



#36 SUMMER 2021/22

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NURSING: A REFLECTION OF A DIVERSE COMMUNITY

FREE EDITION

NOTHING WITHOUT US ABOUT US

DR ODETTE BEST FACN &
BRUCE MARTIN MACN

CORNERSTONES OF LGBTQIA+ CARE DELIVERY

CLINTON MORGAN MACN

LESSON ON EXCLUSION FROM PAST PANDEMICS

DR RUTH DE SOUZA FACN

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CORNERSTONES OF LGBTQIA+ CARE DELIVERY

**Fostering inclusivity through a contemporary,
peer-led health care model that exhibits
compassion, empathy and cultural sensitivity**

As a general practice nurse at Queensland Council for LGBTI Health (QC), Clinton Morgan MACN's role is to provide health care within a multidisciplinary team consisting of GPs, mental health practitioners and allied health professionals. In this edition, Clinton answers some pertinent questions related to caring for LGBTQIA+ clients.

CAN YOU TELL US ABOUT YOUR ROLE AND RESPONSIBILITIES?

This clinic specialises in sexual and mental health and is targeted towards LGBTQIA+ brotherboy and sistergirl communities. In view of this, my role expands to providing advocacy and agency to marginalised populations through education, cultural sensitivity and providing access to quality and contemporary health care.

WHAT ARE THE CORE PRINCIPLES OF CARE DELIVERY FOR LGBTQIA+ CLIENTS?

In carrying out our work, we recognise that every human being, regardless of race, religion, age, gender, sexuality or other individual uniqueness, has the right to quality health care. LGBTQIA+ brotherboy and sistergirl communities deserve health care free from bias, prejudice and discrimination.

HOW DO YOU ENSURE THE CARE PROVIDED IS HOLISTIC AND INCLUSIVE?

This clinic is founded on a peer-led system as there is substantial evidence validating the benefits and advantages of such a system in regard to optimising

consumer outcomes and satisfaction. Operating as a multidisciplinary team with effective intersection and collaboration of disciplines, we deliver holistic health care to all consumers. As majority of the staff are LGBTI identifying, we foster inclusivity through enacting a contemporary, peer-led health care model that exhibits compassion, empathy and cultural sensitivity.

WHAT ARE SOME GUIDELINES WHEN ASSESSING/LOOKING AFTER LGBTQIA+ CLIENTS?

Abandon all assumptions. This can be difficult for health practitioners — although our practice is evidence-based, a degree of our understanding, perception and expectation of a presentation is guided by our experiences and beliefs.

Avoid making assumptions about education, autonomy, risk behaviours, sexual preferences and activities. A great facilitator of client interaction is to consider the type of language you will use with the client. Allow them to decide what pronouns they prefer, what descriptors they use regarding anatomy, etc.

Pronouns, medical jargon and even colloquialisms can be detrimental to sexuality and gender diverse clients if used incorrectly within the context of individual client consultation. An example of this is gendered language, whereby a clinician may refer to the genitalia of a client who may innately refer to a gender with which the client does not identify.

The censorship of language during client consultation is difficult, but the language will become fluent with practice. The

benefit of this consideration is immense for sexuality and gender diverse clients as it demonstrates professionalism, a culturally appropriate practice and respect for each client as an individual.

WHAT ARE THE BARRIERS IN HEALTH CARE SERVICES FOR THEM?

Currently, there is an exponential increase in TG/GD (transgender and gender diverse) youth (<18yr), at least in Brisbane. Fortunately, the gender clinic team at Queensland Children's Hospital not only exists, but cares for this demographic fantastically. The challenge we have in general practice is that these adolescents grow up and are forced into already exhausted adult gender services whereby the wait times can be up to a year. This saturation reflects an amalgamation of GP hesitancy regarding hormone therapy management and poor service access, whether by cost, practice proximity or clinician availability.

Regarding LGBTQIA+ communities, they require health practitioners versed in contemporary health care unique to this population. It is essential to provide a safe, respectful and inclusive practice whereby all clients can receive quality, and relevant and prompt health care free from judgement, bias or discrimination.

HOW CAN HEALTH CARE PROFESSIONALS BE MORE HOLISTIC IN THEIR CARE DELIVERY APPROACH?

LGBTQIA+ health, although unique, isn't complicated. Health practitioners can ensure an inclusive practice that allows



“Abandon all assumptions. This can be difficult for health practitioners — although our practice is evidence-based, a degree of our understanding, perception and expectation of a presentation is guided by our experiences and beliefs.”

clients to express concerns honestly and openly. This will only happen if we remove bias and judgement from our practice and understand that the health concerns of our patients are individual, contextual and significant to them.

A number of organisations, programs and resources can be utilised to educate and empower health practitioners. I believe sensitivity training can also greatly benefit in working with these communities.

Nurses have an innate ability to see the client through a holistic lens and understand a person beyond how they are presenting verbally or physically. Clients who identify as sexuality or gender diverse need greater communication considerations, particularly when it comes to anatomy.

An important lesson I learnt was not to ‘dead name’ transgender or gender diverse clients, i.e., calling them by their legal name rather than preferred name. For many, their dead name is synonymous with a confusing, often negative time in their lives, and is typically incongruent with their current gender identity. This situation carries a potential to cause gender dysphoria with tangible psychological detriment.

Being cognisant about language makes this ‘translation’ easier in day-to-day practice, and makes clients feel included, respected and most importantly, heard.

WHAT CAN YOU TELL US ABOUT CARE FOR LGBTQIA+ CLIENTS IN AGED CARE SETTINGS?

Older adults have sex. For some context, research conducted by the University of Melbourne identified the rates of chlamydia, gonorrhoea and syphilis notifications were rising faster amongst women aged 55 to 74 than that in younger women.

There is a long way to go before health services encompass holistic and contemporary sexual health for aged care residents, let alone those who identify as sexuality and gender diverse. Sexual health has the same underpinnings regardless of age, gender, race and so on; we all want to connect and experience love, intimacy and pleasure, whether by ourselves or with others.

Permitting expression and celebration of aged care residents’ sexuality and diversity is paramount for their mental and physical health. In systems of health care where this is not done whereby the sexual health

needs of residents are ignored, assumed or judged, these people will continue to be denied the right to express and explore their sexuality with dignity and respect.

WHAT ARE SOME POLICY ISSUES SURROUNDING LGBTQIA+ HEALTH RIGHT NOW?

Their rights have been a long-standing contention amongst governing bodies, policy makers and society as whole. Acceptance and recognition of their unique health care needs is growing and becoming more mainstream.

A lot of focus in the LGBTQIA+ realm is on transgender and gender diverse people. There are obvious legal considerations and complications pertaining to this community, especially regarding children and adolescents, and their ability to make informed future decisions about their lives.

The government and other regulating health care bodies have made great progress in making legislative policy more inclusive and free from discrimination. For example, the removal of gender markers for Medicare. As a society, we still need to grow when it comes to acceptance of a sexuality and gender diverse population, but I am optimistic about it. If language defines culture, then perhaps our scrutiny of what we say and how we say it will be fundamental in our evolution as a community.



AUTHOR

CLINTON MORGAN MACN

LESSONS ON EXCLUSION FROM PAST PANDEMICS

We need far more engagement with marginalised groups to avoid making the same mistakes and perpetrating the same injustices over and over



I have three pandemic stories about health inequity. The first is a painful, family one. In July 1961 in Moshi, Tanzania, my aunt died of hospital acquired smallpox caused by the variola virus five days after giving birth to her newborn son, who died a day later.

She left behind her devastated family and a 13-months-old daughter. She had been immunised while at school, so we don't know what happened. We know that some vaccinations in East Africa at that time were unsuccessful because the liquid vaccine had to be refrigerated otherwise it became inactive within three days.

The smallpox vaccine was produced in Nairobi or England and it is possible that temperatures were not maintained during shipping or when the vaccine was transported to distribution centres or health clinics. It could also be that a more severe form of smallpox was present in Tanzania at the time.

Closer to home, there were the smallpox epidemics of 1789, 1829–32 and the 1860s in Australia (McWhirter, 2009). Smallpox arrived with settlers 15 months after the First Fleet arrived in Australia. Macassans were originally blamed for its arrival, but there was no smallpox in Macassar at the time of the First Fleet. Smallpox was widely believed to have come from Asian countries because Asians were thought to be

diseased and different. However, smallpox was endemic to Britain and to a lesser degree, Europe. The three epidemics had a major impact on Aboriginal populations but less so on European settlers.

Smallpox was managed in different ways in the various Australia colonies. Vaccinations became available during the 1829–32 epidemic, but there was no legislation with regard to smallpox in Aboriginal communities.

Rather than being made compulsory, vaccination occurred in an ad hoc manner if an individual settler or doctor was concerned about an Aboriginal person. In Victoria, where I live, the smallpox epidemic of the 1860s had a devastating impact on Aboriginal people. In the racial hierarchy of the time, white settlers were seen as superior to Aboriginal people and people of colour. Aboriginal people were thought to be already at risk of dying, both individually and as a 'race', and were not seen as a threat, a vector of disease or of being in need of a public health response.

Chinese people were also seen as inferior and unsuitable for integration into colonial society. However, they were seen as a threat to British dominance, by virtue of their industriousness and because their numbers swelled through the gold rush era and they were characterised as a source of disease.

A smallpox outbreak in 1857 in Melbourne singled out Chinese people as the source and, despite it being traced to a sailor from Liverpool, led to demands for the compulsory vaccination of Chinese people. An outbreak of smallpox in 1887 was attributed to Indian hawkers or to recently arrived Chinese people. The Tasmanian Chinese Immigration Act 1887 required all Chinese entering the colony to be compulsorily vaccinated, and this was carried out by the Superintendent of Vaccinations, CE Barnard, even as the practice was being challenged among the European population on the grounds of contravening individual liberty.

And now to the present — in Victoria, where I live, where the unfair structural arrangements in our society have been exposed. Nine public housing towers with high populations of migrants and people of refugee background in North Melbourne and Flemington were put in lockdown without notice (Ghumkhor, 2021). This racialised response was also seen in Sydney, where people in the western suburbs were policed heavily compared to the eastern parts of the city.

These past and present examples show that although we might be in the same boat, 'some people have yachts and superyachts' (Siouxsie Wiles). There are the global inequities of vaccine

“Fuelled by fear, we have turned to carceral responses and policing particular areas rather than making public health responses toward equity.”



distribution, as evident now in terms of COVID-19 as in my aunt's time.

At the time of writing this, Canada had a total vaccination rate per 100 people of 155.67 while Tanzania had a rate of 1.63, compromising the effectiveness of vaccination as a public health strategy (Carey, 2021). We know that this massive disparity will have far reaching impacts. Low vaccination rates mean that the virus will continue to spread and increase the risk of new variants emerging globally. Considering health equity would ensure that the places that needed the vaccine the most could be supported with resources.

This is true also of Australia, where there was a lack of prioritisation of vaccine supply for the people with the most need (e.g. essential workers in precarious work, people living in high density housing). An equity lens would require targeting people living in 'LGAs of concern' with early intervention to promote understanding of restrictions, vaccine uptake, and COVID-safe work practices (Reeders, n.d.)

The second and third examples show how race and racial hierarchies have played a part in how infectious diseases are managed in settler colonies like New Zealand and Australia. Fuelled by fear, we have turned to carceral responses and policing particular areas rather than making

public health responses toward equity. These responses rather than community led solutions have been traumatising and reduced trust in population groups that are already distrustful or disengaged from health services (Liddle, 2021). The lack of financial assistance for international students and essential workers spread across different contexts has also exposed how some communities are seen as less worthy of respect or care.

Bringing in an equity lens reveals the limitations of health communication during the pandemic. Firstly, health messaging has not always been accessible for people from culturally and linguistically diverse communities. Initial messaging did not consider fluency in a language other than English, low health literacy or diverse work and social contexts that such communities live in, such as the prevalence of precarious essential labour, irregular shift work or multi-generational households.

The pivot to digital technologies has posed yet another challenge for marginalised communities. Whether for accessing online consultations, using apps to check in at venues and facilities using QR codes, to home schooling and working from home, the mandatory use of unevenly distributed technology has widened existing health inequalities.

Once again, the assumption that middle-class, English speaking communities are the Australia public health needs to serve has prevented us from achieving positive outcomes for all. We need far more engagement with marginalised groups and to welcome their participation in producing healthy outcomes for their communities if we don't wish to repeat the exclusions of the past.

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AUTHOR

DR RUTH DE SOUZA FACN

A vision for equity in health care

Three nurse leaders discuss the current complexities and impact of nursing practice in health care for refugees and asylum seekers



**LEEANNE
SCHMIDT
FACN**

**Clinical Nurse
Consultant, and
Secretariat
Refugee Nurses
Australia**

CORE VALUES AND COMPLEXITIES

Refugee Nursing speciality found me and connected with me in a way that has been different from other areas of my practice. Everyone who works in the sector, regardless of locality, shares core values of humanitarianism and has experienced a deep dive into person-centred care.

I have been in this role 11 years and every day, I see through my clients' experiences and the system barriers that make it difficult to access and navigate our health system. For example, the lack of a national Refugee Health policy to support the work being provided, or not capturing data such as ethnicity or preferred language across all systems, such as My Health Record. Building inclusive systems from the beginning reduces the risk of unconscious bias.

Literacy and health literacy are critical skills that enable us all to participate in our community. Understanding different health care worker roles, primary care and tertiary care are great challenges for people who do not speak English or had limited access to a health professional in the past. The provision of tailored health promotion and education about our health system is critical. Some components include:

- How to say their language so that providers understand which language interpreter to organise – essential if trying to call 000
- What is consent

- The importance of making and cancelling appointments
- What to do when a letter in English is received
- Opportunities to build confidence to ask questions

In my workplace, on an average six people a year have a level of conversational English. Every episode of care requires an interpreter and using plain English communication. Booking an optimal interpreter requires awareness of the client's ethnicity, health literacy requirements of the interpreter, gender preference, understanding of any inter-generational factors that may impact communication. It also means considering the impact of the care episode on the interpreter and ensuring pre-brief and debrief occurs.

The social determinants of health underpin access to health care. Humanitarian arrivals are eligible for Medicare, Centrelink and Healthcare Concession Card. However, there are some people seeking asylum who for many years have had limited/no access to Medicare.

It means no access to primary care, pathology, radiology and medication. They are reliant on pro bono or benevolent providers, but often default to the hospital. The impact is for their whole family and flows onto all aspects of health and wellbeing. If I could ask for one change, it would be that government consider looking at the Canadian model in which there is an obligation to resolve an asylum seeker's application within 180 days.

SUPPORTING THE PROFESSION

Currently, refugee health nursing has no education entry point or pathway. Refugee Nurses Australia (RNA) and others are actively building a platform to address this gap. Nurses and midwives everywhere

are likely to care for people with a refugee background, so it is essential that best practice resources are available.

To commence this journey, I would like to see the development of learning modules to provide a transition to practice pathway, available at little or no cost. The modules should be assessed as recognised prior learning with an attached placement immersion program. My ultimate dream is that there would be a standalone elective tertiary subject for refugee nursing practice.

IMPACT OF THE COVID-19 PANDEMIC

Existing partnerships have been strengthened; new partners and networks have emerged; many system barriers across levels of government have been lessened. Although challenges still occur, the relationships are established now so it is easier to advocate. Successful community engagement has empowered communities to navigate entry points to health and ask for resources.

Due to the pause in humanitarian arrivals, we could do things differently. Communication and the tools to communicate meant utilising virtual platforms and providing literacy support in the use of those tools. Women's participation increased as they didn't need childcare or transport. The pandemic allowed us to change our model of care and allowed our practice to be flexible.

The pandemic continues to be exhausting, but self-care/team care have been normalised. Working with culturally and linguistically diverse COVID-19 outreach immunisation hubs grounded me as each person has been so thankful for the care. It has also been a privilege to deliver education on COVID-19 and vaccinations to them. Vaccine uptake has changed as their questions have been answered and experiences validated.



MERILYN SPRATLING FACN

**Refugee Health
Nurse Practitioner
and Clinical Lead,
EACH, Victoria**

CORE VALUES AND COMPLEXITIES

Refugee health nursing has been my passion for the past 12 years. I started as the Refugee Health Nursing Coordinator at EACH social and community health when the Victorian Refugee Health Program expanded to the east of Melbourne. I completed a Master of Nursing Practice (Nurse Practitioner) and was endorsed as the first Refugee Health Nurse Practitioner in 2014.

Refugee Health Nurses (RHNs) are Registered Nurses and practise in a range of clinical environments that use a primary health care model, and their work is underpinned by the philosophy of trauma informed care. Practice by necessity must be grounded in the knowledge of contemporary political environments, advocacy for the rights of the individual, family and community, and be culturally informed, inclusive, sensitive and safe (Refugee Nurses of Australia, 2021).

RHNs are often the first point of contact for people newly arrived in Australia. They may need to undertake comprehensive, holistic, person-centred health assessment for people, from newborn babies through to the elderly, quickly triage large groups to identify those who need urgent attention (happening currently with the people from Afghanistan), provide complex care for acute and chronic health care issues, immunisations, women's health, mental health and refer to other health care providers including GPs.

RHNs often identify people of refugee and asylum seeker background that have fallen through the 'health care gap' encouraging and supporting people to reconnect with appropriate services. Skills to work effectively with interpreters and knowledge

of the impact of political, social and economic factors on the health of people are essential.

Ineligibility for Medicare significantly impacts access to GPs and other health services, notably radiology and pathology. Additionally, GPs in private practice, who rely on Medicare income, cannot see people of refugee background not covered by Medicare.

Some community health centres provide access to GPs without cost, but they cannot provide radiology and other services or PBS funded medicines without cost to the patient. Some people seeking asylum have income through the Status Resolution Support Services program, but it is a small amount and prioritising health care including medications is difficult as this money must also cover rent, food and other necessities for their families.

This leads to increased demand on emergency departments of public hospitals, when care would be better met by the primary health care system.

IMPACT OF THE COVID-19 PANDEMIC

People on temporary refugee visas and asylum seekers often live in financially challenging situations, either unable to get work or without work rights. Organisations such as the Asylum Seeker Resource Centre have noted significantly increased demand for assistance due to the pandemic. This is also true for refugee health programs who look after people seeking asylum who no longer have enough money to pay for medicines.

The Australian Humanitarian resettlement program is on hold with only a handful of people in extreme crisis arriving in Australia in the past 18 months. Additionally, people from these backgrounds have added concerns about what is happening at home for their families and friends.

My role as clinical lead for the EACH COVID-19 vaccination clinic has in part focused on assisting refugee and asylum seekers to access vaccinations. Some

have been able to navigate the system to make appointments and attend clinics or their GPs for vaccination. But for others, lack of translated information, onsite or phone interpreters, and difficulty getting to clinics has compounded some hesitancy within communities.

EACH and other community health services, in collaboration with leaders of refugee communities, have offered mobile and pop-up clinics in locations more acceptable and accessible, such as mosques, community centres, churches, and a Hindu temple.

SUPPORTING THE PROFESSION

Twelve years ago, when I started my role, people arriving in Australia did not have access to all immunisations on the Australian immunisation schedule. Local advocacy activities involved lobbying local parliamentarians. State-based activities through the Victorian Refugee Health Network eventually resulted in full access for refugees and asylum seekers to all immunisations for catch up programs.

In 2016, the RNA was formed by a group of experienced nurses from all Australian states to provide a national approach to advocating for improvements in refugee and asylum seeker health care.

However, the profession needs support nurse from academics and researchers to develop nurse-sensitive indicators to formally evaluate this specialty. There is a lack of research about the impact of refugee health nursing. RHNs would welcome access to post graduate education programs that specialise in refugee health nursing practice, and which are affordable.

RHNs do not generally have access to debriefing and/or reflective practice as some other health providers do. Working with people in distress, who divulge traumatic stories means nurses may experience vicarious trauma. RHNs in rural areas, who often work alone without the support of a health care team, can particularly benefit from debriefing.



JAN WILLIAMS MACN

Nurse Unit Manager, Refugee Health Service, South Australia

CORE VALUES AND COMPLEXITIES

My responsibilities include managing a multidisciplinary team of clinicians, which includes doctors, nurses, allied health professionals, social workers, psychologists and admin staff.

We provide on arrival primary care services for all humanitarian entrants in SA, and once they understand how the health system works, we link them to community GPs. We also see asylum seekers and other people who have lived in the community longer who may have fallen through the gaps.

The constantly changing demographic of refugees and the State and Federal politics that surround refugee settlement make this work increasingly dynamic, and it always feels like a different job.

We had to respond very quickly with the Syrian crisis a couple of years ago, and mobilized services to respond to a quite a large cohort. Right now, with the emergency Afghan arrivals, we're doing exactly the same; we had to rapidly develop programs to respond to the large volume.

But situations often differ a lot. For example, in recent years we've seen huge numbers of people coming from Central America and South America, whose refugee status has been granted on the basis of their exposure to violent crime through gang warfare. For women particularly, there are gender-based violence issues, and we had not worked with that population group before, so it necessitated rethinking on some of our allied health programs and health screening and so on.

Add to that the disease profiles that people may bring with them. So, in this area, you really need to stay in sync with evidence-based practice and the national and international guidelines on responding to disease profiles in refugee background communities.

IMPACT OF THE COVID-19 PANDEMIC

The pandemic has had a profound impact on people seeking asylum.

The one thing people need to seek asylum is to cross borders and that stopped with the pandemic. That, and the backlog of people waiting to migrate in, have created an incredible burden internationally.

It also sets the scene for what our responsibility is going to be over the coming years at a time when countries are becoming sort of nationalistic, unwilling and nervous about taking their own expatriate arrivals, let alone humanitarian arrivals.

The flipside of all this is that we have had to adjust to telehealth, and we have had the opportunity to focus on things that we usually don't have time to focus on, such as health literacy and community education programs. These have been especially important given the amount of misinformation flowing around vaccinations and the impact that has had on uptake of vaccines in these communities.

I think there's often an over estimation in terms of how health literate people are and how well they are able to navigate applications and information sites, even if they are translated. Literacy and education remain ongoing processes for us. We also have to respond to the whole range of pre-migration vaccines. Our Commonwealth immunisation register isn't yet able to recognise some of those vaccines. And this will become a bigger issue when the borders open.

SUPPORTING THE PROFESSION

We don't have a national refugee health strategy or framework. Every State and Territory has its own refugee health program and some states like Victoria and Queensland have funded policies but there are so many different moving parts. You've got State-based health services working with the Commonwealth humanitarian program that subcontracts settlement support to NGOs, and the interface between all these players gets very complicated. Without a national refugee health strategy, there's so much that's left up to each jurisdiction and sometimes there are inconsistencies in service delivery and client care.

These challenges sometimes breach all the access and equity principles that we really try and promote through our work. And that's essentially what we're about as refugee health nurses: advocating, to ensure equity of access to health care for

our clients and responding to their complex and diverse health needs.

With the recent Afghan crisis, both RNA and the Refugee Health Network of Australia (RHeaNA) reached out to the Commonwealth and offered their expertise on treating and supporting this group. We now have regular meetings with the Department of Home Affairs, and Services Australia to bring to the forefront the health issues and challenges associated with this cohort. In an ideal world, as peak bodies in refugee health, RNA and RHeaNA would have automatically been involved at the onset, in the Federal health and settlement response to this humanitarian crisis.

Health underscores every aspect of refugee settlement including housing, employment and education. If you're not healthy or emotionally together, you can't engage with any of those other aspects of settlement.

The current lack of nursing positions is yet another issue. We aren't getting that refresh of international nurses or movement between the states, so every state is relying on a fairly static and tired workforce.

The other side is that every state still has a flux of new graduates who don't get into graduate programs every year. Universities operate as private institutions, making their income through training, but without any kind of partnership with state governments around providing paid positions for those new graduates and I just think that it's heartbreaking.

The health budget is so consumed by operating the tertiary machinery, procedural specialists and investigations – nursing workforce is pretty low in the priority list. So, nurses often end up being overworked, undervalued and underpaid. The older workforce is not able to move on.

Despite all these challenges, one can't deny what a privilege it is to do this work. It's a unique area of nursing that changes every day; you learn something new every day and are constantly surprised by what it brings with it. Being able to work in a primary health care setting and focusing on preventative health care, having the autonomy to work to one's full scope are some of the greatest aspects of this role.

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Aged care: The ugly truth behind beautiful potential

The systemic issues plaguing the sector have a simple solution. The question is: what will it take to implement it?



What is aged care about? Working autonomously to provide holistic care, catering to complex clinical needs in a home-like environment, building rapport and nurturing residents' social and emotional wellbeing, and providing support in the final moments of their life. This is what aged care should be, and more importantly what it could be.

Instead, the reality of aged care is undervalued and underpaid workers burning out as they try to complete the minimum required tasks set by unrealistic expectations. Staff missing meal breaks and toilets breaks just to ensure that minimum care is delivered, and heaven forbid if someone needs a little extra care.

Residents and families feeling neglected due to the impossible workloads and time restraints. Resident deterioration going unnoticed due to lack of staff. Yet, aged care workers continue to go above and beyond for residents, despite having a government that does not support safe working conditions. Aged care is unmanageable, unrelenting and unsustainable.

The people who work in our aged care sector are some of the most dedicated and compassionate people I have ever met. They care so much for their residents that they continue to work in an environment that

is detrimental to their mental and physical wellbeing, puts their registration at risk, and pays on an average \$300 per week lesser than public sector nurses (ANMF, 2010).

So how can we expect the attraction and retention of highly qualified and skilled nurses?

From personal experience, I can tell you that these issues are real, deeply embedded within the sector, and are having a damaging effect on staff and residents alike. The basic requirements of care and companionship are often neglected due to chronic understaffing, a symptom of systemic issues plaguing the sector.

In my experience alone, aged care is the incomprehensible responsibility of care for up to 100 residents on a shift. It feels as though you can never do enough, nor spend enough time to ensure the bare minimum is accomplished. One often carries the burden of the day home after staying three hours after one's shift just to complete documentation, only to realise you have forgotten something. Aged care is challenging beyond words, but it does not have to be.

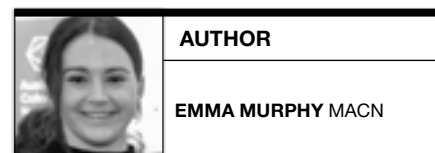
The strain on our staff is so great that they have no mental or physical strength left to fight, because they are fighting every single day to do the best they can, in dire conditions. So those of us who have been

forced out of the sector due to these conditions must continue to fight for them.

Our politicians will argue that these issues are 'complex' and there is 'no easy fix' – these are excuses we refuse to accept. The Royal Commission into Aged Care Quality and Safety (Royal Commission), extensive research, and experience all point to the same simple solution — we need the implementation of mandated skill mix and staffing minimums in all residential aged care facilities.

The Royal Commission has made 148 recommendations which have the potential to pave the way for great change within the sector. These recommendations provide comprehensive rationale, steps for implementation and suitable timeframes. All we need is a government willing to act on these recommendations.

By simply increasing staff and skill mix within residential aged care, we will see greater mental and physical health outcomes for staff and residents. Staffing improvements will allow for the recommendations to be implemented and effectively adhered to throughout the Australian aged care sector.



Understanding end of life law

As nurses are at the frontline of providing end of life care, it is vital they understand the legal issues around this area and its impact on practice

“Nurses providing end of life care can face significant ethical challenges as they balance a range of sometimes competing perspectives on the how to support individual patients.”

The End of Life Law for Clinicians (ELLC) project is designed to help clinicians learn about end of life law and the effects this has on end of life care and palliative care for patients. The course aims to improve nurses' knowledge and awareness of end of life law; prepare them to apply the law in practice; assist them to manage legal issues; and support their delivery of quality end of life care.

Earlier this year, the free national training program launched 10 new and updated online modules for all nurses (Nurse Practitioners, Registered Nurses and Enrolled Nurses). Distinguished Professor Patsy Yates FACN, who was part of the academic team that developed this course, talks about the course and why nurses should consider taking up this training.

PURPOSE OF THE TRAINING PROGRAM

Nurses are at the frontline of providing end of life care. End of life care requires that nurses do their utmost to support patient

choice and promote dignity. Such goals can present significant ethical challenges for nurses as we balance a range of sometimes competing perspectives on how to support individual patients.

It is critical that nurses are supported by an understanding of the ethical and legal frameworks that support their practice, so that they are empowered to provide best possible care for people who are dying.

LEGAL ISSUES AND THEIR IMPACT ON NURSES

Some of the legal issues nurses face include assessing capacity and ensuring informed consent to medical treatment, withholding and withdrawing life-sustaining medical treatment, promoting and using Advance Care Planning and Advance Care Directives in practice, and identifying and supporting substitute decision-making for medical treatment.

Our research demonstrates that these issues present significant practical and emotional challenges for nurses as they

deal with conflicting perspectives and face the existential distress experienced by some patients and their families.

KEY COMPONENTS OF THE TRAINING PROGRAM

The training program addresses the role of law at end of life from the perspective of doctors, nurses and allied health professionals. It covers issues including when consent to medical treatment is required, when it will be valid and how to determine the capacity, and when a decision to withhold or withdraw life-sustaining treatment can be made.

It also explains what an Advance Care Directive is, and the information it can contain and when an Advance Care Directive can apply, as well as what decisions a substitute decision-maker can make. Important clinical concepts such as the doctrine of double effect, its application in practice, how to differentiate between the lawful provision of pain and symptom relief, euthanasia and voluntary



assisted dying are also explored. The program includes interesting modules on the concepts of futile or non-beneficial treatment, and how it is decided.

Importantly, the module provides useful information about how to identify clinical and legal processes for managing disputes where a person does not have decision-making capacity and the role of guardianship bodies, courts and tribunals in resolving disputes about medical treatment. The final modules address the legal status of Voluntary Assisted Dying in Australia.

BEING PART OF THE COURSE DEVELOPMENT TEAM

It has been a very rewarding experience to be part of the team that has developed this course. The team involves leading legal experts who have dedicated their professional careers to ensuring the law supports quality end of life care. They have worked closely with health professionals over many years to help them to understand how the law applies in their practice.

I was especially pleased that the team has focused on the important role of nurses in end of life care, and the unique issues that nurses experience. The respect that the team has for nurses was evident in the considered way they researched the issues and used this research to inform the education program.

MODULES PARTICULARLY IMPORTANT FOR NURSES

All the modules will be relevant for different reasons. Some are relevant because they provide useful, factual information about the law and dispel myths, such as modules about Advance Care Planning and withdrawing and withholding treatment.

Others, such as managing conflict, are useful for nurses who must deal with such dilemmas in their practice.

FEEDBACK FROM THE FOCUS GROUP


Nurses in the focus groups shared their passion for ensuring quality end of life

care, and the distress they experienced at times because they could not deliver the care they felt the person deserved.

Nurses reported that they did not always have a good understanding of the law and how this could help them, and that this meant they did not always know how to respond.

As a result, nurses were very keen to ensure that more work was done to support our profession to advocate for patients and work effectively as a team in end of life care situations.

The course can be accessed for free at palliativecareeducation.com.au

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