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Physician, heal thyself: a need for change from within

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Bullying and sexual harassment of junior doctors within New Zealand hospitals has recently come to light following a damning report published by the New Zealand Resident Doctors' Association (RDA). This problem is not limited to junior doctors. The New Zealand Medical Students' Association (NZMSA) has released a press statement highlighting the "vulnerable position" of medical students. Our goal is to further the current conversation around this pressing matter and push for change.

Bullying and sexual harassment exists in the medical workforce, yet its true prevalence is unclear. Earlier this month, NZMSA conducted a survey of New Zealand medical students on bullying and sexual harassment and the results are alarming. Of the 772 respondents, the majority (54%) of medical students surveyed had experienced at least one event of bullying and/or sexual harassment in the past year alone. Some students reported incidents occurring on a regular basis, weekly or even daily.¹ Although many students experienced such behaviour, 87% of respondents did not report it.¹

From research overseas, we know this problem is not limited to New Zealand. A recent United Kingdom study charting medical students' experiences with bullying and harassment at one site, found 18% of medical students had either witnessed or experienced bullying and harassment.² In a large United States survey, where more than 2300 medical students participated at three different time points in their career, 85% of students reported having been harassed or belittled and 40% experienced both.³ Bullying and harassment is a pervasive, widespread problem affecting medical students around the world. The NZMSA have taken the initial steps in the right direction to precisely quantify the problem in New Zealand.

So how harmful and damaging is a culture of bullying and harassment? Firstly, it is harmful to medical students. Medical students who reported cases of mistreatment are more likely to experience "depression, alcohol abuse, low career satisfaction, low opinion of the physician profession, increased desire to drop out of school and even suicide."^{3,4} Secondly, it is harmful to patients. Medical teams rely on each other to practice safely and effectively. Damaging behaviour from senior staff directed towards junior colleagues and medical students can erode the trust and cohesiveness required within medical teams to deliver high-quality patient care.

There is little to support the counter claim given by some senior medical professionals. They argue a confrontational learning environment will challenge the knowledge and learning capabilities of students. Musselman and colleagues have noted intimidation and harassment in surgical education can commonly be seen as a functional educational tool.⁵ In New Zealand hospitals, harassment and bullying is frequently used in the name of teaching. However

there is a difference. Teaching through bullying and harassment is not the same as teaching with an intensely constructive, challenging and supportive approach. It is this former approach, which we believe must be eradicated from the current hospital teaching culture.

Two major concerns must be addressed immediately: high rates of bullying and sexual harassment, and under reporting by medical students. We have two fundamentally intertwined problems in our hospitals: bullying and sexual harassment and the culture of hierarchy. When medical students are not intimidated and fearful of senior team members, students will feel empowered to speak up. This shift in culture will facilitate increased reporting thereby helping senior authorities to accurately perceive the true rates in our hospitals. As a result, the appropriate actions can be taken by senior staff and management to adequately protect the health and safety of medical students, team members and patients.

Bullying and harassment has been a serious issue since the birth of medicine. It is widespread around the world and in New Zealand. Drastic changes need to be taken to protect the welfare, safety and dignity of not only our doctors of tomorrow but more importantly the patients of today. Furthermore, confrontation is commonly used as a pedagogical tool in medical education. However, students should not withstand abuse in the name of learning. With the heat of public light on this issue, due to the efforts of the RDA and NZMSA, it is crucial we push for change to excise the current culture of bullying and sexual harassment and the culture of hierarchy in our hospitals. Most importantly, to push for change ask yourself this, why is bullying and sexual harassment tolerated in medicine?

REFERENCES

1. New Zealand Medical Students' Association.
NZMSA Final Bullying and Harassment Survey Results.
<http://www.nzmsa.org.nz/wp-content/uploads/2015/08/NZMSA-Final-Bullying-and-Harassment-Survey-Results.pdf> (accessed 16 September 2015).
2. Timm A.
'It would not be tolerated in any other profession except medicine': survey reporting on undergraduates' exposure to bullying and harassment in their first placement year.
BMJ Open 2014;4.
3. Frank E, Carrera JS, Stratton T, Bickel J, Nora LM.
Experiences of belittlement and harassment and their correlates among medical students in the United States: longitudinal survey.
BMJ 2006.
4. Stratton TD, McLaughlin MA, Witte FM, Fosson SE, Nora LM.
Does students' exposure to gender discrimination and sexual harassment in medical school affect specialty choice and residency program selection?
Acad Med. 2005;80(4):400-408.
5. Musselman LJ, MacRae MH, Reznick RK, Lingard LA.
'You learn better under the gun': intimidation and harassment in surgical education.
Med Educ. 2005;39:926-934.

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An issue of respect

Dr Stephen Child

Chair

New Zealand Medical Association

The issue of bullying has recently become very topical, with the publication of two surveys on the topic.

But this is not a new issue. A survey in 2006 in the UK — and repeated in NZ in 2008 with publication in the *New Zealand Medical Journal*¹ — showed rates of up to 50% of students having experienced a single episode of bullying. Results such as these are clearly deplorable and need concerted effort to improve. In my opinion, however, the issue is larger than that captured in the published surveys. The more important issue stems from the age-old concepts of respect, gratitude and 'rudeness'. The 2008 NZ-published survey demonstrated that the perpetrators were split fairly evenly between nurses and consultants (at 30% each) while the rest were patients (25%), peers and radiologists.

Similar studies have also shown that abuse from patients is extremely high in the medical field and is a major contributor to staff burnout within emergency departments. An interesting study we did at Auckland hospital revealed that over 60% of nurses did not say "please" or "thank you" when requesting a HO to perform a task, while nearly 90% of people did use these words when ordering coffee at the hospital. A huge staff values exercise at ADHB listed a simple "thank you" as the number one issue desired by staff in order to feel valued.

It should also be noted that the environment of care within a hospital system is hierarchical in nature and extremely stressful. In stressful situations, people may tend not to prioritise their standard 'manners', at the expense of others within a team. In addition, senior people giving bad feedback to a more junior colleague may also seem to be bullying if the feedback is delivered poorly, such as, for example, being non-specific without examples, giving negative feedback publicly, making feedback personal rather than on behaviour, expressing emotion and so on.

So, while it is appalling to see such high incidence of bad behaviour in our profession, I do think that it is important to compare this to other stressful hierarchal institutions such as the army, police and fire response.

That is not making an excuse for the behaviour, though, as fundamentally it is all unprofessional behaviour. Noting bullet points 1, 2 and 7 of our Declaration of Geneva, we have all sworn to uphold the traditions of our profession, which include respect for others — and indeed in bullet point 1 we consecrate our life to serve humanity!

All disrespectful behaviour is wrong. We are our brothers'/sisters' keeper and should act as we wish to be treated. Positive praise should be prompt and public. Negative suggestions should be planned, private, specific and behaviour-focused only.

"Please" and "thank you" should be part of the lexicon of our profession from the outset. Knocking before entering a patient's room and awaiting a response should be standard. Apologising for error should be as natural as breathing. Kindness, empathy and patience should be embedded in our daily behaviour.

This is not a 'blame' focus. This is not an issue where senior doctors are bullies or the system is bullying or a particular nurse is a bully — but it starts with us. It starts with how we approach an elevator door simultaneously with a stranger: do you step back and let them go first or do you barge ahead? Do you say please and thank you when ordering food in the cafeteria? Do you pick up some rubbish on the floor when walking past?

Anyone on the receiving end of bullying behaviour should feel able to speak up and ask for help. Speak to a supervisor or a colleague. Ask for support — and be prepared to offer it and to speak out if you see instances of bullying around you.

Change starts with us all and change starts from within. Yes, we need to have structural support within our systems and yes, we need to live the values we respect but we also need to look at ourselves and begin the culture change by changing ourselves.

REFERENCES

1. Scott J, Blanshard C, Child S. **Workplace bullying of junior doctors: a cross-sectional questionnaire survey.** *NZ Med J.* 2008; 121(1282). http://www.nzma.org.nz/_data/assets/pdf_file/0005/117807/Vol-121-No-1282-19-September-2008.pdf

Doing aged residential care better – the view from the trenches

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ABSTRACT

In this article, we explore issues within the aged residential care sector from the perspectives of representatives of the workforce and the residents themselves. Qualitative interviews were conducted with residents, nurses and care workers at one residential care facility in Dunedin, New Zealand. Care workers expressed a strong vocational ethic of care but also raised concerns in the areas of wages, career progression, training, resources and workload management. They offered opinions on how the sector could improve on these issues and better support its carework employees. These included increased wages, training programmes, in-house management of equipment and allowing experienced care workers to have a stronger voice in the sector. Opinions expressed by the participating residents supported those made by the staff; they voiced concern on behalf of the care workers in regard to wages, training and workload.

INTRODUCTION

Like many other developed countries New Zealand has an ageing population which is expected to result in increased demand for residential care facilities. In 2011 there were approximately 32,000 older people that were cared for by such services. This number is projected to increase to approximately 38,000 in 2016 and to 52,000 in 2026.¹ The 85 and above age group is the largest user of residential care facilities and their numbers are projected to double between the years 2006 and 2016. Concerns have been expressed about the potential impact upon demand for care.^{1,2} On top of anticipated increasing demand, those in care have become more dependent. A recent Auckland based study conducted by Boyd et al found that over a two decade period from 1988 there was a decrease in the number of residents who were apparently independent (from 16% to 4%) and an increase of those highly dependent (from 12% to 21%). Dependency was quantified by considering factors such as mobility, toileting and continence, orientation, memory and behaviour.³ An overall increase in the dependency of residents puts more pressure on those who are providing care.

These are worrying statistics in light of the current concerns around the quality of aged care in New Zealand. 'A Report into Aged Care' commissioned out by the Labour and Green parties in conjunction with Grey Power New Zealand⁴ uncovered some serious shortcomings in

how older people are cared for. These authors described aged care as an "unregulated, desperately short staffed sector... [They] found a sector fast reaching crisis point, struggling to meet the growing needs of an ageing population and residents' rising acuity levels. The result is that many older New Zealanders are receiving substandard care."⁴ This report, together with the Aged Residential Care Service Review (ARCSR) uncovered many fundamental issues and made a series of recommendations.¹ These included 14 recommendations put forward by the 'Report into Aged Care' and 15 by the ARCSR which ranged from establishing an aged care commissioner to having pay parity for the staff.^{1,4}

Many studies have aimed to quantify the quality of life (QOL) of residents in aged care. Important factors such as leisure activities, family, relationships and independence along with the quality of life of co-residents and physical ability have strong correlations with QOL.^{5,6} Marquis advocated that the quality of care in rest homes should be focused on resident outcomes, such as QOL, and not service outcomes, such as profit. Residential care facilities in New Zealand are audited on a framework of standards set out by the Ministry of Health.⁷ The standards included in the audit are: consumer rights, organisation management, continuum of service delivery, safe and appropriate environment, restraint use and infection prevention, and control.^{8,9} Facilities are given a score ranging from major shortfalls through to commendable.^{8,9} While all the factors included in the audit will affect QOL there is no direct analysis on how the residents of that facility perceive their own quality of life. A limitation to this is that currently there is no standardised way of assessing one's QOL.¹⁰ Some researchers have developed their own measures based on other literature or based on trends that emerged while interviewing participants.^{11,12} More common methods of assessing QOL are the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) or the simplified SEIQoL-Direct Weighting approach.^{13,14} Both methods have been used widely and utilised in many different international settings but have not been universally adapted for New Zealand.^{15,16,17}

A recent study conducted in Spain by Rodríguez-Martín et al examined what quality of care meant for residents of a care facility by conducting a series of interviews.¹⁸ All participants considered the care staff to be a vital aspect. Specifically, staff should be affectionate, kind, good mannered, qualified and able to show personalised attention to detail when assisting with care. Resident independence was also regarded highly. In particular there should be no strict rules to living.¹⁸

As well as the aforementioned research regarding residents there has been some exploration into the challenges that health care assistants and nurses face in regards to working conditions and rates of pay in aged care. According to a recent survey by the New Zealand Nurses Organisation the most frequent source of dissatisfaction from the current staff was the high staff turnover rate and co-worker absence.¹⁹ Factors that contribute to staff absence and the high turnover, which in some facilities has been

found to be as high as 43% over two years, may relate to the nature of the work.^{19, 20} The challenge of providing basic personal care and managing people with dementia combined with receiving near minimum wage, feelings of under appreciation and limited job progression render the sector unappealing to the labour market.¹⁹ In this article, we present findings from a small qualitative research project exploring the perspectives of long term residents and careworkers in one aged care facility on how to sustain quality of care to the highest possible standards.

METHODS

Setting

This research was conducted in a hospital-care wing of a retirement village complex in Dunedin. The participating retirement village is a modern facility with specialist aged care for up to 120 residents.

Participants and recruitment

Consent processes were negotiated between the research team, retirement village management and the University of Otago Human Ethics Committee (HE13/08). All participants were asked to give consent. Furthermore, it was requested by retirement village management that the residents required consent from their next of kin. The facility manager and clinical nurse leader were responsible for recruiting of participants. Despite the negative attention the sector has received we entered the facility with the assumption that there was nothing hidden to be uncovered as the participating home had passed all audits. Five residents, five care workers and three registered nurses (RNs) from the care facility were invited to participate. To participate the residents had to be over 65 years old, lived in the facility for over six months, could speak English, and without deficits in cognitive function. Cognitive function was not formally assessed, instead the nursing staff made judgements relating to the residents ability to participate. The care workers and nurses had to be over 18 years old, worked in the care facility for more than 6 months and could speak English.

Qualitative interviews

The interviews were semi-structured qualitative interviews based around predetermined open-ended questions.²¹ Semi-structured interviews were used as they afford the interviewer the freedom to explore unanticipated and de novo responses while not constricting to a set interview schedule. The interviews were audio recorded. They took place in a private room at the care facility and were conducted one-on-one. Family members of the residents were free to attend as support and one resident chose to have their family member present during the interview. The questions asked focused on identifying issues in the provision of quality care and exploring possible solutions from the perspective of the interviewee. Examples of the questions included, "what are the challenges in providing good care?" and "how could these challenges be overcome?"

Analysis

A general inductive approach, as described by David R. Thomas, was employed to identify and code recurrent themes within the audio recordings.^{22, 23} An innovative method of analysis was utilised so that the audio files themselves formed the basis of analysis. After the interviews were completed, recordings were listened to multiple times. Only selected quotations were transcribed verbatim.^{22, 24} Quotations were selected if the subject content could be categorised by a definable idea or related to an emerging theme. Once the raw data had been converted to text, quotations were read through multiple times and categories of emerging themes were created. The text was broken up and coded into each category. If the text segment reflected more than one common theme this method allowed it to be coded into more than one category. Categories were then refined to reduce overlap and reveal overarching themes that would be included in discussion.

RESULTS

The mean age of the residents was 76. They all identified as NZ European, three were females and two were males. All the staff interviewed were female with a mean age of 35. All the care workers identified as NZ European while there were different ethnicities amongst the RNs.

Care Ethic

A key theme that emerged from the analysis was that participating staff held a very strong ethic of care. All the staff interviewed asserted that the primary reason they remained in aged care work was the enjoyment they get out of their work.

"And the care that we do for the residents means a lot; that is why we are here anyway... For me nursing is who I am. I am passionate about my work. It's not really about the money it's what I do."

"I think it's just my nature to give and care for people. It's something I've always enjoyed - helping people and feeling like you're actually valued for what you are doing."

Against the obvious satisfaction that participating staff gained from their work, they identified wages, training, workload, appreciation and access to equipment as the primary challenges for careworkers and the aged care sector.

Wages

Staff considered that the wage they received did not adequately reflect the demands of the job and the effort they put into their care work. This is a well-documented issue and a strong theme in all of the interviews. The low wage contributed to feelings of lack of value and low job satisfaction and a critical factor contributing to the high turnover of staff. Furthermore, experienced more senior care workers were unsatisfied with the pay increments they have received after such long service.

"They could pay us more; we are quite underpaid for what we do. Sometimes you do wonder why you do it. I could get more money standing out on the street holding a lollypop sign."

A related concern expressed by some participants was that unsuitable people were being employed within the sector. They suggested that increasing the rates of pay would resolve many of the issues in aged care via a follow on effect.

"If you put the wage up higher you'd get more people applying for the jobs. That way you could be picky with the staff you want... when you pay peanuts sometimes you get monkeys... Then it would make a huge difference to patient care, you would just be working with top-notch people who knew what they were doing."

"The big thing to improve a lot of the places would be to pay more. That would bring a lot more experienced people into homes and the more experience that you have the more efficiently the place is run... We do have a lot of experience and we leave and go elsewhere because we are underpaid."

Participating residents were also critical of the low wages paid by the sector to care workers. One resident said:

"Pay, it is very poor... It's almost like a voluntary job for the money they get. It's incredible what they do, they are off their own back... It's a shame really they just couldn't get more pay."

Training

Staff members expressed a need for more accessible training and a more educated workforce. As with the low wage there was a concern that the low level of education required to enter the sector was attracting a cohort of unsuitable individuals into caring roles.

"I do think that the [lack of] qualification is a big [issue] because anybody could walk off the street into here. And the people we get! ... There are people who work here that shouldn't be. They are lovely people but they don't know how to care for the elderly. There's a lot to learn about different ways of dealing with residents in different situations. I think it needs to be more education based."

Many of the staff held the view that increasing the amount of training and making training more accessible would improve the quality of care residents receive.

"A lot of the training they have here is through meetings and lectures and we haven't been able to attend. They have been when we are working and we have to go out for all the bells. I know you can't get everybody all the time but try to vary the timetable a little bit so you can go when your shift is over or your day off. You have to be educated on some of the protocols, [on the] different cares, [such as] aged care and dementia. Just make it easier for people to attend."

Residents were unanimous that care workers should have a higher level of competency before they enter the job and are given responsibility.

"Well they do teach them but perhaps a bit more attention to that... You don't feel very good with someone new because you have to explain to them and that takes a bit of time. I suppose they have to learn but you'd expect them to be taught what to do."

Workload

The workload pressure experienced by care workers was a key concern for most participants. Aged care facilities can be busy and stressful working environments. Our participants felt it was often a struggle to meet the diverse needs of high demand residents.

"This is one of the busiest jobs I've had, there is no down time. We are on the go as soon as you walk in the door to when you leave."

"Sometimes we don't have time to do the little things like finger nails, cleaning out their drawers or making sure their wardrobe is nice and tidy. The little things behind the scenes that need to be done but that get neglected as we don't have time."

"I think that even when we do have full staff we don't have enough. Even when we have what we are supposed to it is not enough."

Some of the residents interviewed also expressed their opinion that the facility was short staffed and that the workers had an unrealistic workload.

"Not enough staff... More staff will solve a lot of the problems."

Appreciation

Care workers viewed care work as a skilled vocation and reported that it is easy to feel unappreciated and inadequately recognized by the sector. They expressed the desire to have a stronger voice in local decisions made about equipment requisitions, social events and resident care plans. They considered that this perceived lack of value also contributes to the high turnover of staff and a high absence rate.

"I don't think staff are appreciated. I believe [the care workers] are the back-bone of the entire industry and our opinion matters. If there is an issue we are not asked our opinion, [as if] we're not really here, we just do the hard work and that's it."

"We do have a lot of experience but we leave and go elsewhere because we are underpaid and undervalued. We have a lot to offer."

"I think appreciating staff [is a solution]. People are not going to come in and work extra shifts if they are not appreciated."

Equipment and resources

An issue identified by many of the staff was the need for facilities to invest adequately in the specialised equipment required in aged care facilities.

"Here we spend an awful lot of our time looking for things such as shower chairs. It would make it easier if those things were more readily available and we were able to find them easily. Then our job will go more smoothly."

Solutions

Many of the staff interviewed offered solutions on how to make care workers' workload more manageable and how to improve the care received by residents.

"I think perhaps working in pairs, because you get through the residents a little bit quicker and it makes your workload easier. Bedding, bathing and things like that, it would be easier with two people as some [of the residents] can be quite heavy."

"This morning I had to answer the phone as well as train somebody, plus do my cares. They could take [a responsibility] off or lessen my group so I don't have so many people to get up. So I have more time to train somebody."

"We [the care workers] don't have meetings with the nurses to discuss our residents fully. We don't have a lot of contribution to their care plans. I think sometimes an RN should actually [carry out a care routine with] a resident before they are doing their care plan to know what their resident would like. They don't actually do the person but they write the paper work up and tell us what to do."

One nurse participant suggested the scope of practice for registered nurses was too narrowly defined in the aged residential care sector. She considered that registered nurses' professional competencies were not being well utilised resulting in delays for residents who required medical attention. She suggested that if nurses had a wider scope of practice residents would receive more prompt resolution to some of their health and clinical concerns.

"Even up until now I still have that funny feeling that I am not doing my level best when I see things and I can't do anything about them, because somebody else is supposed to do it. That makes it difficult for me but I am learning to let go. So that's one of the constraints that I have... I'm not allowed to fly."

RESULTS

The issues in aged care are well publicized because of the attention the sector receives from the media. Absent from the body of literature are the opinions of those on working on the front line of the sector and the opinions of those living in care facilities. Our findings suggest that care workers, nurses and residents can make a contribution on how to improve working conditions of staff and quality of care received by residents. Their key message to the sector concerns the provision of a better wage and a recognised training pathway for care workers. They also identified a need for greater recognition of the value of care working to the sector and input in decision making, better access to resources, notably equipment, and an improved, better managed work load.

The Waitemata District Health Board (DHB) has recently established a dedicated Gerontology Nurse Specialist (GNS) team to try and address some of the issues of aged care in their region.²⁵ The GNS team collaborates with residential care facilities to help them build a functional relationship with the DHB and to offer extra support for the aged care workers. One such initiative the team has established is a clinical hotline that nurses can ring for extra guidance. Since the establishment of the GNS team there have been lower rates of hospital admissions from the care facilities and a lower turnover of staff.²⁵ As well as establishing their own GNS team, the Canterbury DHB has started a Gerontology Acceleration Program (GAP).²⁶ GAP is aimed at mid- to senior-level Canterbury nurses and provides them with a framework of clinical skills relevant to aged care. The aim of this initiative is to develop aged care nursing as a career choice and to strengthen the competency of the workforce.²⁶ Similar initiatives have been started by the Taranaki and Midcentral DHBs aimed at supporting and strengthening the nurses' role in aged care.^{27,28} Such programmes would address one of the issues raised by an RN interviewed in this study. That extra support and training may widen RNs' scope of practice and allow them to resolve more health concerns without the need for a GP visit or hospital admission. The reduction in staff turnover that resulted from the implementation of the GNS team would also address issues raised in this study, including the inconsistency of care.

Care workers expressed the greatest dissatisfaction with the work conditions of care work, more so than the RNs. Residents expressed satisfaction with the care they received and were appreciative of the staff. They particularly complimented the staff on their attentiveness towards their carers and the friendly, cheerful manner in which they go about their tasks. It is a testament to care workers' vocational ethic that the residents reported such a high standard of care. It also suggests that personal dissatisfaction with the sector is not reflected in the care they provide. All residents were aware of the challenges that their care workers face and many expressed solidarity with care workers. We found that the RNs were more content in their role than the care workers. Overall, they did not raise the same concerns regarding pay and working conditions. Perhaps this reflects the positive societal value associated with the nursing profession and the gains made for the nursing sector over the previous decade by the New Zealand Nurses Organisation.

While some aged care organisations offer training programmes for care workers, these do not have the recognition that a nursing degree carries, nor is there a career path associated with current training options. The competencies of care work are not formally recognized in a national tertiary qualification. The nature of care work means care workers are able to develop a familiarity or intimacy with their residents that surpasses that of nurses and managers and this represents a wealth of knowledge that can contribute greatly to the resident care plans and the running of a facility. The initiatives described above to improve aged care target registered and enrolled nurses.^{26,27,28} Experienced care workers represent an untapped resource for the organization of care work.

The solutions offered by our participants echo those put forward in the Report into Aged Care, such as pay parity with other 'unskilled' professions, minimum staffing levels mandated in regulation and government funded training to all aged care staff.⁴ In addition, our interviewees suggested that morning and evening care routines could be run more efficiently by rostering the use of equipment and sharing responsibilities. These are

achievable ways in which to address some of the issues raised.

LIMITATIONS

Sample size was a limitation in this study. Due to time constraints 13 people from the same facility were interviewed. We argue that these findings are likely to be generalizable to the sector within New Zealand. The issues and solutions that emerged are consistent with the existing literature and there was strong internal concordance among our relatively small sample but further research is required in order to claim that saturation was reached.^{1,4,19,20} In addition, the majority of questions asked were designed to elicit responses in relation to the industry as a whole.

The retirement village manager hand-picked the residents and staff to be interviewed potentially introducing selection bias. Those that were interviewed may have been selected due to their contentment or high level of satisfaction with working or living in the facility and those who were vocally discontent may have been avoided, although the responses would tend not support this claim.

It is possible that the results were influenced by social desirability. Studies have shown that older people have the highest degree of social desirability and acquiescence which may have influenced the answers to some of the research questions.²⁹ Furthermore, social desirability may have influenced the answers the staff gave resulting in responses that intended to please the interviewer or protect colleagues and the image of the facility.

CONCLUSION

It is the care workers who are largely responsible for the residents' quality of life, yet it seems there is little infrastructure in place to assure their own quality of work life. They remain in the sector because of a strong vocational ethic of care towards their residents which renders them vulnerable to potential exploitation by the aged care sector. From the interviews it was apparent that all the staff and many residents could identify issues and contributed ideas on how to improve on the shortcomings of the industry. Perhaps the most important finding of this study is the need to strengthen the voice of care workers on the front line so that we can future proof quality care of the current aging cohort.

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REFERENCES

1. Thornton G.
Aged Residential Care Service Review.
Wellington (NZ): New Zealand District Health Boards and Aged Care Association. 2010.
2. Health Workforce New Zealand.
Workforce for the care of older people Phase I REPORT.
2010. Accessed 04 December 2013. http://otago.hosted.exlibrisgroup.com/primio_library/libweb/action/openurl?sessionid=C9
3. Boyd M, Broad JB, Kerse N et al.
Twenty-Year Trends in Dependency in Residential Aged Care in Auckland, New Zealand: A Descriptive Study.
J Am Med Dir Assoc 2011;7(12):535-40
4. Labour; Green Party; Grey Power.
A Report into Aged Care: What does the future hold for older New Zealanders?
2010. Accessed 13 August 2013. <http://www.nzdoctor.co.nz/media/337671/aged%20care%20report%20for%20email.pdf>
5. Hall S, Opio D, Dodd RH, Higginson IJ.
Assessing quality-of-life in older people in care homes.
Age Aging 2011;40:507-12
6. Wilkinson T, Kiata LJ, Peri K, et al.
Quality of life for older people in residential care is related to connectedness, willingness to enter care, and co-residents.
AJA 2012;31(1):52-5
7. Marquis R.
Quality in aged care: a question of relational ethics?
AJA 2002;21(1): 25-9.
8. Standards New Zealand.
Health and Disability Services (Core) Standards.
2008. Retrieved: <http://www.health.govt.nz/system/files/documents/pages/81341-2008-nzs-health-and-disability-services-core.pdf>
9. NZ Ministry of Health NZ.
Rest home certification and audits.
2013. Retrieved November <http://www.health.govt.nz/your-health/services-and-support/health-care-services/services-older-people/residential-care/rest-home-certification-and-audits>
10. O'Boyle CA.
Measuring the quality of later life.
Philos Trans R Soc Lond B Biol Sci 1997;352:1871-9. doi: 10.1098/rstb.1997.0173
11. Kane RA, Kling KC, Bershadsky B, et al.
Quality of Life Measures for Nursing Home Residents.
J Gerontol A Biol Sci Med Sci 2003;58A(3):240-8. doi:10.1093/geronol/58.3.M240
12. Byrne H, MacLean D.
Quality of life: Perceptions of residential care.
Int J Nurs Pract 1997;3:21-8. doi: 10.1111/j.1440-172X.1997.00021.pp.x
13. Joyce CRB, Hickey A, McGee HM, et al.
A theory-based method for the evaluation of individual quality of life: The SEIQoL.
Qual Life Res 2003;12:275-280. doi:10.1023/A:1023273117040
14. Ciarán A, O'Boyle JB.
The Schedule for the Evaluation of Individual Quality of Life (SEIQoL): a Direct Weighting procedure for Quality of Life Domains (SEIQoL-DW): Administration Manual.
Department of Psychology, Medical School, Royal College of Surgeons, Dublin, Ireland. 1993. Accessed 06 November 2013. <http://www.google.co.nz/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCUQ>
15. Abdel-Kader K, Myaskovsky L, Karpov I, et al.
Individual Quality of Life in Chronic Kidney Disease: Influence of Age and Dialysis Modality.
Clin J Am Soc Nephrol 2009;4(4):711-718. doi: 10.2215/CJN.05191008
16. Durner J, Reinecker H, Csef H.
Individual quality of life in patients with multiple myeloma.
myeloma. SpringerPlus 2013;2(397):1-8. doi: 10.1186/2193-1801-2-397
17. Hickey AM, Bury G, O'Boyle, CA.
A new short form individual quality of life measure (SEIQoL-DW): application in a cohort of individuals with HIV/AIDS.
BMJ 1996;313:29-33
18. Rodriguez-Martin B, Martínez-Andrés M, Cervera-Monteagudo B, et al.
Perception of quality of care among residents of public nursing-homes in Spain: a grounded theory study.
theory study. BMC Geriatr 2013;13(65):1-9. doi:10.1186/1471-2318-13-65
19. Walker L.
NZNO Aged Care Survey.
New Zealand Nurses Organisation. 2009. Accessed 06 November 2013. <http://www.nzno.org.nz/resources/research>
20. Kiata L, Kerse N, Dixon R.
Residential care workers and residents: the New Zealand story.
N Z Med J 2005;118(1214):1-11
21. Crabtree BF, Miller WL.
Depth Interviewing.
In: Crabtree BF, Miller WL, eds. *Doing quantitative research.* California: Sage Publications, Inc, 1999: 89-108
22. Thomas DR.
A General Inductive Approach for Analyzing Qualitative Evaluation Data.
American Journal of Evaluation 2006;27(2):237-46. doi:10.1177/1098214005283748
23. Meert KL, Eggly S, Pollack M, et al.
Parents' perspectives regarding a physician-parent conference after their child's death in the pediatric intensive care unit.
Journal of Pediatrics 2007;151(1):50-5
24. Halcomb EJ, Davidson PM.
Is verbatim transcription of interview data always necessary?
Appl Nurs Res 2006;19(1):38-42. Accessed 29 November 2013 <http://ac.els-cdn.com/S0897189705000893/1-s2.0-S0897189705000893-main.pdf>
25. Ministry of Health NZ.
Waitemata aged-care nursing.
2013. Accessed 15 November 2013. <http://www.health.govt.nz/our-work/nursing/showcasing-aged-care-nursing/waitemata-aged-care-nursing>
26. Ministry of Health NZ.
Canterbury aged-care nursing.
2013. Accessed 15 November 2013. <http://www.health.govt.nz/our-work/nursing/showcasing-aged-care-nursing/canterbury-aged-care-nursing>
27. Ministry of Health NZ.
Taranaki aged-care nursing.
2013. Accessed 15 November 2013. <http://www.health.govt.nz/our-work/nursing/showcasing-aged-care-nursing/taranaki-aged-care-nursing>
28. Castaneda R.
Award winning NP scheme gives elders better access to care.
New Zealand Doctor Magazine 2013;6 Nov 6. Accessed 06 December 2013. [nzDoctor.co.nz](http://nzdoctor.co.nz)
29. Vigil-Colet A, Morales-Vives F, Lorenzo-Seva U.
How social desirability and acquiescence affect the age-personality relationship.
Psicothema 2013; 25(3): 342-48. doi: 10.7334/psicothema2012.297

Otosclerosis in New Zealand and the Pacific Islands – a review article

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INTRODUCTION

Hearing loss is the total or partial inability to detect sound waves or to understand sounds that are detected. It can be caused by various environmental, genetic, and etiological factors. Each sound must reach a certain level, known as the hearing threshold, in order to be detected. The hearing threshold is the quietest sound which an average ear with normal hearing can detect in a noiseless environment.¹ Approximately 1 in 10 people have some sort of hearing impairment.² This means, in essence, there are about 400,000 people affected in New Zealand alone. A cross-sectional view of the ear is shown in figure 1.³

Otosclerosis is a disorder in which the abnormal growth of the stapes bone in the middle ear is confined to the endochondral layer of the otic capsule of the temporal bone.⁴ This condition gradually impedes the free movement of the stapes, leading to the abnormal conduction of sound. Hence, the resultant condition has been termed conductive hearing loss. Otosclerosis is usually a hereditary disorder.³ In 70% to 80% of patients, otosclerosis occurs in both ears, usually with the same distribution and extension.⁵ Figure 2 shows the pathological changes seen in an otosclerotic stapes bone.

Otosclerosis is usually diagnosed through a combination of family history, determination of a conductive pattern of hearing loss, and a computed tomography (CT) scan of the temporal bone.³ Although hearing loss due to otosclerosis can show a sensory pattern in initial hearing tests, it usually shows the classical conductive pattern sometime later. CT scans are specific, but not very sensitive for the diagnosis of otosclerosis.³

METHODS

Types of studies

All studies on the topic were included, regardless of the study's date of publication, language, publication status, or strength. All four studies, and an unpublished essay, 6-10 were included in this review.

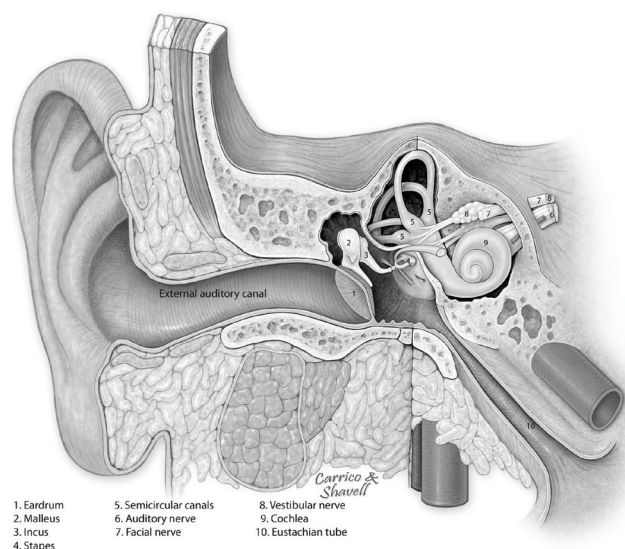


Fig 1. Cross-section of a normal ear.³

Search methods for the identification of relevant studies

Medline through PubMed search was carried out by combining the keyword "otosclerosis" or "otology" with one of the following terms: "New Zealand", "Māori", "Melanesia", "Micronesia", "Polynesia", "Australasia", "Oceania", and "Pacific Island". In addition, Google was used to find unpublished studies on the topic, and the authors were contacted to provide any missing information. Papers were searched for both online and manually, via PubMed/Medline and the Otago University Library catalogue.

RESULTS

Mode of inheritance

Although a variety of modes of inheritance have been proposed, autosomal dominant inheritance with low penetrance (about 40%) seems the most plausible. Many studies on monozygotic twins and familial pedigrees, as well as many epidemiological studies, support this hypothesis.⁴ This disease is reported to be more common in females than males (ratio of 2:1), though histological studies of the temporal bone do not show any sex-specific changes. The average age of onset ranges from 15-45 years old. However, cases in early childhood and after the age of 60 have also been reported.⁵

Prevalence

Otosclerosis can be histological, with only microscopic changes evident. On the other hand, it can progress to such an extent that it causes symptoms.

In these cases, it is referred to as clinical otosclerosis. Different studies and research papers have recorded the prevalence of otosclerosis as either histological or clinical. Despite this inconsistency, otosclerosis has been found to be prevalent to differing extents in different races:

Caucasian population (general):

- Studies have reported different estimates, ranging between 0.2%-2%⁴. Some studies, however, indicate that histological otosclerosis is more likely prevalent, being present in as much as 10% of the Caucasian population.⁵ Most studies agree that the Caucasian population has a markedly higher prevalence than other races.

Black population (general):

- Blacks have been reported to have a much lower prevalence of otosclerosis than Caucasians, with a prevalence of approximately 1%.⁵

Māori/Pacific Island populations within New Zealand:

- Māori population in New Zealand: There is no evidence that the Māori, as a race, have a higher genetic prevalence of otosclerosis than other races. Some have postulated that it is the increased susceptibility resulting from the environment in which indigenous Māori once lived in, or their general attitude towards disease, that makes it seem as if they are more prone to otosclerosis and ear diseases than other races.⁶ During the early 1960s, a survey was conducted on pre-school Māori children in the Waikato Hospital Board's district. Out of 645 children, 14 (~2.2%) were reported to have "other conditions", including congenital and perceptive deafness, although otosclerosis was not specifically diagnosed.⁶
- Pacific Island population in New Zealand: Insufficient numbers of Pacific Islanders, as well as inconsistency in data from different sources, hinder any true estimate of the prevalence of otosclerosis in Pacific Islanders. The estimates of the prevalence of hearing loss, including hearing loss due to otosclerosis, which were based on a 2001 update of a survey done in 1991 and 1992, are shown in table 1.⁷ The different prevalence percentages may be a reflection of differing genetic makeup among these groups.⁷

Pacific Island populations outside New Zealand:

	Māori (%)	Pacific Island (%)	Other (%)
0-14 years	4.6	2.6	1.9
15-64 years	5.0	3.9	5.5
65+ years	14.3	2.6	20.7
Total	3.4	2.5	6.5

Table 1: Estimates of the prevalence of hearing loss for different age ranges and ethnic backgrounds in New Zealand.⁷

- Natives of Easter Island: Easter Island is a Polynesian island in the southeastern Pacific Ocean.⁸ The population of this small, isolated island consists of three ethnic groups: the natives, the mixed race, and the continentals. The natives are of a Polynesian ethnic background.⁸ A study looking at the effect of an industrialized lifestyle on hearing was done in the mid-1980s. A pool of 347 participants (~19% of the population) underwent full otolaryngological and audiological assessments. From this pool, 90 (~26%) were of the native population of Easter Island. Of this native population, the study reported neither a single case of otosclerosis nor a family history of otosclerosis.⁸ Even though the population size may have been too small, not finding a single case raises the possibility of some "hidden" factors that are yet to be determined.
- Fijian population: Medical problems in Fiji can be represented in very two distinctive populations, due to very little mixing between the two major racial groups, which are the Melano Fijians and Indian Fijians. Hence, there is a marked difference in the incidence of otosclerosis between the two racial groups.⁹ According to Stewart, otosclerosis is virtually nonexistent in Melano Fijians, whereas it has a greater prevalence amongst Indian Fijians.⁹ Although specific numbers were not given, Indian Fijians also reported family histories of otosclerosis and hearing loss related to otosclerosis at a more significant frequency. However, this problem is usually left untreated due to a lack of expertise in stapes surgery.⁹
- Tongan and Samoan populations: Discussions of otosclerosis in these populations are very limited in the medical literature. One study reported a prevalence of otosclerosis in these populations that was "similar" to that in Melano Fijians, but provided no further details.⁹ Otological conditions, such as chronic otitis media and mastoiditis, were much more common, which is most likely due to a lack of hygienic practices.⁹

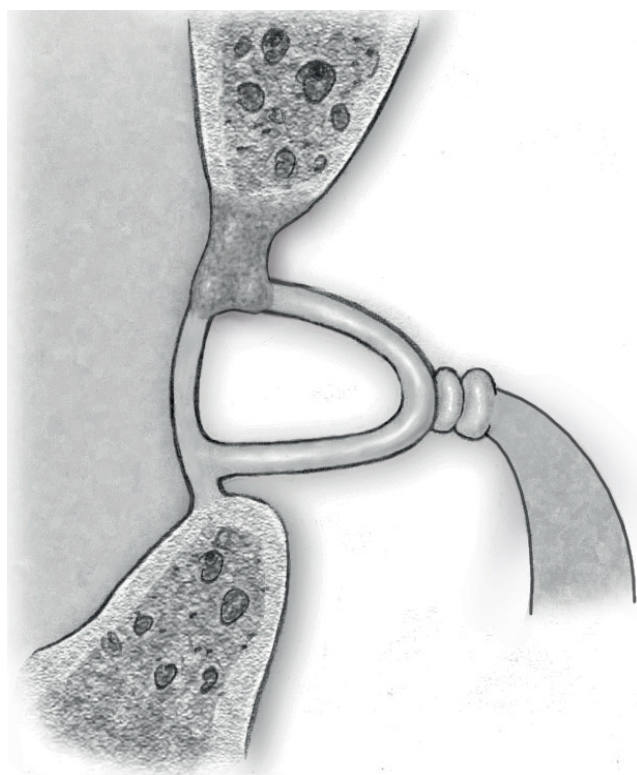


Fig 2. Pathological changes to the stapes bone that are seen in a patient with otosclerosis.³

DISCUSSION

Limitations

Although an extensive review of the relevant literature has been undertaken, it is important to acknowledge the possible limitations of such studies. This is especially important when comparing different studies, as these limitations can distort the true prevalence of otosclerosis. These limitations can be grouped into three categories which will be discussed further:

- Limitations associated with detecting and diagnosing otosclerosis in the wider community.
- Limitations in recruiting patients for such studies.
- Practical limitations.

First, there is usually some difficulty in detecting and diagnosing all cases of otosclerosis in the community. Otosclerosis does not usually present with any pain to the patient, making visits to otologists dependant on social, cultural and economic norms, rather than a sense of urgency and discomfort. This becomes much more evident as we see the distinctive ethno-geographical differences in the prevalence of otosclerosis. Similarly, many cases of otosclerosis are not detected simply because the patient's hearing level has not yet fallen below socially adequate levels.¹⁰ Likewise,

some patients assume that their hearing loss is, for example, noise-induced and, therefore, not treatable.¹⁰

Inclusion criteria for studies of patients with otosclerosis are not ideal. Many studies recruit otosclerosis subjects through their history of stapes surgery. Many patients who are eligible for surgery, however, do not undergo surgery because their air-bone gap is not sufficiently great to justify it.¹⁰ Furthermore, elderly patients are usually averse to having an operation on their ears and would rather continue wearing hearing aids.¹⁰

Finally, conducting such studies poses some practical problems. Factors such as the genetic causality of otosclerosis, as well as the condition's relative mildness, have put otosclerosis on the "back burner" of clinical research. We should also keep in mind the health disparities and discrepancies that occur with patients of Māori and Pacific Island origin, when considering the prevalence of any disease. Even though this problem is not as bad as it used to be 40 or 50 years ago, most of the studies found on this topic have been published during those times, ranging from the 1970s to the 2000s.

Fluoride deficiency hypothesis

Some environmental trace elements are now widely known to be associated with human disease such as iodine deficiency and goiter, and zinc and gastrointestinal problems.¹⁰ Several correlation studies have proposed an association between fluoride deficiency and an increased incidence of otosclerosis. For example, a lower incidence of otosclerosis has been reported in Texas, where the concentration of fluoride in the drinking water is relatively high (1.9 parts per million).¹¹ On the other hand, a lower concentration of fluoride in the drinking water in Missouri (0.6 parts per million) was associated with a higher incidence of otosclerosis.¹¹ Another study showed that fluoride therapy arrested the progression of sensorineural hearing loss in patients with otosclerosis.¹² Unfortunately, both studies included small, unrepresentative populations, so results cannot yet be generalized. It would be interesting to do a randomized, controlled trial on a sufficiently large population to study whether the incidence of otosclerosis truly decreases once a drinking-water fluoridation program has been implemented. To date, only a few observational studies have been carried out, all with small populations, to assess the possibility of an association between fluoride levels in drinking water and otosclerosis status. These studies concluded that the fluoridation of drinking water had a beneficial effect on otosclerotic ears that had not been operated on but no significant effect on the hearing levels of ears after an operation.^{13,14}

CONCLUSION

Otosclerosis is a genetic disease that affects bone homeostasis in the middle ear. Prevalence differs vastly according to genetic makeup, with the White/Caucasian population having the highest prevalence rate all among racial groups. Even though current treatment methods are effective and successful, further research is required, especially in countries and regions with no previous studies on otosclerosis among their populations, such as New Zealand and the Pacific Islands.

REFERENCES

1. Gelfand SA.
Hearing: an Introduction to Psychological and Physiological Acoustics.
4th ed.
United States of America: Marcel Dekker; 2004
2. **Hearing Loss.**
[Online]. [Cited 2008 Aug 31]. ; Available from: URL: <http://audiology.org.nz/Default.aspx>
3. Hain TC, Micco A.
Otosclerosis.
[Online]. [Last updated 2004 July 14]. [Cited 2009 Jun 02]. ; available at: <http://www.tchain.com/otoneurology/disorders/hearing/otoscler.html>
4. Moumoulidis I, Axon P, Baguley D, Reid E.
A review on the genetics of otosclerosis.
Clin Otolaryngol. 2007; 32(4):239-47
5. Menger DJ, Tange RA.
The etiology of otosclerosis: a review of the literature.
Clin Otolaryngol Allied Sci. 2003; 28(2):112-20
6. Phillips-Turner RG.
Diseases of the ear, nose, and throat in Maori children: a survey conducted in the Waikato Hospital Board district.
New Zealand (Wellington): R. E. Owen, Govt. Printer; 1965. p. 18-22
7. Greville KA.
Hearing impaired and deaf people in New Zealand; population numbers and characteristics.
[Online]. Unpublished. 2001 Oct. [Cited 2008 Sep 2]. ; Available at: <http://www.grevilleconsulting.co.nz/Hearing%20impaired%20and%20deaf%20people%20in%20New%20Zealand.doc>
8. Goycoolea MV, Goycoolea HG, Farfan CR, Rodrigues LG, Martinez GC, Vidal R.
Effect of life in industrialized societies on hearing in natives of Easter Island. Laryngoscope.
1986; 96(12):1391-6
9. Stewart IF.
Otology in the South Pacific.
J Otolaryngol. 1990; 19(6):374-6
10. Gristwood RE, Venables WN.
Otosclerosis in South Australia.
Clin Otolaryngol Allied Sci. 1984; 9(4):221-8
11. Daniel HJ.
Stapedial Otosclerosis and Fluorine in the Drinking Water.
Arch Otolaryngol. 1969; 90(5):585-9
12. Derks W, De Groot JA, Raymakers JA, Veldman JE.
Fluoride Therapy for Cochlear Otosclerosis? An Audiometric and Computerised Tomography Evaluation.
Acta Otolaryngol. 2001; 121(2):174-7
13. Vartiainen E, Karjalainen S, Nuutinen J, Suntioinen S, Pellinen P.
Effect of drinking water fluoridation on hearing of patients with otosclerosis in a low fluoride area: a follow-up study.
Am J Otol. 1994; 15(4):545-8
14. Vartiainen E, Vartiainen J.
The effect of drinking water fluoridation on the natural course of hearing in patients with otosclerosis.
Acta Otolaryngol. 1996; 116(5):747-50

Implications of cancer in lesbians

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DEFINITION

The term lesbian originates from the Greek island of Lesbos and is used to refer to women whose emotional, social, and sexual relationships are primarily with women.¹ The lesbian identity encompasses different dimensions including how one self-identifies, the attraction a person feels for another and sexual behaviour.²

WHAT IS KNOWN ABOUT CANCER INCIDENCE AND RISKS IN THE LESBIAN POPULATION?

A lack of appropriate data in national databases and registries translates to a poor understanding of potential cancer incidence disparities in the lesbian population. Possible barriers to health service access and disparities regarding lesbian's health status have been identified as a research priority.³

The first section of this paper serves to highlight cancer risk factors among lesbians and the comparison of these factors between lesbians and heterosexual women. The second section seeks to look at common cancers (breast, cervical and lung cancers) and quality of life in the lesbian population, as well as possible interventions with particular emphasis from a psychosocial point of view. The final section will discuss the implications of cancer in lesbians before concluding with a summary of the issues that have been discussed.

RISK FACTORS FOR COMMON CANCERS AMONG LESBIANS & DIFFERENCES BETWEEN LESBIANS AND HETEROSEXUAL WOMEN

Several risk factors put lesbians at an increased risk for a number of cancers. Modifiable risk factors include smoking, alcohol consumption, obesity, lack of physical activity, poor cancer screening habits and sexual behaviour.⁴ Compared to heterosexual women, a higher prevalence of these factors among lesbians suggests a disproportionately higher risk for multiple cancers.

Smoking and alcohol use

A study by Gruskin *et al* (see Table 1),⁵ showed lesbians and bisexual women, are more likely to smoke (25.4% vs. 12.6%, $P < 0.001$) and drink heavily (9.2% vs 2.6%, $P < 0.001$) than heterosexual women. A multivariate logistic regression analysis (see Table 2) further revealed a higher incidence of current smokers and heavy drinkers among lesbians in the age groups of 20 to 34 years old and 35 to 49 years old compared to heterosexual women.

Physical activity and being overweight/obese

Aaron *et al*⁶ (see Table 3) reported low levels of physical activity in the lesbian group: 34.2% (95% CI = 31.2, 37.2) had no physical activity in past month and 63.2% (95% CI = 60.1, 66.2) had no regular vigorous activity. As for obesity, Cochran *et al*⁷ (see Table 4) estimates that 28% (95% CI = 25.6, 29.9) of lesbians surveyed are obese. This estimate is within normative expectations for women aged 18 to 75 years old in the United States, however the study found a significantly greater percentage of obese lesbians than expected after taking into account the demographic profile of the lesbians being surveyed ($P < 0.05$).

Sexual behaviour and history

Compared to their heterosexual counterparts, lesbians tend to have an earlier sexual debut, are more likely to have multiple sexual partners and engage in risky sexual activities.⁸ As seen in Table 5, lesbians are more likely to report initiation of sexual intercourse before the age of 18 (64% vs. 56%, $P < 0.05$) as well as higher numbers of sexual partners (10% vs. 6.7%, $P < 0.05$). In addition, lesbians are found to use oral contraceptives (protective factor for cervical cancer) less frequently than heterosexual women,⁹ and are 4.7 times more likely to be nulliparous (parity is a protective factor for breast cancer).¹⁰

Cancer screening behaviors

Lesbians are less likely to have a Pap test in the past 2 years¹¹ and are less likely to report annual participation in Pap testing.⁸ It is postulated that poor cervical screening increases the risk of cervical cancer and poorer outcomes for lesbians. As for the development of breast cancer, it has been found that lesbians have the highest concentration of risk factors as compared to any subgroups of women.¹⁴ Studies looking at mammography screening reported that lesbians are less likely than heterosexual women to have had a recent mammogram.^{8,11}

CANCERS

Breast cancer

Breast cancer is the second leading cause of cancer death in women, second only to lung cancer.⁴ Lesbians are at an increased risk of breast cancer

Age, y	Current Smokers			Heavy Drinkers ^a			Abstinence from Drinking		
	L/B	H	χ ²	L/B	H	χ ²	L/B	H	χ ²
Overall	25.4%	12.6%	P<.001	9.2%	2.6%	P<.001	19.8%	32.5%	P=.004
20-34	33.3%	13.2%	P<.001	23.3%	6.0%	P<.001	0%	27.7%	P<.001
35-49	29.1%	14.4%	P=.002	7.1%	2.7%	P<.001	24.5%	27.9%	P=.59
≥50	12.1%	11.3%	P=.89	0%	1.3%	P=.50	29.4%	37.0%	P=.36
χ ² 20-34 vs. 35-49	P=0.69	P=.27		P=.03	P<.001		P<.01	P=.89	
χ ² 20-34 vs. ≥50	P=.04	P=.06		P=.003	P<.001		P<.001	P<.001	
χ ² 35-49 vs. ≥50	P=.07	P=.001		P=.11	P<.001		P<.61	P<.001	

Note. L/B = lesbian and bisexual women; H= heterosexual women.
^aMore than 4 drinks per episode or more than 20 drinks per week over the past year.

Table 1: Cigarette smoking and alcohol consumption, by sexual orientation and age.⁵

Risk Factor		Current Smoking			Heavy Drinking	
		20-34 y OR (95% CI)	35-49 y OR (95% CI)	≥50 y OR (95% CI)	20-34 y OR (95% CI)	35-49 y OR (95% CI)
Sexual Orientation	Lesbian/Bisexual	3.2 (1.4, 7.3)	3.4 (1.8, 6.5)	1.3 (0.4, 3.6)	4.6 (1.9, 11.4)	2.9 (1.0, 8.6)
	Heterosexual	1.0	1.0	1.0	1.0	1.0
Education	College degree/graduate degree	0.3 (0.2, 0.5)	0.2 (0.2, 0.3)	0.5 (0.4, 0.7)	0.3 (0.2, 0.5)	0.5 (0.3, 0.9)
	>College degree	1.0	1.0	1.0	1.0	1.0
Race ethnicity	White, non-Latina	1.8 (1.3, 2.4)	1.5 (1.2, 2.0)	1.3 (1.0, 1.7)	1.2 (0.8, 1.8)	2.0 (1.0, 3.8)
	Women of colour	1.0	1.0	1.0	1.0	1.0
Stress	High	1.6 (1.0, 2.5)	1.7 (1.2, 2.4)	1.5 (1.0, 2.1)	1.2 (0.6, 2.2)	1.9 (0.9, 4.2)
	Moderate	1.3 (0.9, 1.9)	1.1 (0.8, 1.4)	1.1 (0.9, 1.4)	1.1 (0.7, 1.9)	1.7 (0.9, 3.2)
	Low or none	1.0	1.0	1.0	1.0	1.0
Depression	Depression in the last 12 mo	1.6 (1.1, 2.4)	1.6 (1.2, 2.1)	1.2 (0.9, 1.7)	1.9 (1.2, 3.3)	2.0 (1.1, 3.5)
	No depression in the last 12 mo	1.0	1.0	1.0	1.0	1.0
	No. of observations	1526	2351	3920	1551	2381

Note. OR = odds ratio; CI= confidence interval.

Table 2: Risk factors for current smokers and heavy drinkers, by age: Results of multivariate logistic regression analyses.⁵

than heterosexual women as a result of greater rates of risk factors as discussed previously, i.e. alcohol consumption, obesity, lower rates of breast cancer screening and nulliparity.¹³ Studies have reported a relative risk of 1.74 (95% CI = 0.62 – 4.91) of an invasive breast cancer among lesbians,¹⁴ which is a higher prevalence despite similar mammography screening rates as heterosexual women.¹⁰

Barriers on various levels, i.e. Personal issues, patient-practitioner relationships and healthcare systems can all create barriers that influence the adequacy of mammography screening in the lesbian population¹³. As seen in table 6, personal barriers include competing life demands and negative emotions such as fear and embarrassment; patient-practitioner barriers include homophobia and more significantly a lack of trust in the practitioner/health care system. Other system level barriers reported were: cost; discomfort; lack of lesbian-specific resources; and concern about quality and possible harm from mammogram. A study by Matthews *et al*¹⁵ revealed that lesbians are less satisfied with the emotional support they receive from health care providers.

While treatment needs of lesbians are similar to those of heterosexual women, the barriers to adequate care are amplified in the lesbian population. Lesbians who received tailored counselling on breast cancer screening, education and risk assessment by a health provider trained in lesbian health issues were found to have significantly increased adherence to breast self-exam and mammography after a follow up period of 2 years.¹⁶ ¹⁷ Group therapy interventions for lesbians with breast cancer also helped

to reduce emotional distress and improve coping.¹⁸ Health care providers play a vital role and it is absolutely crucial that they receive appropriate training and education in lesbian health issues to be aware of and sensitive to psychosocial factors that influence responses to treatment,¹⁹ and foster good communication with lesbian patients.²⁰

Cervical cancer

Human papillomavirus (HPV) infection is the main cause of cervical cancer and risk factors include early sexual debut, multiple sexual partners, being overweight and cigarette smoking.⁴ As discussed in the first section, lesbians have a higher prevalence of these modifiable risk factors than heterosexual women. Consequently, they have an increased susceptibility to HPV infection and cervical cancer. Variables that contribute to a higher cervical cancer screening rates among lesbians include higher educational attainment, higher income²¹ and having a regular health care provider.²² General barriers to cervical cancer screening included feeling uncomfortable, low perceived risk and access factors.⁸ Lesbians are documented to have less frequent gynaecologic care compared to heterosexual women²³ and an additional barrier to screening for lesbians may be fewer referrals from medical providers for gynaecological screening.⁸ Despite lower rates of adherence to cervical cancer screening recommendations, sexual behaviour risk factors for cervical cancer are prevalent among lesbians.

Similar to breast cancer, patient-provider communication has a substantial impact on whether the lesbian population has adequate cervical screening.²⁴

		ESTHER Weighted Sample % (95% CI)	1998 BRFSS National Sample - Women Only % (95% CI)
Health Behaviour (n)	Current cigarette use (1007)	35.5 (32.5, 38.5)	20.5 (20.3, 20.9)
	Alcohol nonabstainer ^a (937)	57.5 (54.3, 60.7)	44.6 (43.7, 45.6)
	Heavy alcohol drinker ^b (937)	4.7 (3.3, 6.1)	1.1 (0.9, 1.3)
	No physical activity in past month (962)	34.2 (31.2, 37.2)	31.4 (31.1, 31.9)
	No regular vigorous activity (959)	63.2 (60.1, 66.2)	86.3 (86.0, 86.5)
	Overweight: BMI 27.3kg/m (972)	47.8 (44.7, 50.9)	31.6 (31.3, 31.9)
Health Screening (n)	Ever had Pap test (1002) ^c	94.2 (92.7, 95.6)	93.8 (93.6, 94.0)
	Pap test within past 2 years: women with intact cervix (793)	74.9 (71.9, 77.9)	80.3 (80.0, 80.6)
	Ever had mammogram: women aged 40 y (593)	93.3 (91.3, 95.3)	85.1 (84.8, 85.4)
	Mammogram within past 2 years: women aged 50 y (262)	88.1 (84.2, 92.0)	75.8 (75.3, 76.2)
<p>Note. ESTHER = Epidemiologic Study of Health Risks in Lesbians; BRFSS = Behavioural Risk Surveillance System; CI = confidence interval; BMI = body mass index.</p> <p>^aAt least one drink of alcohol in the past month</p> <p>^bSixty or more drinks per month</p> <p>^cConfidence intervals for two samples overlap</p>			

Table 3: Self-reported health behaviors and health screening among lesbians (ESTHER, Pittsburgh, Pa) and Women in a national probability sample (1998 BRFSS).⁶

Health Risk Indicator		Lesbian/Bisexual Sample			Estimates for US Women			
					Standardized, %		Unstandardized, %	
		No.	%	(95% CI)	%	(95% CI)	%	(95% CI)
Obesity	Self-reported body mass							
	Index above normal weight	8115	27.7	(25.6, 29.9)
	NHIS estimate	18.3	(17.5, 19.1)	27.9	(27.3, 28.5)
	EHANES III estimate	19.0	(16.8, 21.1)	30.5	(28.4, 34.4)
	Self-reported obesity/weight problem ^a	7764	43.9	(40.8, 47.1)	55.8	(52.9, 58.7)	62.4	(60.6, 64.1)
Alcohol use	Current user (in past year for US women) ^b	11638	69.6	(67.0, 72.1)	66.9	(63.5, 70.4)	55.2	(51.3, 57.8)
	Alcohol problem history	11638	12.4	(10.8, 14.2)				
	Ever consumed 5+ drinks almost every day ^b				4.0	(2.6, 5.4)	6.8	(5.8, 7.7)
Tobacco use ^c	Current smoker	10752	21.2	(19.0, 23.6)	16.1	(14.8, 17.4)	24.3	(23.3, 25.3)
	Past smoker	9843	34.0	(30.1, 38.1)	20.1	(18.5, 21.8)	19.9	(19.0, 20.8)
Parity	Ever pregnant ^b	9962	28.1	(24.8, 31.6)	66.7	(63.1, 70.3)	81.5	(79.9, 83.2)
	Ever gave birth to live infant ^b	11547	16.0	(14.6, 17.5)	56.9	(52.6, 61.2)	74.5	(72.6, 76.4)
	Ever used birth control pills ^b	8329	36.2	(32.5, 40.1)	79.7	(76.6, 82.8)	65.1	(63.0, 67.2)
	Has health insurance	10171	86.4	(84.4, 88.1)	92.6	(91.2, 94.1)	85.0	(83.4, 86.5)
	Pelvic exam within past 2 years (past 3 for US women) ^c	10811	72.9	(68.9, 76.7)	87.4	(86.0, 88.7)	79.0	(77.9, 80.2)
Ever had mammogram, by age, y ^c	30 to 39	4686	32.2	(28.5, 36.1)	39.6	(36.2, 42.9)	33.8	(31.6, 35.9)
	40 to 49	2808	73.1	(70.0, 76.0)	86.7	(83.4, 89.9)	78.8	(76.0, 81.6)
	50 to 75	960	82.9	(80.2, 85.4)	90.2	(88.2, 92.2)	81.2	(79.4, 83.0)
<p>Note. Prevalence rates among lesbian/bisexual women were estimated in a random effects model. NHIS = National Health Interview Survey; NHANES III = Third National Health and Nutrition Examination Survey.</p> <p>^aIndividually standardized to the age, race/ethnicity (White, non-Hispanic vs other), education level, and geographic region of the lesbian sample for each measured health variable.</p> <p>^bEstimated from the 1994 NHIS.</p> <p>^cEstimated from NHANES III.</p>								

Table 4: Comparisons of health risk indicators among lesbians with standardized and unstandardized estimates for US women from NHANES III and the 1994 NHIS.⁷

Variable	Lesbian	Heterosexual
	N %	N %
Current Smoker	105 (19%)	52 (19%)
1st intercourse before age 18*	349 (64%)	152 (56%)
History of STD	7 (13%)	49 (18%)
Safer sex practices (never)***	389 (86%)	124 (54%)
Abnormal pap smear	138 (25%)	87 (31%)
History of gynecological cancer	20 (04%)	14 (05%)
HIV/AIDS diagnosis	02 (0.4%)	01 (0.4%)
	M (SD)	M (SD)
Number of male partners***	4.8 (8.9)	6.9 (6.2)
Number of female partners***	5.4 (5.6)	0.4 (1.3)
Number of total partners***	10.0 (10.0)	7.3 (6.7)

Note. Sexual orientation differences evaluated by chi-square and t tests.
* P < 0.05.
*** P < 0.001.

Table 5: Cervical cancer risk factors⁸

		Sample 1* (N = 68) %	Sample 2† (N = 68) %
Personal Factors	Competing life demands	19	13
	Lack of motivation	10	38
	Negative emotions (e.g., fear, embarrassment)	7	5
	Not needed (e.g., asymptomatic, no risk, not needed every year)	0	26
	Concern about worth of mammogram	0	10
Client-practitioner relationship factors	Poor interpersonal experience with health practitioner		
	Insensitivity/hurriedness	6	10
	Homophobia/racism	4	0
	Lack of trust in practitioner/medical community	0	15
Systems factors	Discomfort/pain (comfort of procedure)	15	18
	Difficulties with scheduling/system	15	18
	Cost	15	33
	Lack of reminders from clinic	4	0
	Inaccessibility because of special needs (e.g., disability)	3	8
	Lack of lesbian-specific resources	3	0
	Concern about quality, accuracy, and harm from mammogram	0	18
No barriers		41	0

*Responses to the question, "Although you have had a mammogram in the last year, what things did stand in your way of having one? That is, what barriers did you have to overcome, if any?" Interrater reliability: Total percentage of agreement = 98.6%; Occurrence agreement = 85.0%; Non-occurrence agreement = 98.5%.
†Responses to the question, "What stands in your way of having regular mammograms?" Interrater reliability: Total percentage of agreement = 98.8%; Occurrence agreement = 88.7%; Non-occurrence agreement = 98.7%.

Table 6: Barriers most commonly identified in obtaining mammograms¹⁴

Barriers in establishing good communication include a fear of discrimination if sexual orientation is disclosed, in addition to a perceived discomfort from health care providers when sexual orientation is revealed. A study by Rankow *et al*²¹ demonstrated that a health care provider's sensitivity and knowledge of lesbian health issues was a predominant factor in influencing cervical screening rates of lesbians. Targeted education programs should be developed for lesbians and providers should stress the importance of adherence to recommendations for safer sex practices and regular gynaecological screenings.

Lung cancer

Lung cancer is the number one cause of cancer deaths in men and women.⁴ Cigarette smoking accounts for one of the greatest risk factors for lung cancer development. A higher prevalence of cigarette smoking^{5,6} in the lesbian population (see first section) predisposes this group to a higher incidence of lung cancer development. A study by Garofalo *et al*²⁵ examining the association between health risk behaviours and sexual orientation among school adolescents reported that lesbian, gay, bisexual and transsexual (LGBT) youth are significantly more likely to start smoking at an earlier age and on a daily basis compared to their heterosexual peers. This highlights the need for cigarette smoking prevention and cessation programs for the lesbian youth population as well as the LGBT youth population as a whole. Persuasion of youths to quit tobacco use with anti-smoking campaigns can be challenging and applying pressure on the youths to quit may potentially make matters worse. Ways to overcome this include: engaging positive adult role models to provide a sense of community in lesbian youth, having lesbian-specific services lead by lesbian ex-smokers, and create opportunities for youths to discuss and create non-smoking norms.²⁶

QUALITY OF LIFE

Sexual orientation can have a negative impact on communication with health care providers, emotional support and acceptability of treatment interventions.²⁷ In a study by Sinding *et al*²⁸ that looked at the experiences of a group of lesbians receiving cancer care, the majority of participants reported a lack of psychosocial support while a handful reported being denied standard care. Many of them reported support from the lesbian community but experienced homophobia in the broader community.²⁹ Lesbians are also found to have lower satisfaction of care and higher levels of stress associated with diagnosis as compared to heterosexual women.¹⁵

IMPLICATIONS

As detailed above, lesbians have a higher tendency to report less satisfaction with the quality of care as well as poor communication with health care providers.³⁰ Interpersonal behaviour of physicians has been found to be a major predictor of satisfaction among lesbians²⁰ and tailoring interventions towards the lesbian community improves physical and mental health up to a year.¹⁸

More effort should be made to educate health care providers about the importance of encouraging cancer screening and ways to improve the care they provide to lesbian patients. Improving medical provider's knowledge about general lesbian health issues and the risk factors for breast and cervical cancers will increase their recommendations for screenings and their ability to educate their lesbian patients in prevention and screening behaviours. Providers should also be encouraged to inquire about sexual orientation of all patients with the use of gender-neutral language.^{30, 31} Providers can also advertise themselves as lesbian-friendly, attend sensitivity training regarding lesbian lifestyles and acknowledge patient's partners.³²

Besides educating health care providers, lesbian patients should similarly be educated via health promotion campaigns that help address risk reduction. With the significance of embracing psychosocial health and the importance of having engaging activities, health care organizations can partner with community lesbian groups to encourage healthy habits.¹⁷ To facilitate early detection of breast cancer, partners can be encouraged to perform breast self-exam together and to promote it as a routine health

habit.³³ Based on the higher prevalence of breast and cervical cancer risk factors as well as the lower rates of screening in the lesbian population, an educational curriculum for lesbians should include discussion of individual behavioural and sexual risk factors, possible barriers to screening, lifestyle modifications that may reduce the risk of developing these cancers and specific recommendations for surveillance.⁸

There is a dearth of data to guide policy and practice in the area of cancer prevention in the lesbian population. Studies that have looked at cancers in the lesbian population are mainly focused on issues relating to screening and prevention. There is a lack of research on aetiology, incidence, mortality and morbidity. It is therefore important to collect sexual orientation data in national health surveys and institution's databases to provide an accurate picture of the cancer disease burden in lesbians and to identify the nature of cancer disparities for lesbians. More research using innovative methodologies and standard registries is needed to determine differences in cancer risk and risk factors in the lesbian population.

CONCLUSION

Cancer is a major health issue for many people, including the lesbian population. Studies have shown that some risk factors for cancers are more prevalent in lesbians compared to heterosexual women and lesbians may be disproportionately affected by common cancers i.e. breast, cervical and lung cancers. More data is needed to determine cancer risk in the lesbian population and this can be achieved by identifying sexual orientation in data surveillance systems. Heterosexism in the health care system may result in lesbians not receiving preventative care and treatment, placing them at risk of higher cancer-related mortality. The ease of communication with health care providers and access to sensitive, competent health care is associated with the health risks of lesbians. Health care providers therefore play a vital role in influencing lesbian patient's knowledge and adherence to breast self-exam, mammography as well as cervical cancer screening. Public health programs directed at the lesbian community, in the form of health promotion campaigns and engaging activities, may play a role in improving health behaviours to prevent cancer. Finally, more research is needed to determine cancer incidence disparities in lesbians and to establish culturally appropriate methods of prevention and treatment interventions.

REFERENCES

1. Phillips-Angeles E, Wolfe P, Myers R, Dawson P, Marrazzo J, Soltner S, et al. **Lesbian health matters: Pap test education campaign nearly thwarted by discrimination.** *Health Promotion Practice* 2004;5:314-325.
2. Bonvicini KA, Perlin MJ. **The same but different: clinician-patient communication with gay and lesbian patients.** *Patient Education and Counseling* 2003;51:115-122.
3. Solarz A L. **Lesbian health: current assessment and direction for the future.** Washington, DC: National Academy Press, 1999.
4. American Cancer Society. **Cancer facts and figures.** Atlanta: American Cancer Society, 2008.
5. Gruskin EP, Hart S, Gordon N, Ackerson L. **Patterns of cigarette smoking and alcohol use among lesbians and bisexual women enrolled in a large health maintenance organization.** *Am J Public Health* 2001;91(6):976-979.
6. Aaron DJ, Markovic N, Danielson ME, Honnold JA, Janosky JE, Schmidt NJ. **Behavioral risk factors for disease and preventive health practices among lesbians.** *Am J Public Health* 2001;91(6):972-975.
7. Cochran SD, Mays VM, Bowen D, Gage S, Bybee D, Roberts SJ, Goldstein RS, Robison A, Rankow EJ, White J. **Cancer-related risk indicators and preventive screening behaviors among lesbians and bisexual women.** *Am J Public Health* 2001;91(4):591-597.
8. Matthews AK, Brandenburg DL, Johnson TP, Hughes TL. **Correlates of underutilization of gynecological cancer screening among lesbian and heterosexual women.** *Prev Med* 2004;38(1):105-113.
9. Dibble SL, Roberts SA, Nussey B. **Comparing breast cancer risk between lesbians and their heterosexual sisters.** *Women's Health Issues* 2004;14(2):60-68.
10. Valanis BG, Bowen DJ, Bassford T, Whitlock E, Charney P, Carter RA. **Sexual orientation and health: comparisons in the women's health initiative sample.** *Arch Fam Med* 2000;9(9):843-853.
11. Kerker BD, Mostashari F, Thorpe L. **Health care access and utilization among women who have sex with women: sexual behavior and identity.** *J Urban Health* 2006;83(5):970-979.
12. American Cancer Society. **Cancer in our lives: raising awareness in the LGBTQI community.** San Francisco, CA: American Cancer Society, 2006.
13. Denenberg R. **Report on lesbian health.** *Women's Health Issues* 1995;5(2):81-93.
14. Lauver DR, Karon SL, Egan J, Jacobson M, Nugent J, Settersten L, Shaw V. **Understanding lesbian's mammography utilization.** *Women's Health Issues* 1999;9(5):264-274.
15. Matthews AK, Peterman AH, Delaney P, Menard L, Brandenburg D. **A qualitative exploration of the experiences of lesbian and heterosexual patients with breast cancer.** *Oncol Nurs Forum* 2002;29(10):1455-1462.
16. Dibble SL, Roberts SA. **Improving cancer screening among lesbians over 50: results of a pilot study.** *Oncol Nurs Forum* 2003;30(4):E71-E79.
17. Bowen DJ, Powers D, Greenlee H. **Effects of breast cancer risk counselling for sexual minority women.** *Health Care Women Int* 2006;27(1):59-74.
18. Fobair P, Koopman C, DiMiceli S. **Psychosocial intervention for lesbians with primary breast cancer.** *Psychooncology* 2002;11(5):427-438.
19. Arena PL, Carver CS, Antoni MH, Weiss S, Ironson G, Duran RE. **Psychosocial responses to treatment for breast cancer among lesbian and heterosexual women.** *Women Health* 2006;44(2):81-102.
20. Boehmer U, Case P. **Sexual minority women's interactions with breast cancer providers.** *Women Health* 2006;44(2):41-58.
21. Rankow EJ, Tessaro I. **Cervical cancer risk and Papanicolaou screening in a sample of lesbian and bisexual women.** *J Fam Pract* 1998;47(2):139-143.
22. Diamant AL, Schuster MA, Lever J. **Receipt of preventive health care services by lesbians.** *Am J Prev Med* 2000;19(3):141-148.
23. Robertson P, Schacter J. **Failure to identify venereal disease in a lesbian population.** *Sex Transm Dis* 1981;8:75-76.
24. Clark MA, Bonacore L, Wright SJ, Armstrong G, Rakowski W. **The cancer screening project for women: experiences of women who partner with women and women who partner with men.** *Women Health* 2003;38(2):19-33.
25. Garofalo R, Wolf RC, Kessel S, Palfrey SJ, DuRant RH. **The association between health risk behaviors and sexual orientation among a school-based sample of adolescents.** *Pediatrics* 1998;101(5):895-902.
26. Remafedi G, Carol H. **Preventing tobacco use among lesbian, gay, bisexual, and transgender youths.** *Nicotine Tob Res* 2005;7(2):249-256.
27. Matthews AK. **Lesbians and cancer support: clinical issues for cancer patients.** *Health Care Women Int* 1998;19(3):193-203.
28. Sinding C, Barnoff L, Grassau P. **Homophobia and heterosexism in cancer care: the experiences of lesbians.** *Can J Nurs Res* 2004;36(4):170-188.
29. Sinding C, Grassau P, Barnoff L. **Community support, community values: the experiences of lesbians diagnosed with cancer.** *Women Health* 2006;44(2):59-79.
30. Roberts SJ. **Health care recommendations for lesbian women.** *J Obstet Gynecol Neonatal Nurs* 2006;35(5):583-591.
31. Boehmer U, Case P. **Physicians don't ask, sometimes patients tell: disclosure of sexual orientation among women with breast carcinoma.** *Cancer* 2004;101(8):1882-1889.
32. Ott C, Eilers J. **Breast cancer and women partnering with women.** *Nebr Nurse* 1997;30(3):29.
33. Fish J, Wilkinson S. **Understanding lesbian's healthcare behaviour: the case of breast self-examination.** *Soc Sci Med* 2003;56(2):235-245.

Directives in dementia

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INTRODUCTION

Advancements in life-sustaining medical care mean our ageing population is faced with an increasing plethora of medical decisions to make at the end of life. Advance care planning is arguably the "embodiment of the patient's autonomy and right of self-determination".¹ However, issues arise when the advance directive contradicts what is in the current best interests of the patient. This essay will prove that paternalism should over-ride advance directives if the advance directive contradicts the best medical interests of the patient. The first argument supporting this is that doctors have a duty to act in the best interests of their patient. Secondly, advance directives cannot accommodate changes in values and preferences that occur at the end of life, and therefore may not represent the patient's wishes. These arguments are opposed by justice, respect for autonomy and the fear of subjectivity. This essay highlights the need for quality advance care planning but ultimately proves that doctors must first and foremost be trusted to act in their patient's best medical interests*.

BACKGROUND TO ADVANCE DIRECTIVES AND DEMENTIA

Advance Care Planning is a discussion aimed to identify an individual's beliefs and values, and incorporate these into planning future health care in the form of an advance directive.² Advance directives come into action in cases where the patient does not have the capacity to make decisions regarding their healthcare, for example, dementia. Approximately 50 000 New Zealanders suffer from dementia.³ By 2050, it is estimated that there will be 44 000 new cases of dementia a year.⁴ Dementia creates specific challenges for advance directives. The slow, progressive loss of competence while remaining able to interact with the environment and express preferences creates a potential conflict between competent choice and incompetent interests.^{5,6} Other issues relevant to advance directives, such as the role of surrogates or powers of attorney in decision making, will not be discussed.

Doctors have professional duties that prevent them from following advance directives.

Doctors have a professional duty to 'First, do no harm', conferred upon

them when they take the Hippocratic Oath. This maxim could be challenged by advance directives. Let us imagine an incompetent patient with a painful urinary tract infection, treatable with IV antibiotics. However, the patient has an advance directive stipulating that they do not want to receive IV antibiotics. Withholding antibiotics from the patient as requested results in the patient's suffering. Through the omission of treatment, the doctor is allowing harm to come to the patient. Is this considered 'doing harm'? In this example, the patient is being harmed by the doctor's inaction which resulted from the patient's instructions. Some argue that this is not 'doing harm', as the doctor is not doing something actively. However, an act of omission can be as culpable as an action that causes harm. Consider the actions of Professor Herbert Green and others, who intentionally delayed or did not treat women with abnormal smears, allowing cervical cancer to develop.⁷ Similarly, in our hypothetical case of a patient with a urinary tract infection, not treating the infection contradicts the Hippocratic Oath if this leads to harm to the patient.

However, an act of omission that is usually punishable becomes accepted when it is requested by the patient. Patients are able to refuse life-saving dialysis treatment if it is their decision. However, if a doctor did not offer a patient the dialysis (and the patient was eligible to receive it, and in fact wanted it), they would be disciplined. Does a request to withhold treatment through an advance directive also make the previously unacceptable, acceptable? Potentially following the advance directive could result in suffering for the patient and hasten their death. These are serious consequences. If medical professionals are going to withhold treatment because it is requested by an advance directive, they must be sure that the directive is still valid.

Advance directives cannot accommodate changing values and therefore have questionable validity.

The criteria for an advance directive to be valid require the patient to be competent, sufficiently informed, and free from coercion. The patient must also have intended the directive to apply in the current circumstances.⁸ There can be reasonable doubt about all of these aspects, however this will not be discussed further. What challenges the validity of advance directives in dementia is that the patient's preferences, values and satisfaction may have changed as a result of their condition. Critics of advance directives argue "wishes laid down in an advance directive when a patient was healthy—most particularly the limitation of life-preserving treatment—might then be no longer valid."^{5,9}

This issue is emphasised in hypothetical cases, such as Dworkin's 'Margo problem'.¹⁰ Margo is a hypothetical patient who is "happily demented". She made an advance directive when she was competent. Would it be ethical to hold her to her prior decisions if they were to hasten her death? It has been argued that through cognitive impairment, a new identity has formed. Dworkin argues that "personal identity does not sufficiently survive to

justify binding the cognitively impaired person to the decisions of his former self." David Hilfiker, with cognitive impairment himself, similarly notes that he has read stories about happiness of patients with very advanced disease. He comments "maybe most of them aren't suffering much at all".¹¹ This dilemma of 'self-hood' is key in deciding whether advance directives should be honoured. Advance directives are created with the goal of extending personal autonomy. If we have doubts over whether a new identity has formed separate from the 'past self', are we respecting autonomy by applying the advance directive? We would only be respecting the autonomy of the prior, competent patient, not the patient who is currently entrusted into our care. If we are going to respect autonomy, it should be the autonomy of our present patient, not their 'past-self'. This is consistent with current practice where patients can alter and 'opt-out' of their advance directive. They are not bound to decisions they made in advance. In the case of an Alzheimer's patient who has subsequently lost the capacity to review their advance directive, it would seem extremely unethical and unjust to hold them accountable to the decisions they made previously. Not only may they have a new personal identity, but they also do not have the ability to modify their advance directive should their wishes change.

Counter Arguments – Justice, Respect for Autonomy, Fear of Subjectivity

Arguably, life's many experiences change us all so that we develop into new 'selves'. Yet our advance directives made at a prior time, by a prior 'self', are followed. Why should we treat the demented self any different? Without entering the philosophical discussion of whether dementia patients have a new identity, there are many reasons that support following the advance directive, even when it conflicts with the current patient's best interests.

Firstly, in principle, we should respect autonomy. Not honouring advance directives denies patients any autonomy over their medical decisions and paternalism takes over. Section 11 of the New Zealand Bill of Rights Act supports this: "Everyone has the right to refuse to undergo any medical treatment".¹² We create injustice by disregarding directives as people with dementia can therefore not refuse treatment.

Secondly, patients may have valid reasons to create advance directives that will hasten death and are purposefully not in their best medical interests, but rather represent personal values. A person may decide that any treatment prolongs suffering and is therefore undesirable, any treatment prolongs the requirement for care which may create a financial burden to the family, and any treatment allows the patient to progress further into a disease state which they may wish to protect their family from seeing. With such reasoning, it may be appropriate to follow the advance directive even if it contradicts the patient's current best interests. However, the 'worthiness' of reasoning should not be a requirement for the advance directive to be followed if the directive is deemed valid. Medical practice carries out a competent patient's wishes, for example, the refusal of life-sustaining intervention, regardless of how unreasonable the request. Therefore, to act consistently, we must also carry out a directive that is not in the patient's best interests if the directive is valid.

Thirdly, if doctors disregard directives and instead act in the patient's best interests, there is potential for subjectivity and bias. A survey of 500 American physicians found that race influenced physician attitudes towards advance directives and end of life treatments. While 58% of 'white' physicians believed tube feeding in terminally ill patients is 'heroic', only 28% of 'black' physicians agreed.¹³ With ethnicity resulting in such differing views on treatment, there is likely to be huge variation in what doctors decide is the patient's best medical interests. Similarly, decisions of whether to treat inevitably involve judging the patient's quality of life. There is evidence that healthy people rate quality of life for those with chronic illness lower than the patients themselves.¹⁴ For these reasons, some argue it is better to be bound by a decision you made yourself, than to be bound by the will of a third party.¹⁵

Rebuttal of Counter Argument

Even though the counter arguments above support following the advance directive, society has placed a duty on the doctor to protect life. A survey conducted on cancer patients, healthy controls, nurses, and physicians in Germany showed one quarter of patients, and one third of the other

groups, feared 'dictatory' use of advance directives. That is, where physicians use the advance directive without taking into account their knowledge about illness type and prognosis.¹⁶ This supports society wanting doctors to ultimately act in the best interests of the patient, rather than solely respecting autonomy. Combining this societal 'duty' with doubts about the validity of advance directives and self-hood, there is compelling support for doctors to act with beneficence for the patient entrusted in their care. Erring on the side of life is consistent with court rulings for cases where advance directives have been unclear. One such case is that of *HE v A Hospital NHS Trust* (2003). In this case, the incompetent patient required a blood transfusion to survive. However, she had signed an advance directive indicating refusal of blood transfusion because she was a Jehovah's Witness. Since the creation of the advance directive, there was evidence that she had rejected her faith and become Muslim. The court ruled that "doubts must be resolved in favour of the preservation of life".¹⁷ The Taking Care: Ethical Caregiving in Our Ageing Society (2005) report argues that a person's prior wishes should be considered in decisions about care. This report was produced following the case of Terri Schiavo, a woman who was kept on life support for fifteen years due to uncertainty about her wishes. However, to give "those wishes trumping power may force caregivers to forgo doing what is best for the person who is now entrusted to their care; as moral agents themselves, caregivers cannot simply do what they were told but must also try to do what is best".¹⁸ Perhaps doctors are protecting their consciences, and, in America, their legal obligations by favouring life. A survey of American physicians investigating what influenced their compliance to an advance directive, found 52% believed there was less liability in maintaining someone alive against their will than mistakenly allowing them to die (only 30% disagreed).¹⁹

FUTURE OF ADVANCE DIRECTIVES

The focus of advance directives to extend autonomy is impractical unless we want to "privilege competent choice over incompetent interests".⁵ Our focus should not be on patients trying to imagine future scenarios and what care they would like to receive. Instead, increased effort should be put into developing trust between patients and medical professionals. Except in cases of specific religious beliefs where certain procedures are unacceptable, perhaps patients would not require advance directives if they were able to believe that medical professionals would always act in their best interests. Some argue that "[advance directives] make autonomy and self-determination the primary values at a time of life when one is no longer autonomous or self-determining, and when what one needs is loyal and loving care".¹⁸ Another critic argues that even though it is frightening that "there may come a time when we will be unable to direct our lives... assuaging this fear with illusion of the advance directive does the patient a disservice".⁹ Issues with advance directives may mean that people have to accept that dependency and lack of control is inherent to many diseases.

CONCLUSION

As our ageing population is offered a multitude of life prolonging medical treatments, advance directives are important in ensuring our right to refuse treatment is respected. However, this essay has illustrated how doctors must act in the best interests of the patient that is currently in their care. This is supported by the doctors' professional duties of non-maleficence and beneficence, combined with exploring changing identity and 'self-hood' relevant to patient autonomy. Justice, respect for autonomy, and fear of subjectivity create strong counter arguments in support of following directives. These arguments are outweighed by the trust society places in doctors to ultimately support life when it is in the best interests of the patient.

* Throughout this essay, 'best interests' specifically means 'best medical interests'.

REFERENCES

1. Huxtable R.
Law, Ethics and Compromise at the Limits of Life: To Treat or not to Treat?
Oxon: Routledge, 2013.
2. Ministry of Health.
Advance Care Planning: A guide for the New Zealand health care workforce.
Wellington: Ministry of Health, 2011. <http://www.moh.govt.nz> (Search for: 5135).
3. APNZ News Service.
Dementia cases could triple in NZ by 2050.
The New Zealand Herald. 2013 April 22.
4. Access Economics for Alzheimer's New Zealand.
Economic Impact of Dementia in New Zealand.
Wellington: Alzheimer's New Zealand, 2008.
5. Robertson JA.
Second thoughts on living wills.
The Hastings Center Report 1991;21(6):6-9. doi: 10.2307/3562355.
6. de Boer ME, Hertogh CPM, Dröes RM, Jonker C, Eefsting JA.
Advance directives in dementia: issues of validity and effectiveness.
International Psychogeriatrics 2010;22(2):201-8. doi: <http://dx.doi.org/10.1017/S104161020990706>.
7. Cartwright Inquiry.
Unethical Experiment at National Women's Hospital.
2011 Dec. <http://www.cartwrightinquiry.com/> (accessed 24 May 2013).
8. Malpas PJ.
Advance directives and older people: ethical challenges in the promotion of advance directives in New Zealand.
Journal of Medical Ethics 2011;37(5):285-9. doi: 10.1136/jme.2010.039701.
9. Tonelli M.
Pulling the plug on living wills. A critical analysis of advance directives.
CHEST Journal 1996;(110):816-22. doi: 10.1378/chest.110.3.816.
10. Dworkin R.
Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom.
New York: Vintage Books, 1993.
11. Hilfiker D.
Watching the Lights Go Out: A Memoir from Inside Alzheimer's Disease.
2013 [updated 2013]. <http://davidhilfiker.blogspot.co.nz/2013/01/now-it-begins.html> (accessed 06 May 2013).
12. New Zealand Bill of Rights Act 1990.
Pub. Act 1990 No. 109 (Aug 28, 1990).
[updated 1990; cited 2013 May 24]. Available from: <http://www.legislation.govt.nz/act/public/1990/0109/latest/DLM224792.html>.
13. Mebane E, Oman R, Kroonen L, Goldstein M.
The influence of physician race, age, and gender on physician attitudes toward advance care directives and preferences for end-of-life decision-making.
for end-of-life decision-making. Journal of the American Geriatrics Society 1999;47(5):579-91.
14. Lulé D, Zickler C, Häcker S, Bruno M, Demertzi A, Pellas F, et al.
Life can be worth living in locked-in syndrome.
Progress in Brain Research 2009;177:339-51. doi: 10.1016/S0079-6123(09)17723-3.
15. Pierce R.
A changing landscape for advanced directives in dementia research.
Social Science & Medicine 2010;70(4):623-30. doi: 10.1016/j.socscimed.2009.10.037.
16. Sahm S, Will R, Hommel G.
Attitudes towards and barriers to writing advance directives amongst cancer patients, healthy controls, and medical staff.
Journal of Medical Ethics 2005;31:437-40. doi: 10.1136/jme.2004.009605.
17. **HE v A Hospital NHS Trust [2003].**
EWHC 1017 2 FLR 408 (Fam) (2003).
18. Kass LR, Carson BS, Dresser RS, Foster DW, Fukuyama F, Gazzaniga MS, et al, eds.
Taking Care: Ethical Caregiving in Our Aging Society.
Washington: The President's Council on Bioethics, 2005.
19. Burkle C, Mueller P, Swetz K, Hook C, Keegan M.
Physician perspectives and compliance with patient advance directives: the role external factors play on physician decision making.
BMC Medical Ethics 2012;13(31). doi: 10.1186/1472-6939-13-31.

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New Zealand Medical Student Journal
Te Hautaka o ngaa Akongaa Rongoaa

Deadly serious: the definition of death in New Zealand

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Henry Wallace is a fourth year medical student at the University of Auckland. He enjoys learning new things, travelling, and running.

It would appear there is dissociation between the medical and legal dealings of death in New Zealand. We have no statutory definition of death, and the legal profession seems content for medical practitioners and their regulatory bodies to define the concept. Nevertheless at times medicine and law must coincide, giving a necessity for a legal definition of death. This essay will examine this current 'definition' of death in New Zealand and its possible alternatives.

As above, there is no statutory definition of death in New Zealand. The closest statement is in the Human Tissue Act 2008 which states that tissue may not be removed from a human body unless a 'qualified person is satisfied... that the individual concerned is dead'.¹ This is a vague definition showing that the law defers to medicine for its definition of death. This deferral system was first proposed in 1972, when a high court judge the Hon. Mr Justice DS Beattie submitted that doctors should attempt to agree among themselves on what constitutes death, and accord this with what the everyday man would agree with.²

The lack of a statutory definition of death and the proposal that doctors should define it has resulted in death being legally defined by case law. The relevant case is *Auckland Area Health Board v Attorney-General* [1992] 8 CRNZ 634 (HC) involving Mr L, who suffered from an aggressive form of Guillain-Barré Syndrome. Mr L's disease progressed to the extent that he was deaf, possibly blind, and unable to breathe without mechanical support.³ Due to the severity of his condition, the physicians charged with Mr L's care, along with Mrs L, sought legal declaration that withdrawing the life support of Mr L would not be met with criminal prosecution. The motion was upheld and a declaration was given by Justice Thomas J on the basis that "A doctor acting responsibly and in accordance with good medical practice recognised and approved as such in the medical profession, would not be liable to any criminal sanction based upon the application of s 151(1) Crimes Act 1961. He or she would have acted with lawful excuse."³

The lawful excuse referred to above is derived from an ethical argument holding that removing Mr L's life support does not kill Mr L; his disease does. Instead, withdrawing life support (a humane, gradual process) ceases to prolong his life and withholds a futile medical treatment. The former quote also shows that "Good medical practice, which is recognised and approved as such in the medical profession" is what forms the basis for defining who is dead in New Zealand.³ The Judge more clearly shows that the courts

defer to the medical profession in this regard when he says: "...the medical community... has preferred the concept of what is called 'brain death'... While I understand that this definition has not been formally adopted in New Zealand, it is widely accepted throughout the medical profession..."³ So despite Mr L not being pronounced 'dead' in this case, (instead being referred to as the "living dead" for reasons discussed later), the judge and the lawyers in the trial measure his standard of life by the concept of whole brain-death as is accepted by medical practitioners, and thus the law in New Zealand.^{3,4}

The human brain can be simply considered as comprising of two parts: The higher brain (cerebrum and cerebellum) giving conscious thought and sensory perception, and the lower brain (brainstem) which regulates unconscious functions such as breathing, heart rate and wakefulness. According to the whole-brain definition of death, "death is the irreversible cessation of functioning of the entire brain, including the brainstem".⁵ There are many advantages to this approach that have led to its resounding popularity. Firstly, the whole-brain approach was not a revolutionary change from the old cardio-pulmonary definition (cessation of heart-beat and breathing) of death because when the heart and lungs cease to function, so will the brain, and vice versa. So, in some ways, the change of definition merely cemented the changing views that the brain is the most important organ in the body and the integrator of all functions.

Because of the above points, this definition change was highly amenable to the common public and this helped its dissemination.⁵ The standard also has practical advantages in that it can be clinically tested for, and allows organ transplantation of viable tissue, as circulation and respiration can be maintained by external means after brain death. This definition also enables expensive life-support treatment to be switched off in cases of total brain failure.⁵

Proponents of this theory argue that these practical benefits are merely coincidences occurring with a natural biological death. Others say these pragmatic factors are used as a means of justifying an immoral concept.⁵ A disadvantage of this definition is that it also follows that someone with only a functioning brainstem is considered alive in New Zealand. This creates an ethical dilemma for switching off the life-support to these patients, as in a legal sense it is tantamount to killing them. The latter point is relevant to the unique case involving Mr L as his brainstem was functional, but he was unable to regulate his own heart rate or breathing because all of the nerves coming out of his brainstem and spinal cord were defunct.

Hence, in the case he is referred to as the 'living dead' and the judge recognises that the only difference between his condition and the standard definition of death is "a matter of medical description".³ His condition was therefore taken as equal to that of death and the outcome of his case was sufficient to define the whole-brain standard of death for subsequent cases in New Zealand.

Many other western countries use the whole-brain standard to define death, including the USA. However there it is used in tandem with the classical cardio-respiratory definition of death saying: "An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards."⁶ Why have the USA chosen to include this classical definition in their federal law? At the time of enactment, it was a way of pleasing conservatives and progressives alike, synergising a contemporary and classical definition. Their definition also came into law at a time when cardio-pulmonary resuscitation (CPR) and mechanical means of sustaining life were being perfected, meaning for the first time in history, a stopped heart didn't mean certain death. Now however, there is wide acceptance of brain death. So why has the USA retained their dual definition when a simpler brain oriented definition would suffice?

The answer to this question lies in the practice of 'donation after cardiac death' (DCD). DCD is organ donation after confirmed cardiopulmonary death, and occurs when patients have previously agreed to be taken off life-support. These patients are taken to an operating theatre, where life-support is withdrawn, leading to cardiac arrest. The doctors then wait two minutes, and declare the patient dead on the basis of the cardiopulmonary standard.⁵ This allows for organ donation to occur rapidly after death, which could not occur with the whole brain standard which requires extensive confirmatory tests that may take hours after death occurs.⁵ This use of the legal definition of death in the USA has led to an increased ability to meet the demand for donor organs, something the New Zealand medical system struggles with.⁷

Similarly to New Zealand, the United Kingdom definition of death is by case law, but their definition is that of brainstem death.⁸ This has the practical advantage of requiring fewer tests to certify death. It is also, for all intents and purposes, the same as the whole-brain definition because the brainstem contains the reticular activating system. This piece of neuroanatomy switches on our state of consciousness and hence if it is damaged, the higher brain cannot function to maintain consciousness anyway.

Aside from these well-accepted definitions, the most progressive approach to defining death is the concept of higher brain death, which is favoured by some academics.⁹ Higher brain death is given as the irreversible cessation of the capacity for consciousness.⁵ It recognises the human brain as having the ultimate function of enabling consciousness, not the regulation of body function. Academics in favour of this definition like to think of death in terms of "a complete change in the status of a living entity characterized by the irretrievable loss of those characteristics that are essentially significant to it".¹⁰ Thus it is distinguished from other definitions, because it implies that regulation of bodily functions does not necessitate life, as it is not unique or especially significant to humans. This regulation merely provides a vehicle for the maintenance of our consciousness.

This definition has not been put into active use anywhere, and remains more of a philosophical discussion.⁵ If it were to come into practice, there are aspects that would require clarification. Especially unclear would be the time after conception at which humans become 'alive'. This issue arises because under the higher brain definition, life would necessitate consciousness and humans develop this well after conception and possibly after we are born.¹⁰ This definition may also lead to difficulties in criminal law for it could be sympathetically read as splitting the human into two 'beings' – meaning that prosecution for removing the consciousness of an individual would carry a higher sentence than the destruction of their body or capacity for bodily function.

Philosophical discussions aside, New Zealand's legal definition of death is sound. It is the definition best accepted by medical professionals working here, and is comparable to other international standards. The lack of a statutory definition here is also beneficial because it allows for constant debate of the definition in court on a case-by-case basis. This definition will therefore serve us well now and into the future by allowing for change as societies' views on death inevitably shift as they have throughout history.

REFERENCES

1. **Human Tissue Act 2008.**
2. Beattie DS.
Medico-legal aspects of organ transplantation in New Zealand.
N Z Med J 1972;75(477):70-74
3. **Auckland Area Health Board v Attorney-General [1992] 8 CRNZ 634 (HC).**
4. Australian and New Zealand Intensive Care Society (ANZICS).
The ANZICS statement on Death and Organ Donation.
2013:17
5. DeGrazia D.
The definition of death.
Stanford Encyclopedia of Philosophy 2009
6. **Uniform Determination of Death Act 1981.**
7. **WHO Global Observatory on Donation and Transplantation: 2012 activity data.**
Available at: <http://www.transplant-observatory.org/pages/Data-Reports.aspx>
(Accessed 19 June 2014)
8. **Airedale N.H.S. Trust v Bland [1993] A.C. 789 House of Lords.**
9. Rich BA.
Postmodern personhood: A matter of consciousness.
Bioethics 1997;11:206-216
10. Veatch RM.
Death, Dying and the Biological Revolution: Our Last Quest for Responsibility.
New Haven: Yale University Press, 1976

JDocs and surgery as a career

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INTRODUCTION

The Royal Australasian College of Surgeons (RACS) is the leading advocate for surgical standards, professionalism and surgical education in Australia and New Zealand.

The College is a not-for-profit organisation that represents more than 7000 surgeons and 1300 surgical trainees and International Medical Graduates. RACS also supports healthcare and surgical education in the Asia-Pacific region and is a substantial funder of surgical research. There are nine surgical specialties in Australasia being: Cardiothoracic surgery, General surgery, Neurosurgery, Orthopaedic surgery, Otolaryngology Head-and-Neck surgery, Paediatric surgery, Plastic and Reconstructive surgery, Urology and Vascular surgery.

As you start your journey on a medical career, you should consider what your future area of clinical practice might be. The JDocs website is an initiative of the Royal Australasian College of Surgeons that aims to provide career guidance to junior doctors in Australia and New Zealand during the early pre-vocational years for those who would like to pursue an exciting, challenging, rewarding and varied career such as surgery.

Surgeons enjoy the intellectual and practical challenges of the operating theatre and the outpatient clinic. To interact with patients, perform surgery and see their life transformed almost immediately is extremely gratifying. Working with teams of colleagues including other surgeons, anaesthetists, technicians nurses and allied staff to ensure the best outcome for both acute and elective patients also brings a great sense of achievement and satisfaction. There is also significant responsibility to support the patient through their surgical journey.

Using the JDocs Framework and resources as you progress through your first few years in the workplace will expose you to the relevant knowledge and skills that should be achieved during the initial postgraduate years (PGY1–3).

To become a surgeon, you must first complete a medical degree and then work and train in a clinical setting – usually a hospital – for one to two years. The earliest point you can apply to enter the College's Surgical Education and Training (SET) program is during your second postgraduate year (PGY2) after university. Commonly, many doctors apply in PGY3–4.

If your application to enter SET is successful, you will train in one of the following nine surgical specialties. This training occurs primarily in public hospitals and generally takes five to six years. Following successful completion of the SET, you will be eligible to apply to sit the Fellowship examination. Following successful completion of the Fellowship examination, you will

become a Fellow of the Royal Australasian College of Surgeons (FRACS) and will be accredited to practise independently as a consultant surgeon.

The Royal Australasian College of Surgeons launched JDocs, a competency framework supported by a suite of educational resources, in December 2014. JDocs is designed to promote flexible and self-directed learning, together with assessment opportunities to record and log procedural experiences and capture evidence of personal achievements. Supporting resources will be available late in 2015 on an annual subscription basis. Further information about JDocs and subscription is available on the JDocs website, <http://jdocs.surgeons.org> or scan the QR code at the end of the article.

WHY HAS COLLEGE ENGAGED IN THE PREVOCATIONAL SPACE?

The College recognised the need for engagement with prevocational junior doctors to provide guidance and education that would assist with their development towards a proceduralist career. Key to this was to ensure that the doctor entering any procedural speciality program would be well-prepared and clinically competent relevant to their postgraduate year. As a result, the College established JDocs, which is available to any doctor registered in Australia and New Zealand, from and including internship. Depth of engagement is determined by the individual doctor.

The College also recognises that the New Zealand Medical Council has embarked on a mandatory prevocational e-portfolio for PGY1–2 and has consulted with MCNZ to ensure the JDocs Framework complements this program.

JDocs is not mandatory in Australia or New Zealand; it does not guarantee selection into any procedural specialty training program. Engagement with the Framework and its supporting resources describes the many tasks, skills and behaviours a junior doctor should achieve at defined postgraduate levels, and will help the self-motivated junior doctor recognise the performance standards expected prior to applying to a specialty training program. Junior doctors are also eligible to apply for the General Surgical Sciences Examination, which tests anatomy, physiology and pathology to a high level.

WHAT DOES THE JDOCS FRAMEWORK COVER?

The JDocs Framework is based on the College's nine core competencies, with each competency considered to be of equal importance, and is described in stages appropriate for each of the first three postgraduate

clinical years, as well as those beyond. In order to link the Framework to everyday clinical practice, key clinical tasks have been developed that are meaningful for the junior doctor. Achievement of the task demonstrates the competencies and standards outlined in the Framework, and shows that the junior doctor is competent at the daily clinical tasks required to commence specialty training.

ACCESSING JDOCS RESOURCES

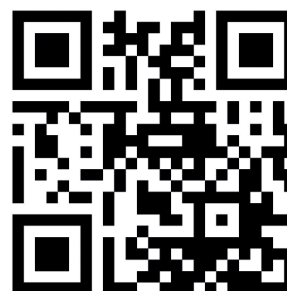
The JDocs website, <http://jdocs.surgeons.org>, provides further information about the Framework and how to access subscription based resources. Doctors can download a copy of the Framework and/or access an online version together with a variety of freely available resources. Other resources will be available on a subscription basis. The JDocs website and social media feeds will also deliver updates as to JDocs launch of subscription based resources, as they become available later this year.

SUMMARY

In summary, the JDocs Framework is about the professional standards and learning outcomes to be achieved during the early postgraduate/prevocational clinical years. It describes and assists early career professional development for junior doctors aspiring to procedural medical careers, including surgery. It strongly promotes work-based assessments for the many prevocational doctors.

Please contact Kathleen Hickey, Director of Education Development & Assessment (kathleen.hickey@surgeons.org) or Jacky Heath, Manager; Prevocational and Online Education (jacky.heath@surgeons.org) with any comments or questions.

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Professionalism

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Daphne Cohen is a PGY1 house officer at MidCentral DHB. She has lived and studied in most of NZ's major cities and managed to pick up a PGDip in Bioethics along the way. Her major interests include General Medicine, social justice, and brunch. She also has amazing hair. She is this year's blogger for the NZMSA First Year blog.

Find more at <http://www.nzmsa.org.nz/category/thefirstyear/>

There's been a lot in the news about bullying and harassment, so now seems like a good time to talk about Professionalism (capital P). Many of you will have held part time jobs before, but unless you took a year off somewhere this may well be your first real 9-5 (or 8-4) job – especially those of you who entered Med via the HSFY. Probably most of the lectures on Professionalism washed over you much as they did over me – something you knew on paper but unrelated to most of your daily life. Even as a TI you're fairly shielded from it – you're rarely the person actually dealing directly with patients, families, other doctors and allied health professionals – but as a house officer you are often the first point of call for everyone.

One of the first things you'll realise is that other people don't know what you know. It may seem silly to point it out, but it's true. I remember thinking nurses must be incredibly stupid for not knowing even the most basic medical facts. For years you have sat at the bottom of the knowledge heap and the idea that you might know more about something than someone else seems implausible, but you really actually do. Remember this when they page you with apparently inane questions. Take the time to explain so they understand. Remember that they think we're stupid for not knowing how to dress a wound or program an IV infusion pump.

Above all try not to shout at them – their day is just as busy and stressful as ours is and they're not deliberately trying to make your life more difficult (mostly, anyway).

Be kind to your fellow house officers. If you can't do that, be civil. Many of you will not be working with your best friends from Med school – you will have to interact and socialise with a group of entirely new and unknown people. Whether you like them or not (and there will always be people you don't like) they are your co-workers and you should respect them as such – especially the ones you don't like.

I wish this went without saying, but unfortunately it doesn't so I'll say it: do not badmouth your co-workers to other staff, even as a joke. If you tried a joke and it went south, then accept that your humour tanked and

apologise sincerely (we're only human). Don't be racist or sexist at them or about them. Don't call them names, and especially don't call them names in front of other co-workers. Don't shout at them, even if you think they really deserve it (chances are there has been some misunderstanding). Do not throw tantrums.

You may end up socialising a lot with your cohort of PGY1s, other house officers, registrars and allied health professionals – remember that you still have to work with these people in the morning. Friendships and relationships are fine, but make sure it doesn't impact the working relationship you still need to have. Not everyone in the cohort will be your BFF – we all need to vent from time to time (including about each other) but think carefully about whom you choose to talk to and what you say.

Don't forget that things you do outside of the hospital can still have work-based, real-world consequences. You are not in high school anymore, you are a working professional with status in society – try and comport yourself appropriately.

If it seems like a lot of this is about not shouting, it's because that's the really basic stuff – Professionalism 101. If you've got it down, then you've got a good base to build on as you take on more responsibility in your career. Obviously professionalism encompasses much more than not being a jerk, but keeping it up all day every day – even when your pager has been going every 5 minutes, you're hangry because you missed dinner, and you've just fielded the most idiotic query in the history of medicine – is actually quite hard.

If you can manage to keep your cool in those moments you're doing well. It's a stressful year and we all slip up – some weeks it's like I can't keep my foot out of my mouth or my temper in check. This is the obvious stuff that can get you a bad reputation. Remember – shouty house officers turn into shouty consultants, and that's how bullying and harassment scandals happen. Nobody wants that.

PRODUCT REVIEW

Medivention diagnostic reflex hammer ultra-compact

Cheyaanthan Haran

Deputy Editor

4th Year Medical Student

University of Auckland

Tendon hammers are ubiquitous in hospitals, but good tendon hammers aren't. A tendon hammer is one of the first pieces of equipment a young medical student may overlook. However, it is one of the very first pieces of medical equipment we use.

The Medivention Diagnostic Reflex Hammer is design is different. At first, it looks like a stylish pen attached to a hockey put, but once fully engaged and locked it resembles a typical tendon hammer. In its ultra compact form it sits at the size of an mobile phone making it the ideal portable tendon hammer. Features include a telescopic extension allowing it to extend out to 25cm, and the tip has a clothing clip allowing it to be securely fastened to your scrubs or pocket. It has a fully lockable swivel head where it can be firmly fixed for use.

It can be purchased from Capes Medical for \$39.95. This is a bit hefty, and for students understandably so, but if you are always on the go you won't look back.



Product Type Diagnostic reflex hammer

Manufacturer Medivention

Materials Stainless steel, silicone

Length 110mm (250mm at full extension)

Retailer Capes Medical

NZ RRP \$39.95

Top Knife

Cameron Bringans

5th Year Medical Student
School of Medicine
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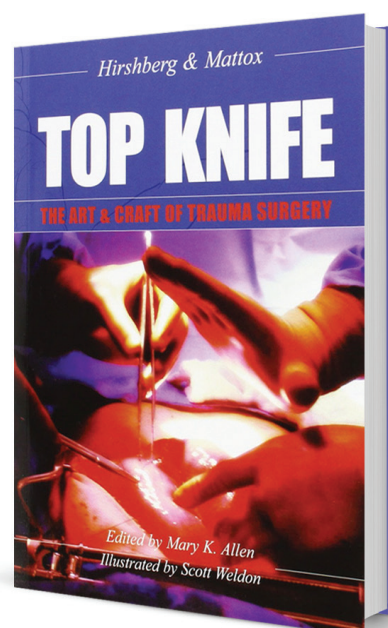
Cam is a 5th year medical student at University of Auckland. He is a Kiwi with a Canadian accent and loves coffee, books, sport and watching the Westpac chopper land.

A 16-year-old victim of a brutal stabbing arrives to the E.R. at 2 A.M. The patient is panicked, tachycardic and hypotensive. As the general surgery registrar on call you examine the patient and find an entry wound on his right chest in the 7th intercostal space. The abdominal ultrasound scan suggests a laparotomy but the torrential pour of dark red blood through his chest drain pleads for a thoracotomy. Chest or abdomen? You ask the scrub nurse to prep both. Three bold strokes xiphisternum to pubis are made. The open abdomen exposes the source of bleeding. A massive liver laceration is hemorrhaging through a perforation in the diaphragm, filling the chest with blood. To keep this patient alive you will need to communicate with your team. Think strategically and use the right surgical tactics.

Top Knife: The Art and Craft of Trauma Surgery teaches you to think like a trauma surgeon by putting you in her blood soaked gumboots as she bulldozes through normal anatomy and discards damaged organs. The authors Hirshberg and Mattox are veterans of the trauma world, with the later being the inventor of the "Mattox Manoeuvre". The book was written with the general surgery trainee in mind so mainly concerned itself with abdominal trauma. However, for the rural surgeon facing a thoracic or peripheral vascular injury the text offers "simple" fixes to keep the patient's heart beating without a cardiothoracic surgeon.

Experienced trauma surgeons perform nephrectomies and distal pancreatectomies with an automaticity that frees their brain to focus on strategy and communication. *Top Knife* deals with the most cerebral element of trauma surgery: the debate between definitive repair and damage control. The text also gives advice on the mental aspects of surgery, such as how to maintain tactical flexibility, simplifying an operation, and avoiding flailing. Anyone who has inserted an I.V. line will have experienced flailing where you dumbly persist with the same technical approach despite repeated failure.

For the most serious branch of surgery this book treats its subject with a surprising creativity and sense of humor. Penetrating trauma to the head of the pancreas is described poetically as a "surgical soul wound". Lee Harvey Oswald's operative notes open the chapter on abdominal vascular trauma.



Illustrations are used throughout the book despite the author's admonition that "medical illustrators are optimists". Nevertheless, the art supplements the description of complex anatomy and manoeuvres.

Top Knife is a 200 page medical thriller with valuable lessons for anyone interested in critical care, emergency medicine, and of course surgery. Sure, it will be a long time before you are performing Kocher manoeuvres or emergency room thoracotomies, but that knowledge is helpful now. To the uninitiated, trauma is seen as a frantic mess. However, with the knowledge gained from this book, readers come to realise that trauma surgery is organised chaos. Medical students can learn from trauma surgeons - we can all act more systematically, communicate better, and avoid flailing.

Title Top Knife – The Art and Craft of Trauma Surgery
Author(s) Asher Hirshberg, Kenneth L. Mattox
Publication date 30 April 2005
Publisher TFM Publishing Ltd Press
ISBN 13 9780199574926
NZ RRP \$59.59 (Paperback)

Clinical Skills

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Hassan Alduhailib is an Auckland-based 5th year medical student with an interest in education. He looks to pursue a surgical career.

Learning clinical skills can be overwhelming. It makes the transition from a pre-clinical medical student to a clinical medical student that much more daunting. Reading *Clinical Skills* by T.A Roper, will definitely help ease the transition and help students acquire clinical skills not only to pass the OSCEs but also to become a distinctly hands-on physician.

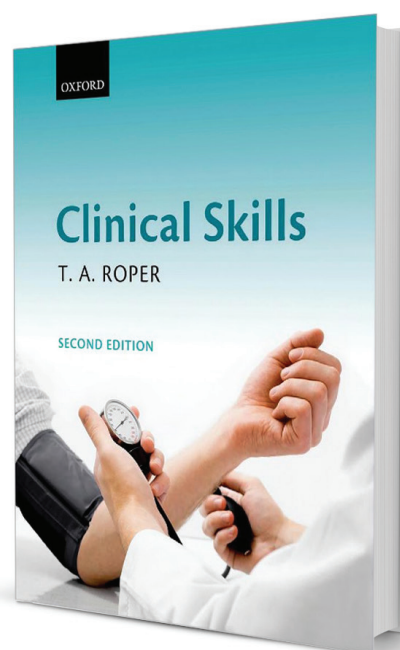
Clinical Skills by T.A. Roper, is a clear and reader-friendly book. It provides a systematic approach to diagnosis; covering history taking and examination. Supported by easy-to-interpret diagrams, tables, cartoons and pictures. It covers all of the systems with additional chapters on how to interpret x-rays and spot diagnosis. In its 2nd edition, chapters on paediatrics examination and genitourinary examination have been added.

Clinical Skills provides a concise and straight to the point approach; organised under simple headings. For example, there are headings for each examination finding (e.g. neck lump, murmur): What is it?; Significance; Causes; and How to examine. With similar heading in the history taking section, describing which questions to ask for each symptom. The material in the book is then illustrated in exemplar cases with discussion throughout each chapter.

At the end of each chapter, there are assessment questions that are ranked in terms of importance. Moreover, it discusses common problems faced by students during examinations, with suggested solutions.

Compared to Talley and O'Connor's *Clinical Examination*, it is cheaper at \$91.21 NZD while Talley's is priced at \$136 NZD (cited: Books Depository). Furthermore, it's written with a simpler and easier to follow style than Talley and O'Connor.

In conclusion, *Clinical Skills* by T.A. Roper is an affordable book, written with wit and clarity that will serve as a survival guide for medical students. It takes next to no time to read and will help you in your OSCEs and on the ward.



Title Clinical Skills

Author(s) T.A. Roper

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INFORMATION FOR AUTHORS

GENERAL INFORMATION

The Editors of the New Zealand Medical Student Journal aim to support medical student development, be a forum for opinions and discussion, and publish the educational writing of medical students. To this end, the Journal accepts submissions in the form of original research articles, academic review articles, feature articles including case reports and conference reports, book reviews and letters. The Journal commits to rigorous peer review and freedom from commercial influence.

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