Small groups of residents were selected and observed for a trial which found that specific care plans were more effective in reducing BPSD. These researchers found it was important to try use of such plans more than once: Backhouse et al (2016) reported staff were required to “stick with it” when residents were unwilling to participate, or it appeared it wasn’t working. However, these authors acknowledged this did require skill and time.

According to Goodwin & Mangan (1985), the key to a successful individualised care plan is for staff to rid their thoughts of a “we/they” relationship with residents, turning instead to an “us” relationship. This message is still relevant 30 years after publication and remains best practice in this context. Gooodwin & Mangan’s (1985) message is that those living in care homes need to be treated more as equals who play an important role in their own care. This requires staff to look at who that person was prior to diagnosis – their hobbies, job, and what they enjoyed or disliked; all important and relevant information for staff. There is a phrase used among health professionals, “short-term pain for long-term gain”, which relates directly to the amount of work required to create and carry out a care plan individualised to the person. Resnick et al (2018) conducted their study by looking at the implementation of person-centred care to observe the correlation between care plans and care-plan checklists and any reduction of the symptoms of dementia. They found there is evidence to suggest care plans and care plan checklists are valid when caring for those with BPSD; however there was no direct link to reducing specific behaviours such as impulsivity, agitation and wandering. Further mentorship and motivation from senior staff did encourage the use of person-centred care plans, which is now the utilised first-line approach in long-term care settings (Resnick et al).

This approach is best found with research conducted by Honda et al (2016), who used a multimodal care approach called Humanitude. This approach, of French origin, is designed specifically for vulnerable older adults, and focuses on their emotions, communication and perceptions. These researchers used Humanitude in an acute-care hospital setting to assess its effect on BPSD. When this approach was compared to conventional care, a reduction was found in exhibited BPSD symptoms. Humanitude emphasises human emotion, with gentle touch, eye contact and verbal communication used in all interactions with patients in the study. It was found that in cases where the patient’s care was more complex or the symptoms more severe, it took longer for this approach to work and required more patience from staff. The other important outcome they found was a reduction in polypharmacy, which led to a reduction in the use of antipsychotics. Saidlitz et al (2016) examined specialised cognitive behaviour units in France which were created as part of that country’s Alzheimer Plan. The approach of these units to person-centred care was a combination of physical activity, relaxation, sensory and cognitive stimulation, and reorientation. These researchers examined the management of psychosocial behaviours (which they consider BPSD to fall under), and the effect it has on symptoms and the use of PRN antipsychotics as the first approach to care. Saidlitz et al (2016) found that using this style of management brought about a significant reduction in behavioural symptoms, particularly disruption to other patient care. There was an improvement in successful nonpharmacological interventions, leading to a reduction in antipsychotic use to treat behavioural issues.

As identified in this review by researchers including Honda et al (2016), Resnick et al (2018), Richter et al (2019) and Saidlitz et al (2016), facilities which used a “human” or individual approach found a decrease in problems with BPSD. Approaching a complex case by observing the whole person (including their past) reduces the risk of distress. This, along with appropriate humanistic cues, such as leading the individual by the hand to a room, ensures that the person feels safe, and is more likely to produce a positive response. Looking the person in the eye when speaking to them and talking to them in a clear and concise manner, gives the individual a better chance of understanding what the staff member is asking of them. Helping the person complete tasks rather than doing things to them, or for them, is the most important point to remember.

The fact that PRN medication is used more frequently than intended when prescribed raises issues about caring for those who present with BPSD. Ozaki et al (2017) suggested that clinicians are reluctant to use approaches other than pharmacological for fear of exacerbating BPSD behaviour. This is sometimes found to be a way for the staff to cope with what they feel is unmanageable or inappropriate behaviour and less about what might be sustainable long term. Learning how to manage clients using humanistic approaches is a skill that can be adapted to each individual’s situation. Using antipsychotic medication as an intervention in these circumstances carries a high risk of sedation and closes off the potential for individual interpersonal responses that may have greater therapeutic benefit in the long term.

LIMITATIONS

Most of the research selected for this review was based in European countries, the United States or Australia. With only three articles based in Asian countries, there was a strong western perspective on managing people affected by BPSD. A limitation of the study is that culturally responsive approaches to care were not specifically identified in the findings of the included studies.

RECOMMENDATIONS

Nursing staff who have completed advanced education in management of complex care/BPSD, and antipsychotic medications and their uses, have a more comprehensive understanding of BPSD and the reasons behind it. These staff are then able to create care plans individualised to the patient which, as seen in the articles reviewed, has a positive effect when conducted correctly, thus encouraging nonpharmacological interventions. These specialised staff are able to role-model this care for fellow staff and provide them with advice and support.

- To ensure individualised care plans are created and used correctly, it is important staff are educated specifically on person-centred behaviour management.
- To encourage ongoing education, using a specialist dementia care nurse (such as a clinical nurse specialist) who provides regular training programmes will give staff the confidence to continue with care plans.

CONCLUSION

BPSD is complex and difficult to manage, complicated by a mix of low staffing, and/or inadequate training opportunities. As the research in this review shows, more training about BPSD and the risks of antipsychotic medication, paired with the use of nonpharmacological care plans, can reduce symptoms. These approaches can ultimately reduce the use of antipsychotic medication as a first response. Having staff in aged-care facilities with specialist knowledge benefits the entire institution. The reduction in BPSD has a ripple effect from the staff who care for these patients, to the management who don’t need to find alternative care or deal with burnt-out staff.

REFERENCES

Ackley, B., Swan, B., Ladwig, G., & Tucker, S. (2008). Finding and Evaluating Research in Practice. In B. Ackley, *Evidence-based nursing care guidelines: Medical-surgical interventions* (p. 7). Mosby Elsevier.

Australian Government. (2015). *Australia's welfare 2015 in brief*. Australian Institute of Health and Welfare.

Backhouse, T., Killet, A., Penhale, B., & Gray, R. (2016). The use of non-pharmacological interventions for dementia behaviours in care homes: findings from four in-depth, ethnographic case studies. *Age and Ageing,* 856-63. doi: 10.1093/ageing/afw136

Backhouse, T., Killet, A., Penhale, B., Burns, D., & Gray, R. (2014). Behavioural and psychological symptoms of dementia and their management in care homes within the East of England: a postal survey. *Ageing and Mental Health, 18*(2), 187-93. https://doi.org/10.1080/13607863.2013.819834

Brodaty, H., & Low, L.-F. (2003). Aggression in the elderly. *Journal of Clinical Psychiatry, 64*, 36-43. PMID: 12672263.

Buhagiar, K., Afzal, N., & Cosgrave, M. (2011). Behavioural and psychological symptoms of dementia in primary care: a survey of general practitioners in Ireland. *Mental Health in Family Medicine*, 227-234. PMCID: PMC3487602

Byrne, E., Robert, P., Verhey, F., Hurt, C., De Deyn, P., Nobili, F., & Vellas, B. (2005). Grouping for behavioral and psychological symptoms in dementia: Clinical and biological aspects. *European Psychiatry, 20*, 490-496. doi: 10.1016/j.eurpsy.2004.09.031.

Carnahan, R., Brown, G., Letuchy, E., Rubenstein, L., Gryzlak, B., Reist, J., Kelly, M., Schultze, S., Weckmanne, M., & Chrischilles, E. (2017). Impact of programs to reduce antipsychotic and anticholinergic use in nursing homes. *Alzheimer's & Dementia: Translational Research & Clinical Interventions, 3,* 553-561. doi: 10.1016/j.trci.2017.02.003

Cloak, N., & Al Khalili, Y. (2022). *Behavioral And Psychological Symptoms In Dementia*. StatPearls Publishing.

Cochrane Library. (2001). *Cochrane PICO search*. https://www.cochranelibrary.com/about/pico-search

Conner, B. (2014). Demystifying literature reviews. *American Nurse Today, 9*(1), 13-14.

Crombie, A., Snell, T., & Boyd, J. (2008). The ABC of managing behavioural and psychological symptoms of dementia. *Geriaction, 26*(2), 14-24.

Dodd, K., Watchman, K., Janicki, M., Coppus, A., Gaertner, C., Fortea, J., Santosi, F., Kelle, S., & Strydom, A. (2018). Consensus statement of the international summit on intellectual disability and dementia related to post-diagnostic support. *Aging & Mental Health, 22*(11), 1406-1415. https://doi.org/10.1080/13607863.2017.1373065

Duong, S., Yeung, K.-T., & Chang, F. (2015). Intramuscular olanzapine in the management of behavioral and psychological symptoms in hospitalized older adults: a retrospective descriptive study. *Journal of Aging Research.* https://doi.org/10.1155/2015/570410

Garrard, J. (2017). Review matrix folder: How to abstract the research literature. In J. Garrard, *Health sciences literature review made easy: The matrix method* (pp. 119-138). Jones & Bartlett Learning

Goldberg, J., Boyce, L., Soudant, C., & Godwin, K. (2022). Assessing journal author guidelines for systematic reviews and meta-analyses: Findings from an institutional sample. *Journal of Medical Library Association, 110*(1), 63-71. doi:10.5195/jmla.2022.1273

Goodwin, S., & Mangan, P. (1985). Cosmic nursing: do old people come from outer space? *Nursing Times, 81*(28), 52-53.

Honda, M. I., Ito, M., Ishikawa, S., Takebayashi, Y., & Tierney Jr, L. (2016). Reduction of behavioral psychological symptoms of dementia by multimodal comprehensive care for vulnerable geriatric patients in an acute care hospital: A case series. *Case Reports in Medicine.* https://doi.org/10.1155/2016/4813196

Imtiaz, D., Khan, A., & Seelye, A. (2018). A mobile multimedia reminiscence therapy application to reduce Behavioral and Psychological Symptoms in persons with Alzheimer's. *Journal of Healthcare Engineering,* 1-9. https://doi.org/10.1155/2018/1536316

Joanna Briggs Institute. (2020). *Critical appraisal checklist for qualitative research.*

Leroi, I., Voulgari, A., Breitner, J., & Lyketsos, C. G. (2003). The epidemiology of psychosis in dementia. *American Journal of Geriatric Psychiatry, 11*(1), 83-91. PMID: 12527543

Lertkratoke, S., Amnatsatsue, K., Kerdmongkol, P., & Nanthamongkolchai, S. (2021). Effectiveness of Thai integrated care program for older adults with dementia in the community: a quasi-experimental study. *Pacific Rim International Journal of Nursing Research, 25*(4), 510-524.

Mallon, C., Krska, J., & Gammie, S. (2019). Views and experiences of care home staff on managing behaviours that challenge in dementia: A national survey in England. *Aging & Mental Health, 23*(6), 698-705. https://doi.org/10.1080/13607863.2018.1452898

Manso-Calderon, R., Cacabelos-Perez, P., Sevillano-Garcia, M., Herrero-Prieto, M. E., & Gonzalez-Sarmiento, R. (2020). The impact of vascular burden on behavioural and psychological symptoms in older adults with dementia: The BEVASDE study. *Neurological Sciences, 41*, 165-174. https://doi.org/10.1007/s10072-019-04071-3

Melillo, K. (2020). Formulating Review Question. In C. E. Toronto & R. Remington, *A Step-By-Step Guide to Conducting an Integrative Review* (pp. 13-14). Springer International Publishing. https://doi.org/10.1007/978-3-030-37504-1_2 11

Moniz-Cook, E. W., Woods, R. T., & Richards, K. (2001). Functional analysis of challenging behavior in dementia: The role of superstition. *International Journal of Geriatric Psychiatry, 16*, 45-56. doi: 10.1002/1099-1166(200101)16:1<45::aid-gps270>3.0.co;2-f

New Zealand Nurses Organisation. (2012). *NZNO Research policies that can transform healthcare: Mandated nursing staff to resident ratios in aged care: Summary of evidence.* https://tinyurl.com/4xz38c6m

NICE and SCIE. (2006). *Dementia: supporting people with dementia and their carers in health and social care.* https://www.scie.org.uk/publications/misc/dementia/

Ozakia, T., Katsumata, Y., & Arai, A. (2017). The use of psychotropic drugs for behavioral and psychological symptoms of dementia among residents in long-term care facilities in Japan. *Aging & Mental Health, 21*(12), 1248-1255. http://dx.doi.org/10.1080/13607863.2016.1220922

Resnick, B., Galik, E., Kolanowski, A., Van Haitsma, K., Ellis, J., Behrens, L., Flanagan, N., & McDermott, C. (2018). Reliability and validity of the care plan checklist for evidence of person-centered approaches for behavioral and psychological symptoms associated with dementia. *Journal of the American Medical Directors Association, 19*, 613-618. https://doi.org/10.1016/j.jamda.2017.10.021

Richter, C., Berg, A., Langner, H., Meyer, G., Köpke, S., Balzer, K., Wolschon, E. M., Silies, K., Sönnichsen, A., Löscher, S., Haastert, B., Icks, A., Wolf, U., & Fleischer, S. (2019). Effect of person-centered care on antipsychotic drug use in nursing homes (EPCentCare): a cluster-randomised controlled trial. *Age and Ageing, 48*, 419-425. doi: 10.1093/ageing/afz016.

Roe, J. C., Coulson, S., Ockerby, C., & Hutchinson, A. M. (2020). Staff perceptions of caring for people exhibiting behavioural and psychological symptoms of dementia in residential aged care: A cross-sectional survey. *Australian Journal on Ageing, 39*, 237-243. doi: 10.1111/ajag.12734

Saidlitz, P., Sourdet, S., Voisin, T., & Vellas, B. (2016). Management of behavioural symptoms of dementia in a specialized unit care. *Psychogeriatrics, 17*, 81-88. doi:10.1111/psyg.12193

The Prisma Group. (2020, April 9). *Transparent reporting of systematic reviews and meta analyses.* http://www.prisma-statement.org

Whittemore, R. &. Knafl, K. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing, 52,* 546-553. doi: 10.1111/j.1365-2648.2005.03621.x.

Zakrzewska-Sito, A., & Kuczyńska, J. (2021). Searching for new drugs for the treatment of dementia-related psychosis. *Postepy psychiatrii neurologii, 30*(4), 270-277. doi: 10.5114/ppn.2021.111942.

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Improving nursing oral care practice for care-dependent older adults through interprofessional collaboration: a study protocol

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ABSTRACT

Background: Oral care is a fundamental part of nursing care, especially for care-dependent older adults, yet it remains one of the most neglected nursing interventions. This is largely due to the lack of standard nursing oral care protocols, effective training and awareness of the benefits for older adults.

Aim: The aim of this research will be to establish evidence-based oral care guidelines, using interprofessional collaboration and education, with the aim of improving nursing oral care practice. We also plan to pilot these guidelines with community nursing staff to determine their effectiveness and acceptability.

Method: The proposed research will use mixed methods and participatory action with co-design, underpinned by interprofessional collaboration and education, to develop evidence-based nursing oral care guidelines, training modules and supporting resources, and to evaluate effectiveness among community nursing staff.

Conclusion: The oral care guidelines, training resources and evaluation approaches we will co-develop will enable community nursing staff to develop their own, locally-approved evidence-based nursing oral health-care protocols. Thus, this study will be a stepping stone in the promotion of nurse-led oral care and normalising of sustainable oral care practice, with the goal of promoting older adults' oral health and overall health and wellbeing.

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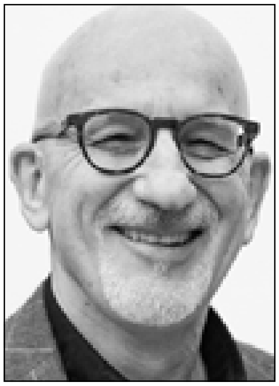

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KEYWORDS

Oral care, nursing, care-dependent, older adults, protocols, interprofessional collaboration and education

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INTRODUCTION

Little is known about oral nursing care practice which supports care-dependent older adults' oral health, especially those ageing in their own homes, owing to a lack of interprofessional collaboration, and nursing oral care guidelines. The lack of nursing oral care for care-dependent older adults is an ongoing problem in aged care. This study protocol will guide the establishment and implementation of a co-developed set of guidelines, training modules and resources, and evaluation approaches based on IPC/IPE (interprofessional collaboration and education) that will provide on-site, hands-on oral health training and support for nursing oral care practice.

This paper presents a research protocol for a study that aims to:

(i) develop a guideline for conducting a nurse-led oral care assessment and developing a support or care plan for care-dependent older adults, and develop associated training and other resources to support the guideline's implementation, utilising interprofessional collaboration and education, and co-design; and

(ii) improve nurses' knowledge, confidence and self-efficacy in oral nursing care, through the guideline and training.

The study aims to answer the following research questions:

(i) whether an oral care guideline can improve nursing oral practice by enhancing knowledge and confidence; and

(ii) whether an oral care guideline can facilitate the normalisation of daily nursing oral care practice.

BACKGROUND

Oral care is a fundamental part of nursing practice (Aagaard et al, 2020; Gibney et al, 2019; Hatchett, 2021; Jablonski et al, 2018; Oda, 2017). Nursing oral care involves oral health education and promotion, supporting or performing oral hygiene procedures, assessing patients for oral diseases and disease risk, and treatment of diseases of the oral mucosa, lips, teeth, gums, and tongue (Kilkenny, 2019). The aim of oral care is to help patients maintain a comfortable and clean mouth and maintain oral functions, including eating, speaking, and smiling (Maruoka et al, 2022).

Oral care is especially important for care-dependent older adults – those being supported to live in the community or those who live in aged residential care (ARC) facilities (Hatchett, 2021; Jablonski et al, 2018). Their complex and high health-care needs place them at substantial risk of oral disease, oral deconditioning and sub-optimal oral health, more so than their independent peers. Many care-dependent older adults have difficulty accessing oral health care services owing to the high cost of dental treatment, and physical and cognitive challenges. In many developed countries, including New Zealand, care-dependent older adults' routine dental care is generally not publicly-funded, subsidised or provided at their place of residence (Schluter, 2021; Smith, 2010).

Nurses have a key role in maintaining good oral hygiene and function among the care-dependent older adults they care for. Nursing oral care can improve oral health-related quality of life, and reduce the risk of oral disease and incidence of aspiration pneumonia and deconditioning, along with subsequent hospital admissions (Oda et al, 2021). In residential settings, nurses play a large part in determining the nature of the support or care that care-dependent older people receive. The support or care plans nurses develop, and that are subsequently implemented by support or care workers, are typically informed by clinical and social information gathered from a range of sources.

Despite its importance, oral care remains one of the most neglected nursing interventions, with care-dependent older adults unlikely to regularly receive basic nursing oral care at their place of residence (Gibney et al, 2019; Schluter et al, 2021; Thompson et al, 2019). Their oral health is rarely assessed as part of the support or care planning process. Consequently, nursing oral care directives seldom feature in older adults' support or care plans. This gap is largely a consequence of a lack of standard nursing oral care guidelines, training and skills; a lack of awareness among nurses of the benefits of nursing oral care for care-dependent older adults; and a lack of formal oral care policies and procedures in community health-care support and ARC systems (Gibney et al, 2019; Jablonski et al, 2018; Woon, 2020). Moreover, there is little research on nurse-led oral care assessments of care-dependent older adults (Manchery, et al, 2020), especially in New Zealand, to inform change.

Providing oral nursing care for care-dependent older people in their place of residence, guided by a set of guidelines, and as a regular feature of assessment and planning systems, would prevent oral disease progression and its sequelae. It would also provide a process for referral to specialist care when required. In turn, these actions would improve older people's overall health and wellbeing, and reduce the subsequent burdens on them, their families, whānau and carers, and the health system.

International guidelines recommend establishing standardised oral care guidelines for care-dependent older adults (NICE, 2016; SA Health, 2008; Zimmerman et al, 2020). The guidelines should be person-centred, evidence-based and delivered by a multi-disciplinary team that includes nurses. The purpose of the guidelines is to improve oral hygiene, prevent oral disease and aspiration pneumonia, enhance dysphagia rehabilitation, and improve overall quality of life (Maeda & Akagi, 2014; Oda, 2017; Quinn et al, 2014; Woon, 2020). Evidence demonstrates person-centred care is critical in the provision of nursing oral care (Jablonski et al, 2018; Zimmerman et al, 2020). For nurses, oral care guidelines need to be relevant to nursing practice, and achievable within nurses' capacity and capability. Three key factors for improving nursing oral care practice are: interprofessional collaboration and education, onsite nursing oral care training, and integration of contextual knowledge and competencies of all stakeholders in oral care provision (Aagaard et al, 2020; Keboa et al, 2019; Lewis et al, 2019; Niesten et al, 2020). Interprofessional collaboration and education helps overcome some of the barriers to nursing oral care by minimising disciplinary silos and hierarchical power dynamics that can occur in an interdisciplinary team (Brocklehurst et al, 2021; Niesten et al, 2020), improving nurses' oral care knowledge and practice skills, and enhancing their capacity to successfully deliver oral care.

METHOD

This study is a key component of a broad programme of research projects that are investigating how to improve the oral health-related quality of life and wellbeing of care-dependent older New Zealanders, and in turn contribute to their overall health and wellbeing. The programme of research aims to:

(i) raise oral health knowledge, and skill and confidence in providing preventive oral health care among staff, and clients or residents, and their family and whānau, and

(ii) determine feasible, acceptable and sustainable preventive oral health care policies and procedures in supported care and ARC facilities to ensure an acceptable standard of oral health and wellbeing among clients and residents.

Ultimately, the research programme's goal is for preventive oral health care policies and procedures to be embedded within community-based health-care support and ARC in New Zealand. This paper presents the research protocol for the nurse-led assessment part of the research programme.

In late 2020, a collaboration was formed among researchers from the University of Auckland's School of Nursing and Public Health, the Department of Public Health at the University of Otago, Wellington, and the Faculty of Dentistry at the University of Otago. The interprofessional research team comprises a registered nurse (KO), two oral health therapists (SM and RH), and dentists and oral health academics (NNB, MS, SB, CAF, WMT). Members of the research team had established prior collaborative relationships with a leading community health-care support provider and an ARC provider; both providers sought to collaborate further with the research team on this study. The research team will work with staff and clients from the community provider, and two ARC facilities (one urban, one provincial), in the lower half of the North Island of New Zealand.

Study design

This study will use a mixed-methods approach. To enhance the active participation of all stakeholders, it uses participatory action research with co-design. Co-design is an approach to working with people that enables the connection of ideas, skills and resources to experiment with new ideas and strategies for research (Zamenopoulos & Alexiou, 2018). To clarify the roles of all stakeholders, including individual researchers within the team, systems mapping (Niesten et al, 2020) was undertaken to navigate the project with all stakeholders. The system map (see Figure 1, p53) illustrates the roles at the policy development (macro), organisational-interprofessional (meso), and individual-clinical (micro) hierarchical levels with the aspiration of upwards feedback to policymakers.

The study comprises two stages:

(I) the development of a nurse-led oral care assessment and planning guideline, and

(II) the development and delivery of nurse and support/care worker oral care and assessment training.

Both stages include measures to evaluate them for effectiveness and acceptability.

Participant recruitment

Inclusion criteria

Those eligible to participate in this study include: nurses and support/care workers who plan and support/provide health care for clients/residents; clinical or training managers, employed by either of the provider collaborators; and clients/residents of the provider collaborator organisations.

Exclusion criteria

Locum nursing staff will be excluded.

Participants will be recruited purposively. The study will be introduced to the providers' staff at a time convenient to the organisations' management teams. Eligible staff interested in participating will advise their managers and will be contacted by the research team to provide them with more information and gain consent. All meetings will be made in arrangement with participants and management and held at times and locations convenient to them. Up to eight nurses (four from the community provider and four from the ARC providers) will be recruited.

Stage I: Development of nursing oral care guidelines

Informed by a review of the current literature and recommendations of leading health organisations, the interprofessional team will develop an initial draft of a person-centred, oral health-care assessment and planning tool for use by nurses. The tool will form the basis of the guidelines for nurses to conduct oral care assessments and develop support/care planning. It is anticipated that by using the oral care nursing guidelines, nurses will be able to identify clients' or residents' clinical oral health-care needs ("normative needs") and their oral health-care preferences ("felt needs"). Subsequently the nurses will be able to develop individualised oral care recommendations for inclusion in clients' or residents' overall support or care plans (for implementation by care/support workers), and regularly monitor clients' or residents' oral health (Mc et al, 2022).

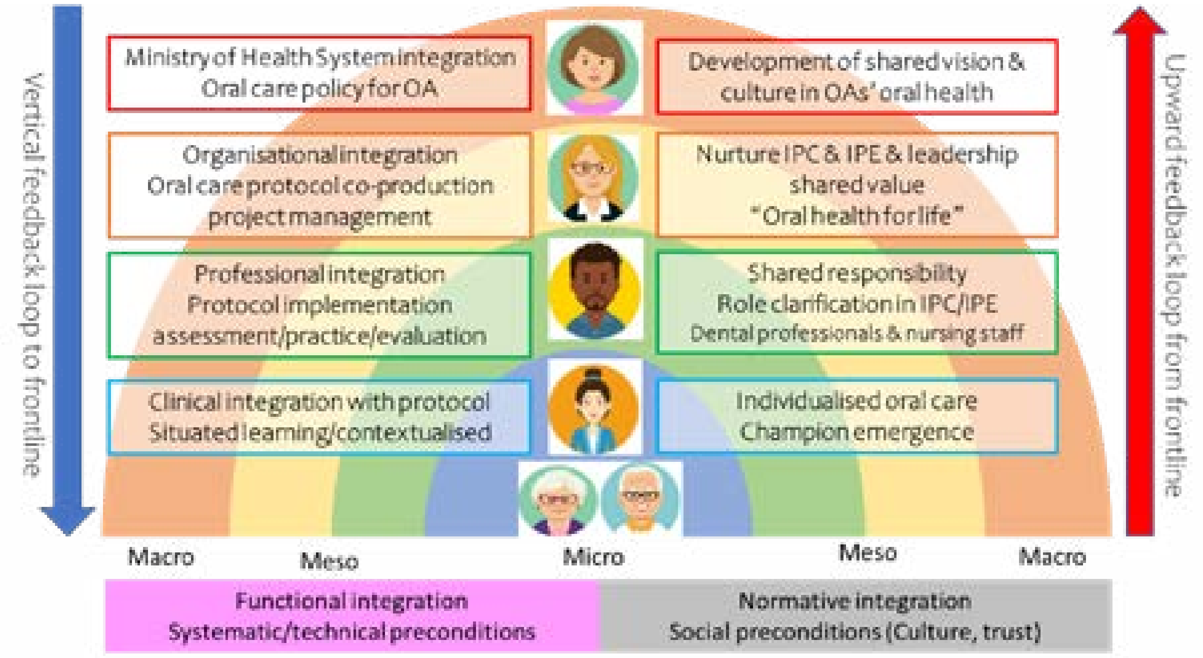
Figure 1:

The tool is informed by the Oral Health Assessment Tool (OHAT) developed by Chalmers et al (2005). OHAT is a validated tool originally designed for use by non-oral health professionals to assess the oral health of older adults with dementia. The assessment comprises eight components: lips, tongue, oral mucosa, saliva, teeth, dentures, oral cleanliness and pain. During the study's formative stages, the research team identified gaps in the OHAT, primarily the absence of an assessment of felt needs. The tool also lacked assessment accuracy, and included minimal individualised oral care planning, minimal capacity to ensure its implementation and measure its effectiveness, and no mechanism for referral to health professionals (Chalmers et al, 2005; Jablonski et al, 2018). The amended tool will likely include mechanisms to monitor changes in clients' oral health over time, and to enable referral pathways and person-centred care.

To support the tool, information resources will be developed. They will include referral pathways to dental services (in the form of flowcharts), a list of dental services available in the region, information on how to apply for publicly-available financial assistance, and infographics on the care of natural teeth and dentures, and approaches for delivering dry mouth care. In addition to use by nurses, the resources (with exception of the referral pathway) will also be intended for use by clients/residents, family and whānau, and care/support workers.

Stage II: Development and delivery of oral care and assessment training

To support the guideline and its application in nursing practice, an initial draft of an accompanying training module for nurses will be developed by the research team. Informed by international guidelines, existing training programmes and the scientific literature, the module will comprise two theoretical, didactic sessions. The first session will inform participants of the importance of oral health and oral health care, and specific information on the care for care-dependent older adults will be included. This session is intended for nurses, other clinical staff (such as clinical managers and trainers) and support/care workers, and will be no more than 90 minutes in duration, including time for questions and discussion. Information resources will be distributed among participants at this session.

The development of the training modules and the accompanying resources will be based on the principles of participatory action research and co-design. Participatory action research with co-design is suitable for community-based nursing oral care quality projects, as nursing staff are practising individualised care in complex home-based environments by sharing power with vulnerable older adults (Stark, 2022). Thus, the researchers and participants are interdependent, and the researchers are aware of their role as facilitators to bring change in practice. This helps to eliminate professional jargon, cuts across discipline silos, connects people, and promotes participation to address a common research goal in a meaningful way for participants. Before the resources are disseminated to the study participants, feedback will be sought from a range of people with knowledge of the care of care-dependent older adults, such as older adults, those working in caregiver roles, oral health professionals, nurse educators and nurses, to ensure that the use of language, the amount and level of information, the visual design and the presentation style are appropriate. Following initial development and prior to delivery, the tool, and the content and delivery plan for the training sessions, will then be shared and discussed with the management teams from both collaborating providers. The research team will gather their feedback on the likely acceptability and feasibility of the intended content and delivery to their nursing staff, and alignment with the organisations' usual training practices and procedures. All material will be amended in accordance with the feedback.

The second training session is intended for nurses and will provide information specifically on oral health-care assessment and planning, and the use of the tool. In this session, the participants will receive practical, hands-on training on conducting oral health assessments and subsequently developing support or care plans, with the support of the team's oral health practitioners. Assessments will initially be conducted in-class with research team members acting as "clients/residents". This will be followed by in-field sessions with clients/residents (that is, in their place of residence), with the team's oral health practitioners in attendance to support the participating nurses. At the conclusion of the in-class session, the participating nurses will be asked to identify and approach clients/residents who they think would be interested in participating in a research project about oral health. They will then describe the study to those clients or residents and gauge their interest in participating, and provide study information sheets and consent forms. The nurses will seek permission from interested clients or residents for their contact details to be passed onto the study team to arrange consent and provide further information. Up to 10 clients or residents will be recruited. Times convenient to consenting clients/residents and nurses for the in-field assessments will be arranged. Following their assessment, the participating clients/residents will be interviewed to gather their views on having their oral health assessed and included in their support/care plan, and suggestions for improvement.

Evaluation

Data collection and analysis

To evaluate the efficacy of the training modules and assessment sessions, the research team will administer questionnaires electronically (Qualtrics) before and after the training sessions. The questionnaires will gather information so that changes in in participants' knowledge, attitude, and confidence in oral care practice can be measured. The questionnaire will comprise 37 items, informed by previous studies (Edwards et al, 2021; Frenkel et al, 2002; Haresaku et al, 2020; Wretman et al, 2020). The knowledge section will comprise 19 items on oral health, seeking "yes/no/don't know" responses; there will also be 13 confidence and self-efficacy items using a 5-point Likert scale; and five items on the usability of the OHAT scale, also seeking Likert responses. (See Appendix 1, p56-57.) Data will be analysed descriptively using *t*-test and Pearson's correlation test by SPSS version 27.

At the conclusion of the training sessions, two focus groups (one from each of the provider collaborators) will be conducted with the participating nurses (up to eight). Guided by a semi-structured interview schedule, the focus group discussion will gather the nurses' feedback on the relevance and delivery of the training module, the acceptability of undertaking an oral care assessment on clients/residents and the feasibility of the tool and its incorporation into their organisations' existing care and care-planning systems. The nurses will also be asked for their suggestions on improvements in the training and the tool. Qualitative data will be analysed thematically to identify oral care barriers and facilitators, and recommendations will be developed for improving the visibility of oral care for nursing staff and clients.

The appropriate level of ethical approval will be sought before data collection starts.

DISCUSSION

Nursing oral care for care-dependent older adults is little practised, largely owing to a lack of training, guidelines and awareness of its importance for older adults, their families and carers, and the health system. There is also a lack of evidence to inform action to address this issue, particularly in New Zealand. The research protocol presented in this paper describes a study that aims to initiate changes in nursing practice, so as to better support care-dependent older adults' health and wellbeing. Through interprofessional collaboration and education, involving nurses and oral health professionals, and a co-design approach, the study aims to develop evidence-based nursing oral care guidelines, and supporting training modules and resources. These will then be evaluated for feasibility and acceptability among nurses and care-dependent older adults they care for. The approaches used in this study are expected to result in a more practical, equitable and sustainable way to meet the oral care needs of care-dependent older adults than through a conventional hierarchical system (Brocklehurst et al, 2021).

The interprofessional collaboration and education will create an opportunity to exchange knowledge and expertise between nursing and oral health-care professionals, and to co-produce clinical knowledge for the delivery of oral nursing care for care-dependent older adults (Buck et al, 2021; Cole, 2020). For example, nursing staff learning from oral health professionals will likely enhance their clinical assessment skills so they can identify the oral conditions that can trigger deconditioning. Oral health is typically isolated from other aspects of health care practice. This study will allow oral-health professionals to learn from nursing staff about gerontological nursing practice and how best to integrate oral care into it (Keboa et al, 2019). Moreover, the onsite support of nursing oral care practice by oral health professionals will likely generate the contextual knowledge required to address clients' daily oral care needs and oral care provision (Aagaard et al, 2020). Consequently, nursing oral care training based on interprofessional collaboration and education will likely be a key factor in ensuring nursing oral care becomes a core competency in gerontological nursing.

At a local organisational level, interprofessional collaboration and education will likely allow for the implementation of train-the-trainer approaches to facilitate sustainable in-house training of nursing and support worker staff (Buck et al, 2021; Truant et al, 2017). Train-the-trainer approaches, based on interprofessional collaboration and education, can enhance leadership among nursing staff and increase the capacity and confidence of nursing oral care assessments. Upward feedback on the barriers and facilitators for oral care provision from frontline nursing staff to decision and policymakers at all organisational levels is an important component of achieving effective changes to oral health care policy for care-dependent older adults (Aagaard et al, 2020; Niesten et al, 2020). Ultimately, the aspiration is to establish a bidirectional feedback system that will enable the provision of ongoing support for nursing staff to deliver oral nursing care for care-dependent older adults in a way that is sustainable and normalised into their overall care practice (see Figure 1).

This study will be one of the first to address nursing oral care practice of care-dependent older adults in the community and to use interprofessional collaboration and education to do so. The guidelines that will be developed will be based on evidence, and international guidelines and recommendations, and the processes developed will be informed by "real-world" information. Although care assessment and planning processes may differ among providers, the tools, resources and processes developed in this study are likely to be useful for other providers, or to be amended to meet their specific needs and align with their processes.

A range of health disciplines have a role in providing comprehensive oral health care for older adults. While this study's interprofessional collaboration team will provide varying perspectives on, and understanding of, oral health care for care-dependent older adults, the absence of other health professionals, such as dietitians and speech-language therapists, may be a limitation. Nevertheless, the team intends to develop a local and relevant oral nursing care guideline and training module, that includes an assessment of felt needs, and extends and contemporises the OHAT, ensuring a comprehensive approach to care-dependent older adults' oral health care. We think the guidelines and training module will likely be suitable for use with ARC residents, providing consistency in oral health-care assessment and planning across the levels of aged care (Takeda et al, 2020).

CONCLUSIONS

This study protocol outlines a critical step towards improving nursing knowledge, practice and awareness of the importance of oral care for care-dependent older adults. The study will do so through co-development of an evidence-based set of guidelines, training resources and evaluation approaches using interprofessional collaboration and education. By helping to break down health-care delivery siloes and hierarchies, the outcomes of this study will likely enhance nursing leadership, and lead to sustainable oral health-care for our older population.

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REFERENCES

Aagaard, K., Meléndez-Torres, G. J., & Overgaard, C. (2020). Improving oral health in nursing home residents: A process evaluation of a shared oral care intervention. *Journal of Clinical Nursing, 29*(17/18), 3392-3402. doi: 10.1111/jocn.15373

Brocklehurst, P. R., Baker, S. R., & Langley, J. (2021). Context and the evidence-based paradigm: The potential for participatory research and systems thinking in oral health. *Community Dentistry and Oral Epidemiology, 49*(1), 1-9. https://doi.org/10.1111/cdoe.12570

Buck, H. G., Boltz, M., Madrigal, C., Eshraghi, K., & Kolanowski, A. M. (2021). Using Appreciative Inquiry to Optimize a Person-Centered Care Training Program for Clinical Champions in Rural Critical Access Hospitals. *Journal of Gerontological Nursing, 47*(8), 7-12. doi: 10.3928/00989134-20210706-01

Chalmers, J. M., King, P. L., Spencer, A. J., Wright, F. A., & Carter, K. D. (2005). The oral health assessment tool – validity and reliability. *Australian Dental Journal, 50*(3), 191-199. https://doi.org/10.1111/j.1834-7819.2005.tb00360.x

Cole, E. (2020). A nurse champion of oral care in community services. *Primary Health Care, 30*(6), 13-15.

Edwards, C. B., Randall, C. L., & McNeil, D. W. (2021). Development and Validation of the Oral Health Values Scale. *Community Dentistry and Oral Epidemiology, 49*(5), 454-463. doi: 10.1111/cdoe.12621

Frenkel, H., Harvey, I., & Needs, K. (2002). Oral health care education and its effect on caregivers' knowledge and attitudes: a randomised controlled trial. *Community Dentistry and Oral Epidemiology, 30*(2), 91-100. doi: 10.1034/j.1600-0528.2002.300202.x

Gibney, J. M., Wright, F. A., D'Souza, M., & Naganathan, V. (2019). Improving the oral health of older people in hospital. *Australasian Journal on Ageing, 38*(1), 33-38. doi: 10.1111/ajag.12588

Haresaku, S., Miyoshi, M., Kubota, K., Aoki, H., Kajiwara, E., Monji, M., & Naito, T. (2020). Effect of interprofessional education on oral assessment performance of nursing students. *Clinical and Experimental Dental Research, 6*(1), 51-58. doi: 10.1002/cre2.248

Hatchett, R. (2021, Sept 20). How to undertake effective mouth care and oral assessments. *Nursing Standard*. doi: 10.7748/ns.2021.e11756

Jablonski, R. A., Kolanowski, A. M., Azuero, A., Winstead, V., Jones-Townsend, C., & Geisinger, M. L. (2018). Randomised clinical trial: Efficacy of strategies to provide oral hygiene activities to nursing home residents with dementia who resist mouth care. *Gerodontology, 35*(4), 365-375. https://doi.org/10.1111/ger.12357

Keboa, M., Beaudin, A., Cyr, J., Decoste, J., Power, F., Hovey, R., LaFrance, L., Ouellet, D., Wiseman, M., & Macdonald, M. E. (2019). Dentistry and nursing working together to improve oral health care in a long-term care facility. *Geriatric Nursing, 40*(2), 197-204. doi: 10.1016/j.gerinurse.2018.10.002

Kilkenny, N. (2019). Oral care in adults. *British Journal of Nursing, 28*(16), 1054-1055. doi: 10.12968/bjon.2019.28.16.1054

Lewis, A., Harvey, G., Hogan, M., & Kitson, A. (2019). Can oral healthcare for older people be embedded into routine community aged care practice? A realist evaluation using normalisation process theory. *International Journal of Nursing Studies, 94,* 32-41. doi: 10.1016/j.ijnurstu.2018.12.016

Maeda, K., & Akagi, J. (2014). Oral care may reduce pneumonia in the tube-fed elderly: a preliminary study. *Dysphagia, 29*(5), 616-621. doi: 10.1007/

s00455-014-9553-6

Manchery, N., Subbiah, G. K., Nagappan, N., & Premnath, P. (2020). Are oral health education for carers effective in the oral hygiene management of elderly with dementia? A systematic review. *Dental Research Journal (Isfahan), 17*(1), 1-9. https://pubmed.ncbi.nlm.nih.gov/32055287/

Maruoka, Y., Michiwaki, Y., Sekiya, H., Kurasawa, Y., & Natsume, N. (2022). What does oral care mean to society? *Bioscience Trends, 16*(1), 7-19. doi: 10.5582/bst.2022.01046

Mc, G. C., Suen, R. P., Mc, K. G., Moore, C., & Wong, M. C. (2022). Oral Health and Successful Ageing – The PROS and dPROS: A Scoping Review. *Journal of Evidence Based Dental Practice, 22*(3), 101714. doi: 10.1016/j.jebdp.2022.101714

National Institute for Health and Care Excellence (NICE). (2016). *Oral health for adults in care homes (NG48)*. https://www.nice.org.uk/guidance/ng48

Niesten, D., Gerritsen, A. E., & Leve, V. (2020). Barriers and facilitators to integrate oral health care for older adults in general (basic) care in East Netherlands. Part 1: Normative integration. *Gerodontology, 38*(2), 154-165. doi: 10.1111/ger.12507

Oda, K. (2017). Oral health vital for hospitalised elderly: ensuring the elderly receive oral care while in hospital can play an important part in preventing functional decline. *Kai Tiaki New Zealand, 23*(10), 14-17.

Oda, K., Montayre, J., Parsons, J., & Boyd, M. (2021). Oral Care in Hospital Settings: Breaking the Vicious Circle of Older Adult Deconditioning. *Journal of Gerontological Nursing, 47*(6), 7-12. doi: 10.3928/00989134-20210507-01

Quinn, B., Baker, D. L., Cohen, S., Stewart, J. L., Lima, C. A., & Parise, C. (2014). Basic nursing care to prevent nonventilator hospital-acquired pneumonia. *Journal of Nursing Scholarship, 46*(1), 11-19. doi: 10.1111/jnu.12050

SA Health. (2008). *Better Oral Health in Residential Care: Professional Portfolio.* Government of South Australia.

Schluter, P. J., Askew, D. A., McKelvey, V. A., Jamieson, H. A., & Lee, M. (2021). Oral Health Among Older Adults With Complex Needs Living in the Community and in Aged Residential Care Facilities within New Zealand. *Journal of the American Medical Directors Association, 22*(6), 1177-1183. doi: 10.1016/j.jamda.2020.06.041

Smith, M. B. (2010). Oral health and well-being of older adults in residential care facilities: issues for public health policy. *New Zealand Dental Journal, 106*(2), 67-73. https://pubmed.ncbi.nlm.nih.gov/20608311/

Stark, P., McKenna, G., Wilson, C. B., Tsakos, G., Brocklehurst, P., Lappin, C., Quinn, B., & Mitchell, G. (2022). Interventions supporting community nurses in the provision of oral healthcare to people living at home: a scoping review. *BMC Nursing, 21*(1), 269. doi:10.1186/s12912-022-01051-5

Thompson, L., Jiang, T., Savageau, J. A., Silk, H., & Riedy, C. A. (2019). An Assessment of Oral Health Training Among Geriatric Fellowship Programs: A National Survey. *Journal of the American Geriatrics Society, 67*(5), 1079-1084. https://doi.org/10.1111/jgs.15755

Truant, T. L., Green, E., de Calvo, L. E. A., McCarthy, S. M., MacDonald, D., Patel, K., Stewart, J., Brunelli, M., Cullen, C., Estrada de Ellis, S., Nunes, L., & Salles, P. (2017). Enhancing Nurses' Oral Therapy Practice in 4 Latin American Countries: A Collaborative and Participatory Approach. *Cancer Nursing, 40*(6), E49-E59. https://doi.org/10.1097/NCC.0000000000000434

Woon, C. (2020). Improving oral care for hospitalised patients: choosing appropriate products. *British Journal of Nursing, 29*(9), 520-525. https://doi.org/10.12968/bjon.2020.29.9.520

Wretman, C. J., Zimmerman, S., Ward, K., & Sloane, P. D. (2020). Measuring Self-Efficacy and Attitudes for Providing Mouth Care in Nursing Homes. *Journal of the American Medical Directors Association, 21*(9), 1316-1321. https://doi.org/10.1016/j.jamda.2020.02.007

Zamenopoulos, T., & Alexiou, K. (2018). *Co-design as collaborative research*. Bristol University/AHRC Connected Communities Programme.

Zimmerman, S., Sloane, P. D., Ward, K., Wretman, C. J., Stearns, S. C., Poole, P., & Preisser, J. S. (2020). Effectiveness of a Mouth Care Program Provided by Nursing Home Staff vs Standard Care on Reducing Pneumonia Incidence: A Cluster Randomized Trial. *JAMA Network Open, 3*(6), e204321. doi: 10.1001/jamanetworkopen.2020.4321

APPENDIX 1

Please respond to the following 19 oral health statements with YES/NO/DON'T KNOW

1) Dentures should be taken out at night.
2) Denture cleaning solutions can clean dentures without you needing to brush them as well.
3) Dentures should be rinsed after every meal.
4) People without any natural teeth only need a dental check-up when they have a problem.
5) If people have a gum infection under their dentures, they also experience discomfort.
6) A dirty denture is unlikely to cause disease in the mouth
7) Wearing a denture increases the risk of mouth infection.
8) A toothbrush with soft bristles is better than one with hard bristles for cleaning teeth.
9) A smaller-headed toothbrush is better at cleaning teeth than one with a large head.
10) Toothbrushes should be changed every three months or when the bristles are worn.
11) A strip of toothpaste should be applied across the top surface of the toothbrush.
12) Older people's teeth are less likely to become decayed than younger people's teeth.
13) Brushing teeth will also improve the condition of the gum.
14) If people have a lot of sugary food and drink, their teeth are more likely to decay.

15) Cleaning teeth with a wet gauze or a clean towel is a good alternative to a toothbrush for cleaning teeth.

16) People who have dry mouth will tend to get less decay.

17) Even if the gums around the teeth are inflamed or bleeding, they do not usually cause any pain.

18) For health and safety reasons, you should wear protective gloves when cleaning older people's teeth or denture.

19) Once gum disease has started. it is almost impossible to stop it.

Please respond to the following 18 statements with 1. Strongly agree, 2. Somewhat agree, 3. Neither agree nor disagree, 4. Somewhat disagree, 5. Strongly disagree.

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1. It is nursing staff's responsibility to keep care-dependent clients' natural teeth clean.
2. I feel more uncomfortable helping clients cleaning their teeth, mouth or dentures than I do with most other kinds of personal care.
3. I believe I can help in preventing my clients' teeth from becoming decayed and getting gum disease.
4. I think that only the dentist can prevent clients' teeth from decaying and getting gum disease.
5. Brushing teeth is a very personal thing that you should not be expected to do for somebody else.
6. In my opinion, clients need to see the dentist whether they have a problem or not.
7. When I clean my client's teeth, mouth or dentures, I'm unsure if I am doing it right.
8. Nurses can assess clients' oral hygiene status.
9. Nurses can assess the presence of dental caries in clients.
10. Nurses can assess the presence of periodontal disease in clients.
11. Nurses can assess clients' level of oral health self-care.
12. Nurses should do oral health assessments to plan appropriate oral health care for clients.
13. Nurses should encourage their clients who have dental problems to see a dentist.

OHAT statements

1. The Oral Health Assessment Tool can act as a reminder to assess oral health when doing my nursing home rounds.
2. The Oral Health Assessment Tool is a quick and easy tool to use during nursing home rounds.
3. I would use the Oral Health Assessment Tool during my rounds in the nursing home.
4. The Oral Health Assessment Tool can help me recall categories of the mouth that need to be assessed therefore improving my assessment skills.
5. I could prescribe the Oral Health Assessment Tool to be used as an assessment tool in the nursing home.

Research brief

Deciding on a safe site for intramuscular injections in an acute mental health setting

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Keywords

Acute mental health, intramuscular injection, dorsogluteal site, safe administration

Abstract

THE RISKS and benefits of different intramuscular injection (IMI) sites are still debated in the acute mental health literature. Although a few primary studies have investigated the issue of the safe site for intramuscular injections, the evidence remains varied and sometimes contradictory. This research brief reports on a systematic review that determined whether accessing the dorsogluteal (DG) intramuscular site is safer in an inpatient acute mental health setting where there is the potential for violence and agitation, as well as during personal restraint. The overall goal of this article is to provide practical guidance for health-care providers to help ensure the safe and effective administration of intramuscular injections in acute inpatient mental health settings.

Background

Implementing best practice standards is crucial for promoting patient safety and providing culturally safe treatment in mental health care. Te Whatu Ora New Zealand uses Lippincott to guide clinical decision-making. When choosing an intramuscular injection site, several factors must be considered, including the patient's physical condition, as highlighted by Cocoman and Murray (2010). However, selecting an appropriate site is a contentious issue, with the traditional dorsogluteal site being the primary option for intramuscular injections in mental health care, as reported in Reynolds & Saxton (2015).

Despite the widespread use of the dorsogluteal site, concerns have been raised about potential damage to the sciatic nerve and major blood vessels, as noted by Nettina (2018). This has led to suggestions to adopt the ventrogluteal (VG) intramuscular injection site, which is purportedly safer. However, Greenway (2014) reports that nurses in clinical practice have been reluctant to use the ventrogluteal site and continue to use the dorsogluteal site. Nurses have raised concerns about the precise landmarking of the ventrogluteal site and the risk of needle-stick injuries from the V-finger approach, as identified by Wynaden et al (2015).

The administration of an intramuscular injection to a non-adherent or aggressive client in the mental health environment can elicit an unexpected or impulsive response, as Brown et al (2015) noted. Consequently, other authorities have disputed the safety of the ventrogluteal site, particularly when personal restraint is used, and advocate for the consideration of trauma-informed care. To maintain a safe environment for the client without inducing further anxiety or stress, it is critical to adopt a consistent approach to trauma-informed care and meet the seclusion reduction target set by the Health Quality & Safety Commission (2022).

Non-adherence remains problematic, necessitating consideration of what the client prefers for the administration site. Amid the ongoing debate, a few studies have reported on the relative safety of these sites, with some findings contradicting each other. This review aims to synthesise the best evidence to support the delivery of best practice intramuscular injections in New Zealand mental health settings, to address the ongoing challenges faced by health-care professionals in this area.

Methodology and methods

This was a realist review that took an interpretive theory-driven approach, integrating evidence from quantitative, qualitative and mixed-methods research (Papoutsi et al, 2017). Realist reviews often refer to the "philosophy of science informing research" (Kirst & O'Campo, 2014, p. 105), and seek to determine an explanation while not adhering to a strict hierarchy of evidence (Kirst & O'Campo, 2014, p. 107). Realist review focuses on understanding how and why a procedure works and refining theory underpinning practice. This review sought to determine whether the dorsogluteal intramuscular injection site is safer to access in an acute mental health setting, where there is an increase in risk and considering client preference and trauma-informed care, versus the ventrogluteal site preferred by nurses (Nettina, 2018). The ability to provide findings that explain how and why context can affect outcomes is a strength of the realist approach. In taking this approach, the question we ask is: what is identified as best practice when choosing an intramuscular injection site for medication administration in a mental health setting where personal restraint may be needed?

Database search

The initial search terms used were 'dorsogluteal' and 'ventrogluteal' and 'intramuscular injection sites' and limited by 'mental 'health'. I accessed a number of relevant articles of interest by using 'Dorsogluteal intramuscular injection site' which appeared to focus on the comparison of the two sites (dorsogluteal and ventrogluteal) and some which were specific to mental health. The databases searched include CINAHL, found in EBSCO host, Science Direct, JBI, ClinicalKey and grey literature. References of the studies found were also explored and manual searches done for further articles.

Data screening

Studies from databases and grey literature were imported into Endnote and duplicates removed. Title, abstract and full-text screening were undertaken by HW and cross-checked by IA, the academic

Table 1. Context-mechanism-outcome

CMOc#	Context of intervention (study)	Strategy (preferred IMI site based on evidence)	Mechanism (rationale for the preferred site)	Outcome (clinician preference)	IMI site (study findings)
Strohfus et al, 2017	Needle length consideration for gender/BMI	Use of VG as preferred site	Use of critical assessments including weight, BMI, gender, site, needle length, the volume of medication	59% confident with VG, 41% do not use VG/not confident	VG preferred site
Wynaden et al 2015 **Arslan & Ozden 2018** **Walsh & Brophy, 2010** **Fekonja et al, 2021**	Current practice (IMI site preference)	Use of VG as preferred site	Clinicians consider client preference, safety and risk	Majority of nurses use the DG despite the evidence to support VG	VG preferred site
Mishra & Stringer, 2010	Injury based on IMI site (sciatic)	Use of VG as preferred site	Risk of sciatic nerve damage with use of DG site	Only 9% of NZ nurses use the VG	VG preferred site
Coskun et al, 2016 **Larkin et al, 2017** **Kaya et al, 2015** **Elgellaie et al, 2018** **Larkin et al, 2018** **Tuğrul et al, 2020** **Zaybak et al, 2007**	Gender/BMI/ muscle thickness consideration	No significant differentiation between DG and VG muscle thickness	Clinicians should base their site selection and needle size choices following assessment of gender/BMI	Site selection should include assessment of BMI, and considerations of gender and needle length	If best practice guidelines are followed, both DG/VG can be used

adviser for this project. The articles chosen for the review were identified by the reviewer's judgment on how they related to the discussion topic for synthesis.

Data extraction

A pre-tested data extraction form was used to retrieve information on study characteristics. Details extracted was guided by the context, site of injection, outcome in terms of safety and undesired effects.

Synthesis of findings

The data were synthesised to determine which intramuscular injection site was safer to use in a mental health setting while maintaining the safety of both the clinician and the client and also considering client choice and trauma-informed care.

Context-mechanism-outcome configurations (CMOcs)

As a means to determine the safest intramuscular injection site for a mental health setting, context-mechanism-outcome configurations (CMOcs) were identified, based on the studies included in the review. Each study focused on preferred intramuscular injection sites, while some also went on to discuss safety, needle length and body mass index (BMI) to determine successful intramuscular injection administration. Each CMOc was identified based on evidence-based practice, best practice guidelines underpinned by anatomy of the intramuscular injection site, gender, safety and current practice. The rigor and relevance of the studies were paramount in the research findings and discussion. Table 1 (above) identifies four CMOcs from 13 of the studies.

Ethical/cultural considerations

The studies included in this review received appropriate ethical approval. As secondary research, this review did not require ethical approval. The included studies were considered for their rigour and usefulness in informing a realist synthesis focussed on safe intramuscular injection administration in a mental health setting.

Findings

This review sought to find out whether the dorsogluteal intramuscular injection site was safer to access in an acute mental health setting than the ventrogluteal site where there is a degree of risk and during personal restraint. The data reviewed in this paper identified the ventrogluteal site as the preferred site based on evidence-based practice. However, a number of studies also allude to the safe use of the dorsogluteal site when best practice is maintained in a mental health setting to reduce risk.

The findings of this review highlight nurses' preference for using the dorsogluteal site for intramuscular injection administration despite evidence-based practice recommending the ventrogluteal site as the safest option. Ideally, when administering medication by intramuscular injection, nurses should opt for the site preferred in the guidelines and procedures. However, there are circumstances where safety is a concern and other factors need to be taken into account, including where clients are being treated under the Mental Health Act. In situations where risk is minimal and the client is amenable, then best practice would be to use the ventrogluteal site as evidence-based practice has identified it as the preferred site. This eliminates any risk of potential damage to the sciatic nerve and surrounding blood vessels and has a greater chance of the medication being administered to the muscle tissue. In an acute mental health setting, risk can be increased exponentially, and care should be taken to ensure safe practice in terms of trauma-informed care and client preference.

Sciatic nerve injury complications are preventable by avoiding the dorsogluteal site. However, if using this site is essential, it is crucial to use best practice guidelines for landmarking (Kim & Park, 2014). When choosing an intramuscular injection site, the manufacturer's recommendations should also be considered, as well as the clinician's assessment of the client .

Discussion

This review aimed to identify which intramuscular injection site (ventrogluteal/dorsogluteal) is the safest to use in a mental health setting, taking account of evidence-based practice and circumstances which could include risk, client preference and trauma-informed care. This review showed that evidence-based practice backs the use of the ventrogluteal site to avoid sciatic nerve injury and potential damage to major blood vessels. The CMOcs highlighted that in some situations the dorsogluteal is preferred when considering risk, and when best practice is maintained with land-marking.

Best practice guidelines are significant as they protect nursing practice and guide critical thinking to identify issues. Evidence-based practice is the integration of researched evidence into clinical practice and is the underpinning of safe and effective nursing care. While using best practice to guide nursing care, it is equally important to use critical thinking in situations where safety may be an issue. Considering clients' preferences for how a treatment is performed, and taking regard of trauma-informed care, can enhance client adherence and recovery.

Despite the evidence to support the best practice of the ventrogluteal site over the dorsogluteal site, nurses in clinical practice are reluctant to use it (Greenway, 2014) and continue to rely on the dorsogluteal site (Small, 2004). In a review conducted by Cocoman and Murray (2008), the evidence on the administration of psychotropic medications via intramuscular injection suggests that nurses tend to rely on known practices that are common in clinical areas, and are reluctant to change. This is supported by Wynaden et al (2015), who said nurses may be averse to changing to the ventrogluteal due to the difficulty in landmarking the site accurately and the potential of sustaining a needle-stick injury while using the V-finger method. This is especially the case when administering an intramuscular injection to a non-adherent/aggressive client in the mental health setting (Brown et al, 2015).

Conclusion

The safe landmarking of the dorsogluteal site should be researched further, considering the lack of evidence of actual sciatic nerve injury and the high percentages of nurses, internationally, who report greater confidence in the use of this site.

Although the ventrogluteal is the preferred site for intramuscular injection of medication in a medical setting, there is a need for guidelines to support the use of the dorsogluteal in an acute mental health setting. This would help support client choice, and thus promote adherence, trauma-informed care and safety.

References

Arslan, G. G., & Özden, D. (2018). Creating a change in the use of ventrogluteal site for intramuscular injection. *Patient Preference and Adherence, 12,* 1749–1756. https://doi.org/10.2147/PPA.S168885

Brown, J., Gillespie, M., & Chard, S. (2015). The dorso-ventro debate: in search of empirical evidence. *British Journal of Nursing, 24*(22), 1132, 1134, 1136–1139. https://doi.org/10.12968/bjon.2015.24.22.1132

Cocoman, A., & Murray, J. (2008). Intramuscular injections: a review of best practice for mental health nurses. *Journal of Psychiatric and Mental Health Nursing, 15*(5), 424–434. https://doi.org/10.1111/j.1365-2850.2007.01236.x

Cocoman, A., & Murray, J. (2010). Recognising the evidence and changing practice on injection sites. *British Journal of Nursing, 19*(18), 1170–1174. https://doi.org/10.12968/bjon.2010.19.18.79050

Coskun, H., Kilic, C., & Senture, C. (2016). The evaluation of dorsogluteal and ventrogluteal injection sites: a cadaver study. *Journal of Clinical Nursing, 25*(7-8), 1112-1119. https://doi.org/10.1111/jocn.13171

Elgellaie, A., Ashcroft, E., & Larkin, T. A. (2018). Effects of thickness of muscle and subcutaneous fat on efficacy of gluteal intramuscular injection sites. *British Journal of Nursing, 27*(6), 300-305. https://doi.org/10.12968/bjon.2018.27.6.300

Fekonja, U., Fekonja, Z., & Vrbnjak, D. (2021). The assessment of knowledge and practical skills of intramuscular injection administration among nursing staff: a cross-sectional study. *Australian Journal of Advanced Nursing, 38*(3). https://doi.org/10.37464/2020.383.234

Greenway, K. (2014). Rituals in nursing: intramuscular injections. *Journal of Clinical Nursing, 23*(23-24), 3583-3588. https://doi.org/10.1111/jocn.12627

Health Quality & Safety Commission. (2022). *Zero seclusion: Safety and dignity for all – change package.* https://www.hqsc.govt.nz/resources/resource-library/zero-seclusion-change-package/

Hough, D., Lindenmayer, J.-P., Gopal, S., Melkote, R., Lim, P., Herben, V., Yuen, E., & Eerdekens, M. (2009). Safety and tolerability of deltoid and gluteal injections of paliperidone palmitate in schizophrenia. *Progress in Neuro-Psychopharmacology and Biological Psychiatry, 33*(6), 1022–1031. https://doi.org/10.1016/j.pnpbp.2009.05.014.

Kaya, N., Salmaslıoğlu, A., Terzi, B., Turan, N., & Acunaş, B. (2015). The reliability of site determination methods in ventrogluteal area injection: a cross-sectional study. *International Journal of Nursing Studies, 52*(1), 355-360. https://doi.org/10.1016/j.ijnurstu.2014.07.002

Kim, H., & Park, S. (2014). Sciatic nerve injection injury. *Journal of International Medical Research, 42*(4), 887-897. https://doi.org/10.1177/0300060514531924

Kirst, M., & O'Campo, P. (2014). Realist review and evaluation: What do we know about what works? In J. Burke & S. Albert (Eds.), *Methods for Community Public Health Research* (pp.105-124). Springer Publishing Company.

Larkin, T. A., Ashcroft, E., Elgellaie, A., & Hickey, B. A. (2017). Ventrogluteal versus dorsogluteal site selection: A cross-sectional study of muscle and subcutaneous fat thicknesses and an algorithm incorporating demographic and anthropometric data to predict injection outcome. *International Journal of Nursing Studies, 71*, 1-7. https://doi.org/10.1016/j.ijnurstu.2017.02.017

Larkin, T. A., Ashcroft, E., Hickey, B. A., & Elgellaie, A. (2018). Influence of gender, BMI and body shape on theoretical injection outcome at the ventrogluteal and dorsogluteal sites. *Journal of Clinical Nursing, 27*(1-2), e242–e250. https://doi.org/10.1111/jocn.13923

Mishra, P., & Stringer, M. D. (2010). Sciatic nerve injury from intramuscular injection: a persistent and global problem. *International Journal of Clinical Practice, 64*(11), 1573-1579. https://doi.org/10.1111/j.1742-1241.2009.02177.x

Nettina, S. M. (2018). *Lippincott manual of nursing practice* (11th ed.). Lippincott Williams and Wilkins.

Papoutsi, C., Mattick, K., Pearson, M., Brennan, N., Briscoe, S., & Wong, G. (2017). Social and professional influences on antimicrobial prescribing for doctors-in-training: a realist review. *Journal of Antimicrobial Chemotherapy,* *72*(9), 2418–2430. https://doi.org/10.1093/jac/dkx194

Reynolds, T., & Saxton, L. (2015). Developing Training in Intramuscular Injections. *Mental Health Practice, 18*(9), 14-19. https://doi.org/10.7748/mhp.18.9.14.e971

Small, S. P. (2004). Preventing sciatic nerve injury from intramuscular injections: literature review. *Journal of Advanced Nursing, 47*(3), 287-296. https://doi.org/10.1111/j.1365-2648.2004.03092.x

Strohfus, P. K., Paugh, O., Tindell, C., & Molina-Shaver, P. (2017). Evidence calls for practice change in intramuscular injection techniques. *Journal of Nursing Education and Practice, 8*(2), 83. https://doi.org/10.5430/jnep.v8n2p83

Tuğrul, E., Khorshıd, L., & Tunçyürek, Ö. (2020). Anthropometric measurements of the ventrogluteal injectıon area: A cross-sectional study. *Journal of Human Sciences, 17*(3), 900-910. https://doi.org/10.14687//jhs.v17i3.5873

Waikato District Health Board. (2016). *Mental Health & Addictions Strategy 2016-2021*. https://www.waikatodhb.health.nz/assets/Docs/About-Us/Key-Publications/Strategies/76275ab51b/MHAS-Strategic-Plan-2016.pdf

Walsh, L., & Brophy, K. (2010). Staff nurses' sites of choice for administering intramuscular injections to adult patients in the acute care setting: Sites of choice for intramuscular injections. *Journal of Advanced Nursing, 67*(5), 1034-1040. https://doi.org/10.1111/j.1365-2648.2010.05527.x

Wynaden, D., Tohotoa, J., Al Omari, O., Happell, B., Heslop, K., Barr, L., & Sourinathan, V. (2015). Administering intramuscular injections: how does research translate into practice over time in the mental health setting? *Nurse Education Today, 35*(4), 620-624. https://doi.org/10.1016/j.nedt.2014.12.008

Zaybak, A., Güneş, Ü. Y., Tamsel, S., Khorshid, L., & Eşer, I. (2007). Does obesity prevent the needle from reaching muscle in intramuscular injections? *Journal of Advanced Nursing, 58*(6), 552-556. https://doi.org/10.1111/j.1365-2648.2007.04264.x

Oral history: A rich tapestry of information

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Heather Woods

ORAL TRADITIONS are embedded in most of the world's cultures and have long been an important part of te ao Māori (Taonui, 2005). History has been passed down by word of mouth for millenia. The development of writing in many civilisations then resulted in people relying on written documents for information about the past. Oral histories can provide another piece of the jigsaw, if you are researching a particular topic or issue. They provide context and a different perspective, along with giving a more rounded view of all the issues that arose relating to an incident or event. The facts and figures relating to an event are vital; however oral histories are a useful research source to provide a more complete picture. Interviews are not about collecting truth – they are about collecting people's memories. One may argue that a person's memories are their truth.

What is oral history?

Oral history is a research methodology used by students, academics, journalists, documentary-makers and podcasters, along with community-based and family historians. It involves extended, recorded interviews undertaken for a specific purpose and, on occasion, results in eventual archiving for preservation and public access.

Developments in sound-recording technology have enabled us to collect and accurately preserve, as oral history, word-of-mouth stories and memories about a subject of historical interest. We can now record and preserve the unique memories and life experiences of ordinary yet amazing people, along with more prominent and well-known individuals. We can eavesdrop on past events, feelings, attitudes and ways of life (Hamilton Libraries, n.d.).

Through the recording of oral history, we are able to capture the view of eyewitnesses, therefore providing new or additional information and insights. This provides an opportunity to hear from those people who are often left out of historical records – the ordinary people who have taken part in significant events and have an invaluable and unique perspective (Oral History Australia, 2023).

There are two main types of oral history interview:

1) Life history interviews – for example, an interview that focuses on the life and the changes experienced by a person in their lifetime.

2) Topic interviews – these record information about a specific subject, such as an interview with someone about the history of a workplace or occupation or industry sector.

The recording and use of oral history may give rise to ethical considerations. The National Oral History Association of New Zealand has published a Code of Ethical and Technical Practice (NOHANZ, 2023) that sets out the responsibilities of interviewers and collectors of oral history. In some cases there are access and use restrictions on oral history material. It's important to bear these in mind and follow any use protocols that are in place. Some interviewees share thoughts and experiences with the interviewer that they may not have ever told anyone before and it can be a painful yet cathartic experience. If a researcher is intending to republish, in the public domain, quotes from an interview, then confidentiality and privacy consideration may need to be taken into account. It's a matter of balancing the need to tell the story and share it with a wider audience against whether it may cause stress and upset to any of the parties that are mentioned in the interview (Gorter, 2023). Another issue that can arise in oral history is that there may be competing versions of the "truth":

> *"In an interview you get one person telling one story and then another one tells you a whole other conflicting story. Cross checking is important; if there is written material and other accounts, read it. . . . Whānau interviews are not about collecting truth, they are about collecting people's memories. The thing to note is that there are different accounts and [to] respect the differences".* (Ministry of Education, n.d.)

By interviewing a relative, genealogists are often able to find a missing link when compiling whakapapa or a family tree. Oral histories are often the best way for families to capture and preserve the life stories and experiences of their parents and grandparents. Imagine the social and technological changes an 85-year-old person has witnessed in their lifetime.

Oral History and Sound Collection

There are more than 10,000 recordings in the the Oral History and Sound Collection at the Alexander Turnbull Library (NatLib, n.d.). Recordings include interviews with people from throughout New Zealand and the Pacific, of various ethnicities, iwi (tribe) and hapū (sub-tribe), occupations, political affiliations and interests. Most of the collection has been recorded since the 1960s and covers New Zealand society, culture, community and political history from the late 19th century to the present. Interviews usually have accompanying documentation, including an abstract – a detailed time-coded index providing quick access to the contents of the recording. Within that collection are oral history interviews with New Zealand nurses.

EXAMPLES OF INTERVIEWS IN THE NERF ORAL HISTORY PROJECT:

- ***Ailsa Douglas McCutchan*** *gives some family background information. Describes several years in the Women's Auxiliary Air Force (1942-1945) as librarian, mess-hand and link trainer mechanic in Whenuapai, Blenheim, Hamilton and Hobsonville. Explains why she commenced training as a nurse in 1945 at preliminary school called 'Cargun', a building in Eden Cres, Auckland. Describes tutors with reference to Sister Saker and staff nurse Turner; morning duty in women's surgical ward; hierarchy; 'divide nurse' – split duties; effects of shortages of food and linen after the war; Auckland Hospital buildings in the 1940s and the military annexe with reference to nurses' attitudes to this all-male ward; dysentry contracted during first year of training; measures to avoid spread of infection".* (Recording of Ailsa McCutchan, 1983-84)

- ***Judith Christensen*** *discusses her nursing background and her appointment as Head of School, Nursing, Health and Environmental Studies, at Wellington Polytechnic. Recalls participation in nursing education changes in colleges in Quebec. Discusses: Curriculum requirements and development; doctors' participation; pilot programme; accommodation of School of Nursing – cottages in Finlay Terrace and Tasman St; bedmaking and basic skills; equipment and facilities; public response to the nursing programme and PSA opposition. Mentions Elsie Boyd (Health Department); Shona Carey (NZNA); Dr Helen Carpenter; Pauline McGuiness; Shireley Bohm and Jan Hough.* (Interview with Judith Christensen, 1984)

- ***Isabelle Sherrard*** *trained as a nurse at Christchurch Hospital c.1956. Discusses orientation to the hospital and the programme. Recalls marrying 10 days after sitting State exams. Explains how career was subsequently influenced by husband's work and education, taking her to Northern Ireland in 1962 where she spent six months in a geriatric hospital on the outskirts of Belfast before moving to Houston, Texas, working in intensive care unit, and later to Ann Arbor, Michigan, working at the University of Michigan in the burns unit. Discusses different kinds of nursing education/training in the States. Recalls return to New Zealand with two children and fitting in part-time work at the Chalet Hospital, Dunedin Hospital, and in 1976 settling in Auckland. Mentions Carpenter Report and its effect on nursing in New Zealand. Mentions undertaking nursing courses at Massey University, gaining a BA in Education. Discusses appointment as tutor at ATI (Auckland Technical Institute), with reference to Yvonne Shadbolt, Lani Kelliher and Sue Otto. Commenced at Carrington Polytechnic (1985) and discusses involvement in employing staff and setting up Advisory Committee, with reference to male dominated hierarchy. Discusses curriculum and demands of clinical and theoretical components of the programme; student selection and criteria; Māori and Pacific Island applicants; cultural safety, with reference to Paul Spoonley and Irahapete Murchie, cultural awareness and Treaty of Waitangi. Mentions Judy Kilpatrick at the Nursing Council.* (Interview with Isabelle Sherrard, 1996)

Nursing History website

The Nursing History website is an online archive of New Zealand nursing oral histories. Its aim is to create a resource that nurses, students, academics, researchers and family members can access in order to gain a better understanding of our country's nursing history (NERF, 2015).

The website is funded by NZNO's Nursing Education and Research Foundation (NERF) and includes the Oral History Project undertaken by the University of Auckland in 2012 and 2013. The project team, comprised of Professor Linda Bryder, Associate Professor Margaret Horsburgh, Dr Debbie Dunsford and Dr Kate Prebble, recorded the stories of nurses who trained during the 1950s and 1960s. Linda Bryder worked with two University of Auckland History Department summer scholars, Emma Cotton and Kaitlin McLeod, over the summer of 2014/15, to select highlights from the interviews to post on the website. You can listen to these excerpts on the website and see other associated photos and information. The full oral histories collected by the University of Auckland project team, as well as earlier ones, are stored with the Alexander Turnbull Library's Oral History and Sound Collection in Wellington

Nursing Education and Research Foundation

The origins of the Nursing Education and Research Foundation (NERF) can be traced back to donations placed in a memorial fund established by NZNO to commemorate the life and work of Flora

J Cameron OBE (former director, Division of Nursing) who died in 1966. These donations formed the basis of a permanent fund which would provide New Zealand nurses with travel grants, scholarships and other assistance to enhance opportunities for continuing education, professional development and research (Stevenson, 2000).

NERF Oral History Project

NERF promotes excellence in nursing and health care by providing funding opportunities for education and research. A range of NERF's scholarships and funding opportunities are offered through the New Zealand Nurses Organisation (NZNO) website (NZNO, 2014).

In 1982, NERF began the first in a series of projects to collect the oral histories of nurses in New Zealand. All of the interviews can be accessed via the Alexander Turnbull Library, with permission granted by the NZNO librarian on behalf of NERF (contact library@nzno.org.nz). Although digitalisation of many of the interviews has begun, some are still only in taped format (NERF, 1983-84).

A total of 22 volunteer interviewers undertook 185 oral history interviews in the initial NERF Oral History Project and they were deposited with the Alexander Turnbull Library Oral History Centre in September 1984.

These included:

- 13 interviews with nurses registered before 1920
- 59 with nurses registered from 1920-29
- 70 with nurses who had registered between 1930 and 1939
- 36 with nurses registered between 1940 and 1949
- three with nurses registered after 1950.

Further individual and private additions to the collection were made between 1984 and 2000 including:

- the Psychiatric Nurses Oral History Project (six interviews) (NERF, 1988-89)
- the transfer of nursing education from hospitals to polytechnics (38 interviews), Yvonne Langridge (NERF, 1993-94)
- nursing biographies (five interviews), Yvonne Langridge
- nursing biographies – Wellington Polytechnic 1973-1998 (21 interviews), Yvonne Langridge
- Nurses & Midwives Oral History Project (seven interviews), 1992-3, Marie Burgess
- Neonatal Nursing Oral History Project (20 interviews), Penelope Dunkley
- Wartime Nurses Project (11 interviews), 1999, Anna Rogers
- "Oranje" Oral History Project (10 interviews), Marie de Joux
- Nursing in World War II (two interviews), Valerie Fisher
- Royal NZ Plunket Society (20 interviews), Plunket Society
- Little Company of Mary (nursing order) (12 interviews), LCM & Ann Trotter

In 2011, NERF called for tenders to continue to grow the NERF Oral History Archive. A project team from Auckland University were appointed and during 2012 and 2013 collected the following interviews with people who trained as nurses in New Zealand in the 1950s and 1960 (NERF, 2012-14):

- One participant who trained in the 1930s (Joyce Oliver).
- Thirty participants who trained in the 1950s.
- Thirty participants who trained in the 1960s.

For examples of the interviews in the NERF Oral History Project, see the box on page 63.

References

Gorter, S. (2023). The importance of gaining trust when conducting an oral history. *Agora, 58*(2), 38-40.

Hamilton Libraries. (n.d.). *Oral History.* https://hamiltonlibraries.co.nz/heritage/archives/oral-history/

Interview with Isabelle Sherrard (1996, December). OHInt-0520/36 [Interview]. In OHColl-0520 : *NZ Nursing Education and Research Foundation : the transfer of nursing education from hospitals to polytechnics 1993-1994* [Collection] https://tiaki.natlib.govt.nz/#details=ecatalogue.243475

Interview with Judith Christensen (1994, January 20). OHInt-0520/01 [Interview]. In OHColl-0520 : *NZ Nursing Education and Research Foundation : the transfer of nursing education from hospitals to polytechnics 1993-1994.* [Collection]. https://tiaki.natlib.govt.nz/#details=ecatalogue.242144

Ministry for Culture and Heritage. (2022). *A guide to recording oral history.* https://nzhistory.govt.nz/hands/a-guide-to-recording-oral-history

Ministry of Education – Te Tāhuhu o te Mātauranga. (n.d.). *The contested nature of oral histories.* https://eng.kiamau.tki.org.nz/Teachers-notes/Teaching-history/The-contested-nature-of-oral-histories

National Library of New Zealand. (n.d.). *Oral history and sound.* https://natlib.govt.nz/collections/a-z/oral-history-and-sound

National Oral History Association of New Zealand (NOHANZ). (2023). *About us.* https://www.oralhistory.org.nz/index.php/home/about-us/

New Zealand Nurses Organisation. (2014). *Nursing Education and Research Foundation.* https://www.nzno.org.nz/groups/nursing_education_and_research_foundation

Nursing Education and Research Foundation (NERF). (1983-1984). *New Zealand Nursing Education and Research Foundation oral history project.* OHColl-0014. https://tiaki.natlib.govt.nz/#details=ecatalogue.144888

Nursing Education and Research Foundation (NERF). (1988-1989). *Psychiatric nurses oral history project.* OHColl-0139. https://tiaki.natlib.govt.nz/#details=ecatalogue.145096

Nursing Education and Research Foundation (NERF). (1993-1994). *The transfer of nursing education from hospitals to polytechnics.* OHColl-0520 https://tiaki.natlib.govt.nz/#details=ecatalogue.242098

Nursing Education and Research Foundation (NERF). (2012-2014). *Nursing Education and Research Foundation (NERF) nursing oral history project.* By Dunsford, Deborah (Dr), active 2001-2012; Prebble, Kate (Dr), active 2007-2014. OHColl-1260. https://natlib.govt.nz/records/47734227

Nursing Education and Research Foundation (NERF). (2015). *An online archive of nursing oral histories in NZ.* http://www.nursinghistory.org.nz/index.php/An_Online_Archive_of_Nursing_Oral_Histories_in_NZ

Oral History Australia. (2023). *What is oral history?* https://oralhistoryaustralia.org.au/guidance/what-is-oral-history/

Recording of Ailsa McCutchan (6 August 1983 & 6 August 1984). OHInt-0014/100. In OHColl-0014. New Zealand Nursing Education and Research Foundation oral history project. 1983-1984. [Collection]. https://tiaki.natlib.govt.nz/#details=ecatalogue.146422

Stevenson, A. 'Cameron, Flora Jean', *Dictionary of New Zealand Biography,* first published in 2000. Te Ara – the Encyclopedia of New Zealand, https://teara.govt.nz/en/biographies/5c3/cameron-flora-jean

Taonui, R. (2005). *Ngā Tatai – Whakapapa dynamics in Māori oral tradition*: A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy (PhD) in the Department of Māori Studies at the University of Auckland. http://hdl.handle.net/2292/20659