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# AJAN

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# Outbreak management in residential aged care facilities –prevention and response strategies in regional Australia

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## KEY WORDS

aged care; disease outbreaks; influenza; gastroenteritis

## ABSTRACT

### Objective

To identify the outbreak prevention and response preparedness of residential aged care facilities (RACFs) in the Hunter New England area of New South Wales (NSW).

### Design

A cross-sectional telephone survey.

### Setting

RACFs who provide full time nursing care in regional NSW.

### Subjects

Twenty randomly selected RACFs including nine metropolitan and 11 rural facilities within the regional Hunter New England (HNE) district of NSW.

### Main outcome measures

Percentage of staff and residents vaccinated against influenza in 2013; availability and use of a surveillance system to detect outbreaks; knowledge of national outbreak resources; and presence of a facility outbreak management plan.

### Results

Across the 20 facilities more than 85% of residents were vaccinated against influenza in 2013. Staff influenza vaccination rates varied from less than 50% in six facilities to greater than 80% in nine facilities. Overall, 18/20 (90%) facilities reported having outbreak management plans available; however only 5/20 (25%) facilities reported having an outbreak surveillance system in place.

### Conclusion

RACFs in this sample reported varying levels of outbreak prevention and preparedness strategies. Nursing staff working in RACFs need to ensure strategies are in place to prevent and respond to communicable disease outbreaks. In particular all facilities are encouraged to have an outbreak surveillance system in operation, especially during the peak seasons. RACF accreditation should consider including outbreak prevention, preparedness and management outcomes in the review measures to ensure all RACFs have strategies in place to protect vulnerable residents from common communicable disease outbreaks.

## INTRODUCTION

Respiratory and gastroenteritis outbreaks within residential aged care facilities (RACFs) cause considerable morbidity and distress, and impact negatively on staff, resources and residents' activities (Kirk et al 2010; McCall et al 2007). Outbreaks within RACFs are frequent, with an estimated 17% of RACFs in Australia experiencing an outbreak of gastroenteritis each year, most of these occurring in Australia's winter (June – August) (Kirk et al 2010). Surveillance conducted in Australia, between 2002 and 2008, identified 3257 reported outbreaks in RACFs affecting 84,769 people; and resulting in 1577 hospitalisations and 209 deaths (Kirk et al 2010). The potential severity of outbreaks is highlighted by an influenza-like-illness outbreak in a RACF in New South Wales (NSW) which affected 26 residents, resulted in 14 hospital admissions and was associated with six deaths (Turahui et al, 2008). The reported number of outbreaks likely under-represents the actual number of outbreaks within facilities (Eastwood et al 2008).

Elderly people living in RACFs are more vulnerable to gastroenteritis and respiratory illness due to physiological reasons (Slotwiner-Nie and Brandt 2001); comorbid medical conditions associated with ageing (Gavazzi and Krause 2002); close living arrangements; and frequent contact with visitors and staff (Strausbaugh et al 2003). Infectious diseases may be introduced into RACFs through staff, visitors from the community, hospital admissions and transfers from other facilities (Strausbaugh et al 2003).

Early recognition of outbreaks by nurses, and implementation of outbreak control measures, is important for reducing the spread of infectious gastrointestinal and respiratory diseases within RACFs. Early recognition by RACF nurses allows the timely implementation of outbreak control measures including: environmental cleaning and disinfection; use of personal protective equipment; infection control signage and education; isolation of ill residents; and cohorting of ill residents and staff (Department of Ageing and Aged Care, 2014). In addition, RACFs can minimise the transmission of infectious enteric and respiratory diseases to staff and residents through outbreak prevention and preparedness strategies, which include: annual influenza vaccination of residents and staff (Communicable Disease Network Australia (CDNA), 2017); discouraging ill visitors and staff attending the facility; and provision of hand washing facilities for residents, staff and visitors (Jefferson et al 2010). Outbreak preparedness can include outbreak management plans, communicable disease surveillance and awareness of outbreak resources (Eastwood et al 2008).

The Hunter New England Local Health District is located in northern NSW and the Public Health Unit (HNE PHU) has worked with RACFs within the district over the past decade to provide advice and to strengthen the capacity of RACFs to respond to communicable disease outbreaks. Support to RACFs by the HNE PHU includes:

- telephone advice from nurse consultants to RACFs following the notification to the PHU of a respiratory or gastroenteritis outbreak;
- promoting national outbreak guidelines and resources including line listing templates on the HNE PHU website;
- RACF site visits if requested by the facility or if indicated by the course of the outbreak;
- dissemination of a monthly RACF-specific report identifying current communicable disease issues and links to outbreak management resources;
- annual RACF teleconference discussing outbreak prevention and preparedness strategies prior to influenza season; and
- periodic review of preparedness. Computer assisted telephone interviews were conducted in 2004, 2005 and 2006 with over 100 RACFs in the HNE region.

In NSW, gastroenteritis outbreaks in institutions and laboratory-confirmed influenza cases are notifiable under the NSW Public Health Act, 2010 (NSW Parliament 2010). During the period 2010-2012, 150 gastroenteritis outbreaks and 12 influenza outbreaks were reported to the HNE PHU.

There are limited published evaluation reports of outbreak preparedness strategies in RACFs in Australia and nurses roles in outbreaks. In this study we explored outbreak prevention and preparedness strategies used by RACFs within a regional area of NSW, Australia.

The project aimed to:

1. review outbreak prevention and response preparedness of RACFs;
2. identify opportunities for the public health unit to work with RACFs to reduce the burden of gastrointestinal and respiratory outbreaks; and
3. compare outbreak prevention and preparedness between regional, metropolitan and rural RACFs.

## **METHOD**

### **Setting**

The Hunter New England Health Local Health District (HNELHD) in northern NSW includes metropolitan, rural and remote areas; covering an area of 130,000km<sup>2</sup> it includes the coastal cities of Newcastle and Lake Macquarie, and inland regional centres of Maitland, Tamworth and Armidale. The district has a population of approximately 875,000 people (Health Statistics NSW 2013) and 131 RACFs comprising 58 metropolitan and 73 rural facilities.

### **Design**

A short telephone survey assessing outbreak domains was developed which included questions relating to outbreak prevention and preparedness measures; outbreak surveillance systems; and resident and staff immunisation coverage. The survey was developed using a combination of validated questions from a previous RACF questionnaire used by the HNE PHU in 2005 (Eastwood et al 2008) and additional questions developed by the project team.

RACFs included in this study were defined as nursing homes and hostels located in the Hunter New England area of northern NSW that provide full time nursing care. Twenty RACFs were randomly selected from the 131 RACFs using Excel randomisations in two strata, metropolitan and rural. The sample of 20 was used to fit with the available resources to complete the study and provide a reasonable snapshot of current practice. The same researcher conducted all interviews. Pilot testing of the survey was conducted with two RACFs that were not selected in the randomisation process and these results are not included in the analysis.

### **Data collection**

In June 2013 a letter was sent to all 20 selected RACFs inviting them to participate in the study. A copy of the questionnaire was also included to assist facilities to have appropriate information available for the telephone interview. The person interviewed at each RACF was either the facility manager; facility care manager; or infection control delegate. The phone interviews were conducted over a period of three weeks with each interview taking between 20-30 minutes.

### **Analysis**

All questionnaire responses were recorded in a Microsoft Excel worksheet. Frequencies were generated using SAS software version 9.1.3 for Windows. Relative risks with 95% confidence intervals were calculated in Excel, and compared vaccination coverage, staff vaccination availability and access. To allow meaningful comparison the vaccination coverage was divided into three categories >80%, 50-80% and <50%.

## Ethics

The HNE Local Health District Human Research Ethics Committee classified this research project as a quality improvement project.

## FINDINGS

The participating facilities included nine metropolitan and 11 rural facilities. Seven were hostel-based facilities, six were nursing home facilities and seven offered both nursing home and hostel-based care; the participating facilities differed in sizes (table 1). The nursing workforce varied according to the size of the facility with 18/20 facilities employing up to 100 nursing care staff. Sixteen of the facilities were owned by private organisations, thirteen of these being not for profit organisations, while the remaining four facilities were run by local government councils (table 1). Half (10/20) of the RACFs reported that over 80% of nursing staff were permanently employed and in the remaining 10 facilities 50 – 80% of nursing staff were permanently employed. Nursing agency use was relatively infrequent with 10 facilities reporting they never used nursing agency staff and six facilities stating they used agency staff less than once per month.

**Table 1: Residential Aged Care Facility location, level of care provided, size and attachment to larger organisation, Hunter New England, June 2013**

	Metropolitan	Rural	Total
<b>No. of facilities (n = 20)</b>	9	11	20
<b>Level of care provided</b>			
Hostel	3	4	7
Nursing Home	3	3	6
Nursing Home and Hostel	3	4	7
<b>Size of facility</b>			
Small (0-50 residents)	2	8	10
Medium (51 – 100 residents)	5	2	7
Large ( more than 100 residents)	2	1	3
<b>Ownership</b>			
Private	3	0	3
Private, Not-for-Profit	6	7	13
Public	0	4	4

Nineteen facilities reported having an influenza vaccination register for residents and 80% (16/20) of facilities reported having an influenza vaccination register for staff that was updated annually. The reported percentage of residents immunised against influenza across all facilities in 2013 was above 85%, with 15 RACFs stating that greater than 95% of residents had been vaccinated during that year (table 2). A higher proportion of metropolitan RACFs reported having vaccination coverage over 95% (RR = 1.4 (95% CI 0.84 – 2.31)) compared to rural RACFs for the 2013 influenza season however the difference was not statistically significant.

**Table 2: Influenza vaccination coverage for Hunter New England RACF residents in 2013 by location, June 2013**

	Number and percentage of RACFs		
	<i>Metro</i>	<i>Rural</i>	<i>Total</i>
<b>Percentage of residents who received influenza vaccination in 2013</b>			
Less than 85%	0	0	0/20 (0%)
85 to 95%	1	4	5/20 (25%)
More than 95%	8	7	15/20 (75%)

Reported staff vaccination rates were less than 50% for six RACFs and more than 80% for nine RACFs (table 3). The majority of facilities (15/20) reported they offered influenza vaccine at no cost to staff and made it available at the workplace. Staff vaccination coverage using the three categories is described in table 3. The majority of sites with staff vaccination coverage >80% offered free vaccine to staff however this did not reach statistical significance (RR = 1.17 (CI 0.35 -3.88)).

**Table 3: Staff influenza vaccination coverage in 2013 by location and availability of free vaccine on-site, Hunter New England, 2013**

Percentage of staff who received influenza vaccination in 2013	Number and location of RACFs		Free vaccine offered on-site		Total
	<i>Metro</i>	<i>Rural</i>	<i>Yes</i>	<i>No</i>	
Less than 50%	1	5	3	3	6/20 (30%)
50 – 80%	4	1	5	0	5/20 (25%)
More than 80%	4	5	7	2	9/20 (45%)

All RACFs reported that alcohol hand gel or hand washing basins were provided at the entrance to the facility for visitor and staff use. The majority of facilities (18/20) reported having signage throughout the year at public entrances requesting ill (symptomatic) visitors not to enter the facility; the remaining two facilities displayed signage only during a facility outbreak. Five facilities reported verbal screening of visitors by staff prior to entry.

Only five facilities (25%) reported having a regularly reviewed and documented surveillance system for detecting an outbreak of gastroenteritis or respiratory illness. Nineteen facilities reported having a nominated infection control coordinator; however, in many of these facilities (12/19) this role was integrated with another nursing position with no set hours dedicated to infection control.

Nineteen facilities were aware of the Department of Health Ageing and Aged Care (DOHAAC) 'Gastro Kit' (DOHAAC 2014) and 18/20 facilities reported being aware of the Department of Health Ageing and Aged Care 'Influ Kit' (DOHAAC 2014). Ten facilities (50%) reported their awareness of the Communicable Diseases Network Australia 'Influenza Guidelines for Residential Aged Care Facilities' (Communicable Diseases Network Australia (CDNA) 2009).

Outbreak management response plans were available in 18/20 (90%) facilities, a similar proportion (106/108) to that identified in an earlier study within the local area (Eastwood et al 2008). Ten facilities reported they had an agreement with a single general practitioner who would coordinate medical services during an outbreak in their facility.

## DISCUSSION

This RACF survey provided insight into various aspects of outbreak prevention and preparedness for metropolitan and regional RACFs in the study region of northern NSW. Nurses play an important role in reducing the risks of outbreaks in RACFs through high rates of resident influenza vaccination, awareness of national outbreak management guidelines and use of outbreak management plans. Weaknesses in outbreak prevention included low staff influenza vaccination rates at some facilities and the limited use of surveillance systems to detect communicable disease outbreaks.

Immunisation is regarded as one of the most effective ways to prevent and control seasonal influenza outbreaks (CDNA 2017). The Department of Health, Ageing and Aged Care recommends all residents and staff working in RACFs be provided with influenza vaccination annually (ATAGI 2015; DOHAAC 2014). Local RACFs reported higher resident influenza vaccine coverage than reported in an earlier study (Eastwood et al 2008) although both resident and staff vaccination levels in the study population remained below national RACF influenza vaccination targets and these were not validated by viewing records (CDNA 2017).

Staff influenza vaccination rates varied across the region. Studies have shown nursing and other staff vaccination coverage is associated with various factors including previous vaccination uptake, personal health issues, and concerns about side effects and doubts about vaccine effectiveness (Chalmers 2006; Halliday et al 2003). An internet survey of over 1,000 health care personnel (HCP) in the United States of America in 2014-2015 found that influenza vaccination coverage among health care personnel was 64.3% with the highest coverage amongst HCP working in hospitals (78.7%) and lowest amongst HCP working in long-term care facilities (54.4%) (Black et al 2014). An Australian study in 2000 found that just 28% of RACF nurses and other staff in the Australian Capital Territory received influenza vaccine (Halliday et al 2003), a similar percentage (27%) reported in a NSW RACF during an outbreak of influenza-like illness (Turahui et al 2008). Poor uptake of influenza vaccination amongst RACF nurses and other staff continues to occur despite national recommendations, and is a major gap in the ability to protect vulnerable residents from influenza transmission within their home environment. Strategies for increasing RACF staff influenza vaccination uptake need to be implemented and supported by managerial staff, in addition to addressing concerns about vaccine side effects, and providing targeted education on vaccination as a measure to reduce risk for patients and staff.

Comprehensive resources are available to assist RACFs prepare outbreak response plans but not all facilities reported being familiar with them. Public health units have a role in connecting RACFs to key national resources and encouraging the management of outbreaks within these guidelines.

The use of a surveillance system, which is regularly reviewed and easily identifies clusters of similar illness across the facility, can assist in early outbreak identification and response (Eastwood et al 2008). An effective outbreak surveillance system identifies residents or staff members with respiratory or gastroenteritis symptoms which may precede or indicate early stages of an outbreak. "Facilities should have the capacity to count those with ILI (influenza like illness) each day and identify a potential influenza outbreak (i.e. 3 cases of ILI in a 3-day period)" (CDNA 2017, p12). The current study identified limited use of surveillance systems amongst RACFs. Surveillance in RACFs can be challenging due to high patient to staff ratios, limited numbers of nurses with experience in surveillance, high staff workloads, inability of residents to communicate symptoms and atypical symptoms in the elderly. There is substantial room for improvement in ensuring the development and use of a surveillance tool to identify disease clusters within RACFs.

Since 2014, all RACFs within Australia are subject to accreditation by the Australia Aged Care Quality Agency (AACQA). Facilities are assessed under four standards comprising of 44 outcomes to ensure residents across Australia are provided with optimal and standardised care (Australian Government ComLaw 2014). The

accreditation process offers a unique opportunity to directly monitor RACFs outbreak prevention, response and management practices and ensure facilities have strategies in place to prevent and respond to communicable disease outbreaks. Public health agencies could advocate with the AACQA to develop standards within these accreditation outcomes that include outbreak prevention and management strategies. Currently the accreditation standards for RACF infection control are inadequate. The standards must include reportable indicators for staff and resident influenza vaccination alongside effective disease surveillance systems if real change is to occur. Passive interventions such as monthly reports, promotion of resource documents and telephone communications have been used extensively in the HNE district with an inadequate effect and it is evident that more active measures may need to be employed.

There are a number of limitations to this study. Due to small numbers of facilities participating in the study the results may not be representative of all RACFs either in the study area or elsewhere. The majority (17/20) of local RACFs interviewed were small to medium sized facilities with less than 100 residents which may differ with other health regions. Larger facilities may have a higher risk of respiratory and gastrointestinal disease outbreaks due to the difficulty in managing a greater number of patients, but may also have greater resources to prepare response plans. We did not attempt to verify responses through alternative data sources; however, response bias is likely to favour improved performance such as reporting higher vaccination coverage and knowledge of resources.

## CONCLUSIONS

RACFs across a regional area of New South Wales demonstrated variable quality of outbreak prevention and preparedness, and some RACFs did not have adequate outbreak preparedness measures in place. Nursing staff working in RACFs play an important role in ensuring facilities are adequately prepared to respond to communicable disease outbreaks through high resident and staff vaccination rates; a robust surveillance system to detect clusters of illness; and implementation of guidance from national outbreak resources. RACF accreditation should include assessment of the RACFs capacity in outbreak prevention, preparedness and management. Robust prevention strategies are critical to protect vulnerable residents from communicable disease outbreaks.

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# Glycaemic response to three main meals or five smaller meals for patients on rapid-acting insulin

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## KEYWORDS

type 2 diabetes mellitus; insulin aspart; glycaemic control; diet

## ABSTRACT

### Objective

To compare seven-point blood glucose profiles of patients with type 2 diabetes mellitus using rapid-acting insulin, when daily calories were provided as three main meals versus five smaller meals (three main meals + two snacks), while maintaining the same total daily calorie intake and composition of carbohydrates, fats and protein.

### Design

A cross-over study.

### Setting

Xiamen University Zhongshan Hospital, China.

### Subjects

Over a four week period, 22 patients with type 2 diabetes mellitus using fixed doses of rapid-acting insulin were recruited into the study. Two patients failed to complete the study and data from the remaining 20 subjects were analysed.

### Intervention

The subjects using fixed doses of rapid-acting insulin were randomised to five smaller meals versus three main meals treatment periods. Glycaemic response to each meal pattern was measured by seven-point blood glucose profiles.

### Main Outcome Measures

The mean seven-point blood glucose levels and the risk of hypoglycaemia.

### Results

The mean seven-point blood glucose levels with the pattern of eating five smaller meals was lower than that with three main meals (9.1mmol/L vs. 9.5mmol/L), however the difference was not statistically significant ( $F=0.524$ ,  $P=0.474$ ). There were no differences in mean blood glucose levels across the seven-point profile. The risk of hypoglycaemia was also not statistically significant.

### Conclusions

This suggests that it may be unnecessary for patients using rapid-acting insulin to have five smaller meals.

## Acknowledgements

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## INTRODUCTION AND LITERATURE REVIEW

Type 2 diabetes mellitus (T2DM) is a progressive disease, with continued loss of  $\beta$ -cell function after diagnosis. The UK Prospective Diabetes Study (UKPDS) found that nine years after diagnosis, approximately 80% of patients with T2DM were unable to achieve glycaemic targets with diet or monotherapy (Wright et al 2002). Accordingly, many patients with T2DM progress to need insulin therapy. Diabetes health professionals often suggest that patients using insulin switch from eating three main meals throughout the day to three main meals with several snacks, while maintaining the same total daily calorie intake (Lu 2014; Dai et al 2010). This is standard practice in China. The current Chinese Diabetes Education and Care Guidelines recommend that patients should eat fruit between meals as a snack, particularly when insulin therapy is required (Dai et al 2010). However, this dietary regulation is difficult for many patients with diabetes, therefore, this recommendation is often unfeasible in clinical practice.

The advice centres on the assumption that switching from eating three main meals to several snacks throughout the day will minimise postprandial glycaemic excursions and prevent hypoglycaemia. In the past, short-acting insulin formulation, i.e., regular insulin, had been a mainstay of diabetes management. The peak time of short-acting insulin is 2-4 hours so it was postulated that patients on short-acting insulin should eat a snack between meals to prevent hypoglycaemia (Heinemann et al 2011). Owing to the more rapid onset and shorter duration of action of rapid-acting insulin frequently used today (Franzè et al 2015; Home 2012), there is a question as to whether snacks are still necessary. This had not previously been systematically investigated.

Therefore this randomised cross-over study aimed to compare seven-point blood glucose profiles in patients with T2DM treated with fixed doses of rapid-acting insulin when daily calories were provided as three main meals versus five smaller meals (three main meals + two snacks). A further aim was to observe whether there was a difference in relation to hypoglycaemia risk.

## METHOD

### Participants

This study was conducted in the endocrine ward of Xiamen University Zhongshan Hospital in China. Over a four week period 22 patients with T2DM who had been admitted for rapid-acting insulin therapy were recruited into the study. Patients under the age of 18 as well as patients with DKA and unconscious hypoglycaemia, stroke and heart attack were excluded. Pregnant patients, as well as those using medications known to interfere with glucose metabolism were also excluded. A total of 22 patients with T2DM using Continuous Subcutaneous Insulin Infusion (CSII) therapy were recruited for this study. One subject failed to finish the two study periods because of diarrhea. One subject required their dose of insulin to be changed due to significant hyperglycaemia (preprandial blood glucose levels > 16 mmol/L). The results of these two subjects were not included in the analyses leaving data from a total 20 subjects for analysis.

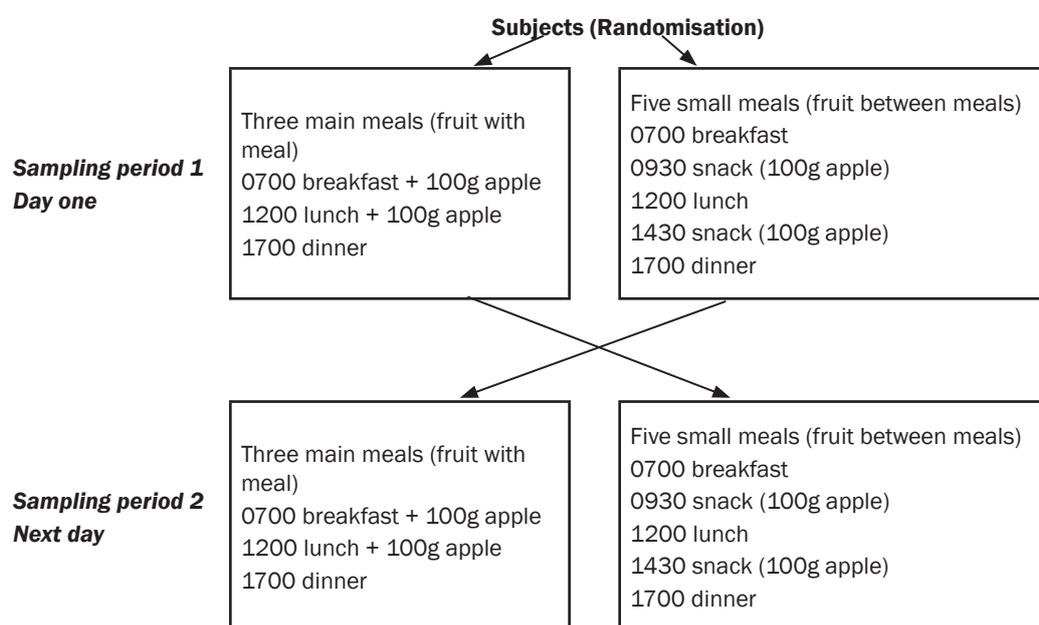
### Procedures

In this study, all subjects received rapid-acting therapy using CSII (Medtronic MiniMed 712, USA). The insulin pump infusion set was sited in the subcutaneous tissue on the abdomen and the insulin pump was filled with rapid-acting insulin aspart. Insulin doses, including bolus insulin and basal insulin rates, were determined for each subject on an individual basis by their treating physician and were kept constant throughout the study. Subjects requiring the dose of insulin to be changed due to significant hyperglycaemia (preprandial

blood glucose levels > 16 mmol/L) or hypoglycaemia (blood glucose level < 3.5mmol/L) were excluded from this study.

Subjects were randomized using a random digit table to one of two possible sequences as shown in figure 1. Trial procedures were performed over two consecutive days. The total daily caloric content of hospital diets for each subject were set up according to the criteria of 25–30 kcal/kg (standard weight) by a dietitian. The total daily calories and composition of carbohydrates, fats and protein were kept identical between the two study periods. The only difference between the two periods was whether the calories were given as three main meals or five smaller meals. Subjects were fed a standardised evening meal the night preceding study period. This was followed by an overnight fast of 10h to limit the impact of the meal on the fasting glucose level.

**Figure 1: The meal distribution in the two study periods**



As shown in figure 1, when randomised to three main meals, the subjects were fed a standardised breakfast and 100g apple at 0700hrs. This was followed by a standardised lunch and 100g apple at 1200hrs and a standardised dinner at 1700hrs. When randomised to five smaller meals, the subjects received the same standardised breakfast, however the 100g apple was held over and consumed as the first snack at 0930 hrs. At 1200hrs the subjects were fed the standardised lunch with the 100g apple given as the second snack at 1430hrs. At 1700hrs the subjects received the same standardised dinner. All the foods were weighed using digital scales (CUBIII, METTLER-TOLEDO INTERN, 3kg max/ 1g resolution). No additional food or drink (except water) was consumed during the study periods unless required to treat hypoglycaemia, which for the purpose of this study, was classified as a blood glucose level <3.5mmol/L.

A standard dose of bolus rapid-acting insulin was administered using CSII immediately prior to each main meal by a ward nurse not involved in the study. No bolus of insulin was administered with the snack. The subjects kept the same activity and were asked to abstain from extra exercise during the two study periods. Seven-point blood glucose levels were monitored using an Optium Xceed blood glucose monitor (Abbott Laboratories, Maidenhead, UK) for all the subjects. Preprandial blood glucose level measurements were collected immediately before boluses of insulin were administered and postprandial blood glucose level measurements were collected at two hours post-meal (2h post-meal). Bedtime blood glucose level was measured at 2200hrs each night.

### Statistical analysis

This sample size was calculated by the software of statistical considerations for a cross-over study developed by Harvard University (David 2015). A sample size of 20 patients provided 80% power to demonstrate a 0.7mmol/L difference in mean seven-point blood glucose concentration, assuming a standard deviation for this measure of 1.0mmol/L at the 5% significance level.

Data were analysed using Statistical Package for the Social Sciences (SPSS) 16.0 software. Continuous data were checked for normality and presented as mean  $\pm$  standard deviation (SD). Categorical data were presented as proportions. A two-way ANOVA model for cross over design, including patients, treatment and period effects, was used to compare all variables. Statistical significance was based on 2-sided t-test and accepted at the  $p < 0.05$  level of significance.

### Ethics Approval

This study was approved by the local ethics committee of Medical College Xiamen University Medical Research Ethics Committee and written informed consent was obtained from all participants.

## RESULTS

Descriptive data are presented as the mean  $\pm$  1 standard deviation. The twenty subjects included in the study had a mean age of  $59.4 \pm 15.6$  years; body mass index  $25.3 \pm 3.0$  kg/m<sup>2</sup>; duration of diabetes  $8.6 \pm 6.0$  years, and 60% were male. The majority of patients had sub-optimal glycaemic control as indicated by glycosylated haemoglobin (HbA1c) of  $8.7 \pm 1.4\%$  ( $95.0 \pm 15.0$  mmol/mol). The fasting blood levels of C-peptide was  $0.45 \pm 0.24$  pmol/ml (normal range:  $0.3 \sim 0.6$  pmol/ml) and the levels of C-peptide after-75g glucagon stimulationin at 120min was  $1.44 \pm 0.76$  pmol/ml. The bolus insulin dose was  $22.5 \pm 9.0$  units per day and the basal insulin dose was  $14.1 \pm 6.2$  units per day.

### Seven-point blood glucose profile

When the subjects were randomized to eat five smaller meals each day, the mean seven-point blood glucose levels was lower than when they ate three main meals ( $9.1$ mmol/L vs  $9.5$  mmol/L). However, the ANOVA for cross over design indicated that the difference was not statistically significant ( $F=0.524$ ,  $P=0.474$ ). The differences on mean preprandial blood glucose levels, postprandial blood glucose levels and preprandial to postprandial glucose excursions at all meals were also not statistically significant (table1).

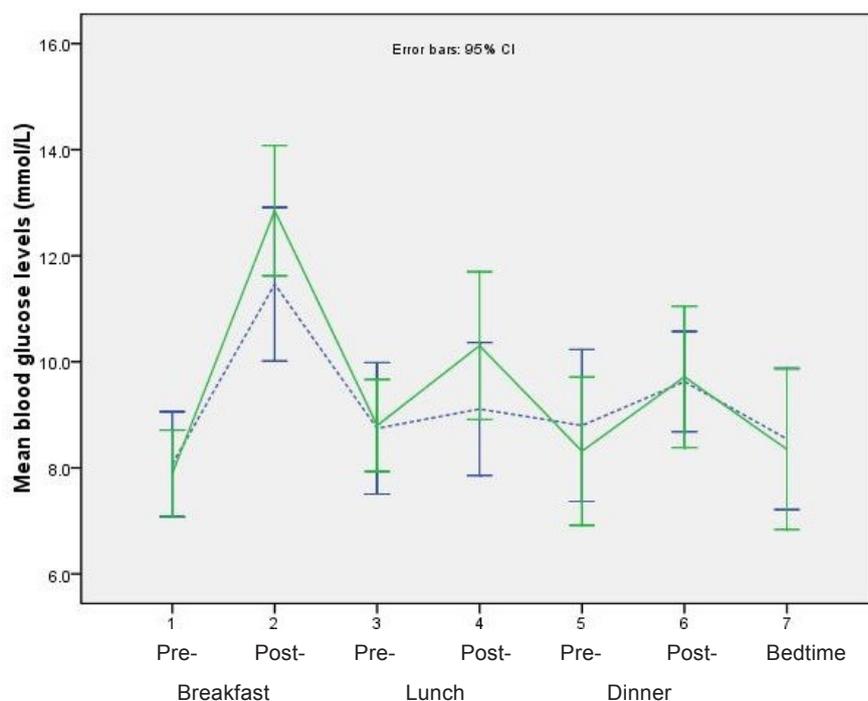
**Table 1: Mean blood glucose levels [ $\pm$  sd(mmol/L)] in 20 patients randomised to five smaller meals versus three main meals**

	Five meals	Three main meals	F	P
Seven-point blood glucose levels	$9.1 \pm 1.7$	$9.5 \pm 1.8$	0.524	0.474
Preprandial blood glucose levels	$8.5 \pm 2.1$	$8.3 \pm 1.8$	0.105	0.748
Postprandial blood glucose levels	$10.0 \pm 1.7$	$10.9 \pm 2.2$	1.926	0.174
Preprandial to postprandial glucose excursions	$3.0 \pm 1.1$	$3.5 \pm 1.0$	2.036	0.162

There were no differences in blood glucose levels across the seven point profile as shown in figure 2. Pre-breakfast blood glucose level did not differ between treatment groups (five smaller meals vs three main meals [ $8.07 \pm 2.12$  vs  $7.89 \pm 1.76$ ,  $P=0.742$ ]). Post-breakfast blood glucose level (five smaller meals vs three main meals [ $11.47 \pm 3.09$  vs  $12.85 \pm 2.62$ ,  $P=0.129$ ]), pre-lunch blood glucose level (five smaller meals vs three main meals [ $8.75 \pm 2.65$  vs  $8.80 \pm 1.85$ ,  $P=0.925$ ]), post-lunch blood glucose level (five smaller meals vs. three main meals [ $9.11 \pm 2.68$  vs  $10.31 \pm 2.97$ ,  $P=0.179$ ]), pre-dinner blood glucose level (five smaller meals vs. three main meals [ $8.80 \pm 3.06$  vs  $8.32 \pm 2.99$ ,  $P=0.635$ ]), post-dinner blood glucose level (five smaller meals vs three main meals [ $9.63 \pm 1.96$  vs  $9.72 \pm 2.77$ ,  $P=0.909$ ]) and bedtime blood glucose level (five smaller

meals vs three main meals [ $8.55 \pm 2.85$  vs  $8.35 \pm 3.04$ ,  $P=0.856$ ]) were also not statistically significant between treatment groups (figure 2).

**Figure 2: Seven-point blood glucose profiles [mean $\pm$ sd(mmol/L)] among the 20 patients when randomized to eat five smaller meals (dash line) or three main meals only (solid line)**



### Hypoglycaemia

There were no episodes of hypoglycaemia (blood glucose level  $<3.5$  mmol/L) during the two study periods. One subject felt hungry at bedtime in both study periods but the blood glucose levels remained within the normal range on both occasions, 3.9 mmol/L and 4.4 mmol/L respectively.

### DISCUSSION

In this study, the differences in seven-point blood glucose profiles were not statistically significant for subjects using rapid-acting insulin regardless of whether their total daily caloric intake was divided between three meals or three meals and two snacks. Postprandial blood glucose levels at the three main meals group was slightly higher than the result at the five smaller meals group, which is probably attributed to the three main meals having a higher intake of carbohydrate with the main meal, but the difference was not significant ( $P=0.174$ ). The main reason for this result may be due to the more rapid onset of action of rapid-acting insulin and more effective prandial insulin coverage is available (Takeshita et al 2015; Tanaka and Hiura 2015).

Theoretically, with rapid-acting insulins' shorter duration of action (Morrow et al 2013; Nosek et al 2013), snacks eaten between meals, when rapid-acting insulin action has decreased, the peak time of rapid-acting insulin is about 1 hour (Home 2012), and may result in slightly elevated blood glucose prior to the next meal. In our study preprandial blood glucose levels for those receiving five smaller meals was slightly higher than the result of the three main meals group, (five smaller meals vs. three main meals 8.5 mmol/L vs. 8.3 mmol/L), but the difference was not significant ( $P=0.748$ ).

Previous studies have shown the importance of controlling blood glucose variability in relationship to attenuating

the risk for cardiovascular complications. In this study, the difference on the glycaemic variability, based on preprandial to postprandial glucose excursions at all meals was also not statistically significant.

This study also showed no difference in risk of hypoglycaemia. Of note, one subject had a relative low blood glucose level when measured before bed during both of the study periods, 3.9mmol/L and 4.4mmol/L respectively. These levels were recorded 4.5 hours after dinner, by which time most of the meal time bolus of rapid-acting insulin would have been absorbed (Nosek et al 2013). These low blood glucose levels are more likely to be related to basal insulin and could be addressed by changes to CSII basal insulin rates.

## LIMITATIONS

A continuous glucose monitoring system was not used in this study. Further research is required to better understand the 72 hour glucose profiles for patients using rapid-acting insulin to eat three main meals versus five smaller meals.

## CONCLUSION

Due to changes in insulin preparations seen within recent decades, this advice to switch three main meals to five smaller meals may no longer be evidence based. This study has shown that there is minimal impact on day to day glycaemic control if the daily caloric intake is consumed as three main meals or five smaller meals. There were no differences in mean blood glucose levels across the seven-point profile and the risk of hypoglycaemia was also not statistically significant for patients on rapid-acting insulin. To switch from eating three main meals throughout the day to five smaller meals may not be necessary, thereby allowing people with diabetes to follow a more flexible diet.

## RECOMMENDATIONS

The important finding is people do not need to switch from eating three main meals throughout the day to five smaller meals, as this advice is often misinterpreted. We mean 'spread your calories/carbs across the day' whereas many patients interpret this as 'eat extra'.

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# No one said he was dying: families' experiences of end-of-life care in an acute setting

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## KEYWORDS

death and dying, end-of-life care, communication, advance directives, bereavement, rural nursing

## ABSTRACT

### Objective

To explore the family's experience of end-of-life care for their dying family member during the last few days of life in an acute rural hospital.

### Design

Interpretive design using qualitative methods, including 1:1 semi-structured interviews.

### Setting

The study was undertaken in a large regional health service in Victoria.

### Subjects

Twelve relatives who were next of kin of people who died between 1 January 2012 and 30 June 2013 in an acute ward at the health service agreed to participate in the study.

### Main outcome measure

Families' perceptions of end-of-life care for their dying family member.

### Results

Data analysis identified five themes that were grouped into two general dimensions – communication (guidance for family member's role in end of life care, the family's preparation for death, the dying experience) and care and support (the hospital care experience, follow-up after death).

### Conclusion

A lack of open and candid communication hindered family members' engagement in decision-making and involvement in their loved ones' last days of life. The absence of formal processes for end of life (EOL) care planning resulted in families being unprepared for what they perceived as their family member's 'sudden death'.

## INTRODUCTION

Acute hospitals are increasingly being required to provide care for people at the end of their life (Australian Institute of Health and Welfare 2014, World Health Organization 2014). However, the effective management of people who are dying in acute care environments is challenging. The overall focus of acute hospitals is generally on diagnosis and treatment with a view to cure and discharge. In this context, recognition of the fact that a person may be approaching the end of life and in need of conversations about their goals of care, limitations of treatment, a palliative approach to care, or provision of terminal care are often delayed. Communication and care planning with patients and families may be poor and the dying person's preferences may be neglected. The quality of end of life (EOL) care has important implications for the individual patient and also for their family, whose experience of EOL care will live on long after their loved one dies.

Most research on the quality of EOL care has been conducted in palliative settings, as traditionally EOL care is associated with terminal illness, such as cancer (Australian Institute of Health and Welfare 2014). However, a substantial number of people die from life-limiting illnesses, such as chronic obstructive pulmonary disease and congestive cardiac failure (Murray et al 2013). Hospitals provide episodic care over many years for chronic illness exacerbations and during any of these admissions death can occur (Murray et al 2013). It is estimated that on average nearly 40% of people who die in hospital receive life-sustaining measures that are considered unlikely to be of benefit right up until the moment of death (Cardona-Morrell et al 2016). Decisions about whether it is appropriate to escalate life-sustaining measures for people with a chronic, life-limiting illness are often postponed until there is a sudden deterioration. It is then, that families and health care workers are required to make medical decisions without knowing the dying person's preferences (Winzelberg et al 2005). While there is increasing patient-centred research related to EOL in hospital settings, there has been minimal examination of the quality of EOL care in Australian acute care facilities (Kearns et al 2017; Waller et al 2017).

Policy and program developers are placing increasing importance on listening and responding to the views of patients and their families (Australian Commission on Safety and Quality in Health Care 2015). Listening to people who are dying has been a cornerstone of palliative care since Dame Cicely Saunders and John Hinton pioneered the modern hospice movement in the 1960s (Saunders 2003). Previous studies have typically used satisfaction-based surveys that provide a limited understanding of the patient and families' overall experience of care in hospital (Robinson et al 2014). Only a small fraction of EOL care research has been conducted on how patients and their relatives experience care at the end of life in Australian acute healthcare settings (Kearns et al 2017; Robinson et al 2014).

Even less EOL care research has been conducted in regional settings and there is a need for research exploring rural/regional family member/caregiver experiences of EOL care (Robinson et al 2009). In Australia, people living in regional and remote areas experience death rates between 10-70% higher than in major cities (Australian Institute of Health and Welfare 2008) and also have less access to specialised EOL care services (Wilson et al 2006). That review stated more research is clearly needed to fully understand family caregiver experiences, and what support would be most helpful in these settings.

The aim of this study was to explore the family's experience of EOL care for their relative during the dying process – the care that was provided in the last days and hours of life, in a large regional acute hospital.

## METHOD

### Design

An interpretive research methodology was used to explore how the participants made sense of the experience of their loved one dying in the acute setting. Interpretive research is a post-positivist approach to research

that suggests the researcher is not value free but is affected by social, cultural and political points of view (Schneider et al 2013). A critical aspect of interpretative research is listening and observing, with data collection through the use of interviews. This methodology is also useful when previous research has been limited (Adams 2010). Nursing in particular has found this type of inquiry particularly useful as it moves “beyond established qualitative methodologies in order to generate credible and meaningful disciplinary knowledge” (Thorne et al 2004, p3).

### **Setting**

This research was conducted in a large regional health service, located in a large provincial city of 100,000 people and servicing a 48,000 square kilometre area in regional Victoria, Australia.

### **Participants and recruitment**

Participants were recruited using convenience sampling. Written invitations were sent to all next of kin (NOK) of patients who had an expected death (as established by the Health Service’s mortality review) between 1 January 2012 and 30 June 2013 in an acute ward at the health service (n=81). Inclusion criteria included:  $\geq 18$  years of age; English-speaking; able to consent to participate; the participant’s relative’s death was expected i.e. the relative had a life-limiting illness; and the participant’s relative was  $\geq 18$  years of age. Next of kin who were a government appointed entity, such as a carer, guardian or administrator, were excluded.

### **Data collection**

Semi-structured interviews were conducted one-to-one and face-to-face with the participants. Interviews were conducted between three and 12 months following the death of the participant’s relative. Participants were allowed to decide for themselves when to be involved in an interview (Bentley and Connor 2015).

### **Data analysis**

Each interview was audio recorded and transcribed verbatim. Two researchers independently listened to and read the transcripts and then met to agree on identified themes (Rasmussen et al 2012). The themes were then defined with clear descriptions and supported with data from the transcriptions.

### **Ethics**

Ethics approval for the study was obtained from the relevant Health Service Human Research Ethics Committees (Ballarat Health Services and St John of God Hospital Ballarat Human Research Ethics Committee LNR/13/BHSSJOG/50).

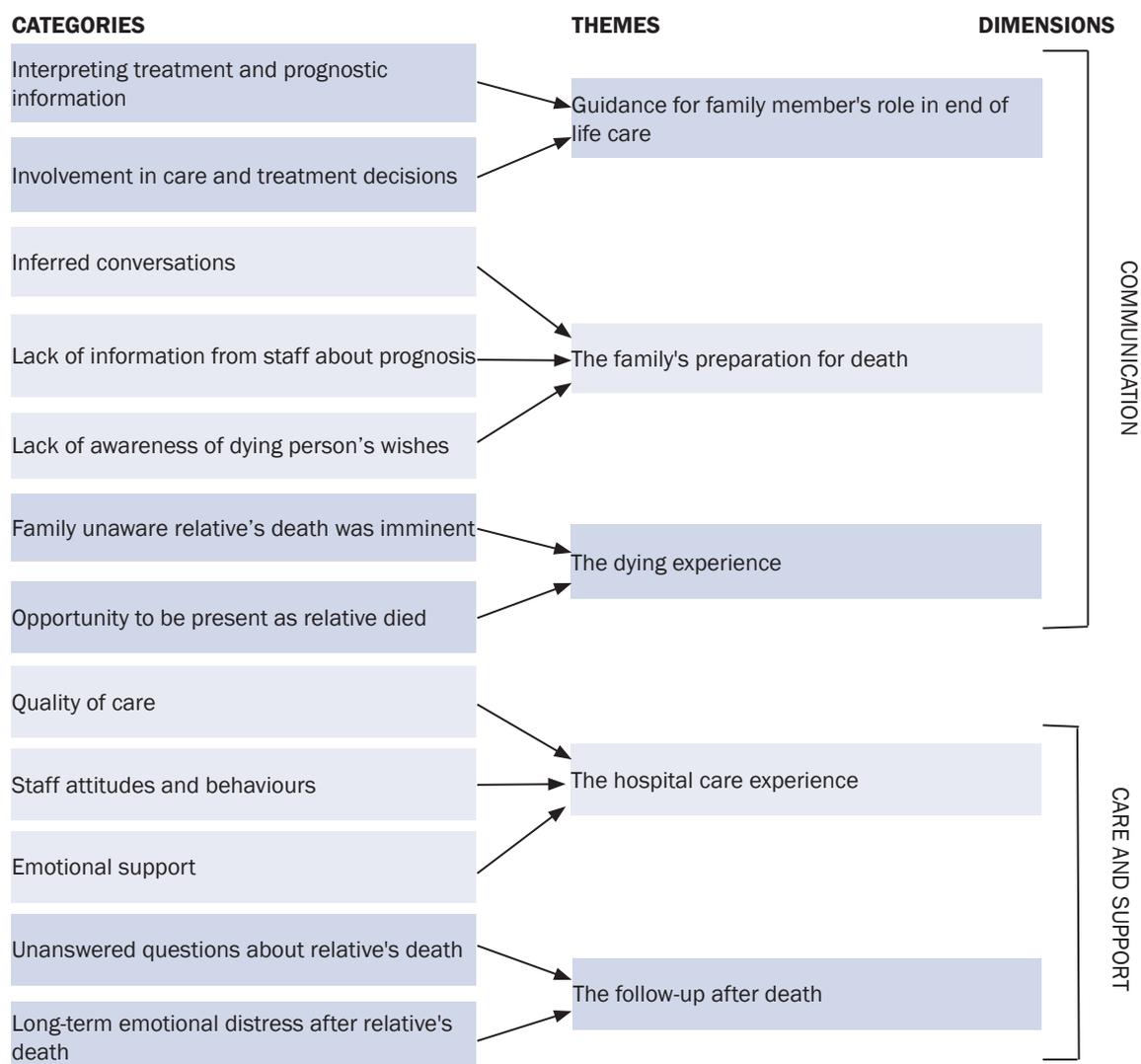
## **FINDINGS**

There were 12 participants (10 females and two males, response rate 14.8%) who agreed to participate in the one-to-one interviews. On average the interviews lasted 35 minutes, with the interview length ranging from 16 minutes to 1.5 hours. Data saturation was achieved. Five themes emerged following analysis of the interview data (table 1): guidance for family member’s role in end of life care; the family’s preparation for death; the dying experience; the hospital care experience; and follow-up after death. These themes were grouped into two general dimensions (figure 1): Communication; and Care and Support.

**Table 1: Definitions of identified themes**

Theme	Definition
Guidance for family member’s role in end of life care	Health professionals’ communication on the current health status and/or prognosis of their relative. This may have included formal family conferences or bedside conversations.
The families’ preparation for death	Health professionals’ communication about the dying process. This may also include conversations between family members and their loved one.
The dying experience	Health professionals’ communication that relative’s death was imminent.
The hospital care experience	Family members’ perceptions of the care their relative received, including quality, staff attitudes and emotional support.
The follow-up after death	Any contact from the health service after the relative’s death.

**Figure 1: Categories, themes, and dimensions**



## Communication

Families' experience of communication with health professionals in the acute hospital setting was a dominant theme in this study. Family members described positive and negative instances of communication style, content and consistency.

### **Theme 1: Guidance for family member's role in end of life care**

Family members asked for guidance in interpreting what doctors say to them, especially in understanding what treatment means and how treatment can be distinguished from prognosis. Pseudonyms have been used in order to maintain confidentiality of the participants.

*Meg: You need somewhere to go where you can ask, Can you explain what's going on? Why can't they say, "Today the doctor came and this is what happened."*

*Jane: We had a couple of meetings, two meetings, on that Friday morning with the doctor that was looking after him and the nursing staff and they didn't actually say, "He is going to die." But in a roundabout way, when they said, "He's going to be severely disabled" [my sister] and I both got the impression that they were sort of softening us up like, "We'll keep the machine on for as long as you like but really, you need to just let him go."*

Family members reported a tension between the need for prognostic information about their relative's changing condition and wanting to hear things from doctors that allow hope.

*Kate: Yeah, so, I don't know. And that's the thing, it's all that I don't know whether people don't want to tell you things or whether they're concerned. I mean you're already in a state of shock and how much, at that stage, would I have been able to cope with? I'm not sure.*

Some family members had clear and open conversations with the health professionals and reported being comfortable with the care decisions made.

*Dom: He said "Your father's back in hospital because his breathing's not good, and his cough, and he's not coping. I've had a discussion with your father... he wants no more treatment. He said doesn't want anything and he's finished with it." I said, "Okay." ... we respected dad's wishes.*

Some family members felt peripheral to important discussions between the doctor and their family member.

*Meg: A couple of times they made her cry and I felt so awful for her. I know down the track you've got to do this, but sometimes I wish they'd just take the family aside and say to the family, "This is what your mum or your dad might have to do." Let us break the horrible news. They're our parents*

### **Theme 2: The families' preparation for death**

Some family members received very little explicit communication from staff about the dying process. Many family members reported that health professionals used euphemisms – "he'll go tonight" and "her time is near". Family members were forced to make inferences when interventions or services were withdrawn.

*Julie: ... we just guessed...with everything disconnected, like Saturday he was connected to glucose or some clear glucose stuff and he had oxygen and yet when we got there Sunday morning he was connected to nothing.*

In the absence of clear communication, the realisation that their relative's death was imminent was unexpected and upsetting for these family members.

*Betty: Then the nurse said, "The doctor wants to see you." I thought, "Oh yeah, the doctor's going to tell me 'Lance's really crook'. The doctor just sat there. He didn't say anything. I just said, "He's gone has he?" And he said, "Yes."*

*Dom: So he said, "Okay, in that case you'll need to come now." And that sort of shocked me. Because dad's been limping along for so long. He said, "You'll need to come, it'll be in a few hours, or, it'll be tonight."*

*Vera: I'll be honest, no-one ever mentioned that it was getting near. No-one.*

The ability of families to prepare for the death of their relative relied not only on good, timely communication from health care staff, but also on the communication within the family. Some family members reported feeling well prepared for their relative's death and were aware of their wishes.

*Mary: She didn't want any intervention. Every time she went in there she said, "You're not doing anything to me, if anything happens." She had already signed a form thank God, before she was diagnosed with Alzheimer's, that she didn't want to be resuscitated.*

Other family members felt they did not have a clear idea of their relative's wishes for care at the end of their life.

*Jill: ... he never actually said, "If I have a massive heart attack I just want to be left to die"... they said, you know, "What do you think he would want?" My sister said "It's really hard to choose for someone else, when you're ending their life"*

### **Theme 3: The dying experience**

Some family members expressed that they knew or had a sense that their family member was dying, however, many were not aware when their relative's death was imminent. Several family members were distressed and disappointed that they were not present at the actual moment of death. Some family members described their relative's death as a sudden event or traumatic death.

*Julie: So we've just gone in thinking they've either shut it [the curtain] to give him a wash and as I've pulled it back I've just gone, "Oh my God, what's wrong with [husband]?" My daughter said, "Mum, he's gone."*

*Betty: I had about fifteen minutes with him. I was really cheesed off with the hospital that they didn't ring me and tell me how desperately ill he was,*

Where families were made aware that their relative was close to death, they reported being grateful for the opportunity to make the most of that time with their relative.

*Dom: ...but that was really his last cognisant evening and we all stayed at the hospital with our partners and we just sort of sat round the bed and he had a lovely time. He chatted, I mean his words were a bit slurred sometimes or he'd forget words.... He just had a lovely time that last night.*

## **Care and support**

### **Theme 4: The hospital care experience**

The care received from members of the health care team varied in quality. Some family members perceived that their relative received "good" care.

*Dom: The staff were brilliant. They explained things that they were doing for dad. They'd come in and say, "Okay, we're just checking out this or that."*

Other family members perceived the attitudes and behaviours of staff towards their dying relative as demeaning and unacceptable.

*Meg: A lot of that care was just not right. She even knew that herself. You don't have to be told to "Do it in bed" rather than going to the toilet. She never wanted us to complain. I don't know whether she got afraid that if we complained that they might be nasty to her. I would go to see her every morning and every night and she would say, "Meg, we're old. They don't care about us anymore." I just think to myself, "You guys, you're going to be there yourself one day." When someone doesn't treat you with dignity .... The dignity just isn't there.*

Several family members perceived a lack of emotional care from health professionals, both for themselves and their dying relative.

*Meg: That woman in ED, I couldn't believe it. She nearly tackled us to the ground. Like we were in a rugby team. We've just been told mum is dying and we're going out to see her and she said, "Two at a time."*

The option of dying at home was discussed with some family members and their dying relative. However, there was often a lack of practical support to make it happen, particularly for people who came from rural and regional areas.

*Kerrie: I first heard news that the doctor there thought that he would die in hospital within weeks. I said, "Well, I'd like to take my grandfather home." That was completely dismissed by that doctor and in an arrogant way too. He basically said, "I'm not going to talk about that at this point."*

### **Theme 5: Follow-up after death**

In addition to the care experienced while their relative was dying, many family members commented on the need for support following the actual death.

*Mary: Probably I think, perhaps that follow-up phone call, particularly considering the circumstances around Peter's death. I felt that perhaps that could have been explained to me a little bit better.*

Some of the family members expressed long-term grief issues and emotional distress following the death of their relative.

*Judy: You've looked after them for years and years and years and then all of a sudden they're gone. It's like someone closing the door and it's bang. There's nothing behind it. You're on your own. I just want to end everything.*

*Interviewer: So you are having suicidal thoughts?*

*Judy: Yeah, I did.*

## **DISCUSSION**

As the number of people dying in acute hospitals grow, family members will increasingly participate in decisions for medical procedures and the withdrawal of treatments. The findings of this study describe how next of kin (NOK) experienced the end of life care for a family member who died in a large acute hospital in a rural setting. These experiences provide important information on how families perceived communication from health professionals and their own role in EOL care. Understanding family members' perceptions and involvement in hospitalisation at the end of life is essential to providing quality EOL care in acute hospitals (Swerissen and Duckett 2014).

The lack of open and clear communication from health professionals was a major issue raised by family members. This finding is consistent with previous research, including a review of integrated care pathways for end of life (Neuberger et al 2013), in which failure to communicate was clearly one of the most serious concerns raised by relatives and carers (Swerissen and Duckett 2014). Family members in this study highlighted problems with communication that reflected a lack of recognition of their role in EOL care for their family member. In this study family members clearly expressed their desire for different kinds of information and engagement with EOL care and decision-making. The families' comments suggested they not only wanted the 'facts', but also needed help interpreting those details in order to be able to recognise death was imminent. This finding is similar to that of the study by Russ and Kaufman (2005) involving 26 family members of patients who had

died in a California community hospital. That study found that families' feedback indicated they often 'knew' in retrospect, but couldn't 'hear' at the time, suggesting families did not need more information, rather, they needed more interpretation of details and facts. Helping families understand information about prognosis and its implications is important to prepare them for the decision-making that precedes death.

A lack of open and transparent communication made some of the NOK feel marginal to important communication and decision-making related to EOL care for their dying relative. Higher levels of shared decision-making during EOL care have been associated with higher levels of family satisfaction with care (Young et al 2009), and poor communication is a major factor in complaints relating to EOL care (Australian Commission on Safety and Quality in Health Care 2013). Health professionals need high-level communication skills and need to be able to provide guidance to NOK around their responsibilities surrounding their family member's dying.

Many of the NOK felt they were unprepared for their family member's death. Next of kin reported difficulty with changing their mindset from hoping for the best to having to face their family member's imminent death. They also reported feeling unprepared for the decisions demanded of them very near the time of death, such as the withdrawal of treatment or emergency resuscitation. This finding is consistent with previous research related to surrogate decision making, where discordant expectations about prognosis were found to be common between patients' physicians and surrogate decision makers (White et al 2016). Family members in the study by Russ & Kaufman (2005) reported similar experiences. In that study, family members accustomed to interventions and discussions of how to "turn this around" reported experiencing the final decline as a "death without dying" (p. 117).

Several factors may be related to NOK's perception of their family member's 'sudden' death. Firstly, there is often a delay in identifying patients whose imminent death could have been anticipated (Gott et al 2011). Of the people in Australia who died in an acute hospital, 70 per cent received treatment aimed at cure up until the time of death, suggesting that health professionals did not recognise that the person was dying (Hillman 2010). General practitioners and hospital specialists have previously reported difficulties with timely recognition of patients at risk of dying (Gott et al 2011). Tools, such as the Supportive & Palliative Care Indicators Tool (SPICT™) (Hight et al 2013) and the "surprise question" (Moss et al 2008), may prompt identification of patients at risk of deteriorating and dying.

Despite understanding that a person with a life-limiting illness is dying, families often do not recognise when death is imminent (Australian Commission on Safety and Quality in Health Care 2014). Many family members reported that health professionals used euphemisms – "he'll go tonight" and "her time is near". Family members were forced to make inferences when interventions or services were withdrawn. Previous research has shown that health professionals are often uneasy discussing death and dying with patients and their families and do not feel they have the required skills to have difficult conversations (Noble et al 2015). Inadequate role preparation for the provision of high quality EOL care has been identified as a significant problem, particularly in rural settings (Robinson et al 2009). Only a small number of studies have explored rural health professionals' perspectives on providing EOL care and further research is needed to evaluate if specific health care delivery issues exist in these settings. Problems with talking about and planning for death is one of the most significant obstacles to improving the quality of EOL care (Swerissen and Duckett 2014; Australian Commission on Safety and Quality in Health Care 2013).

Finally, some NOK were not clear about their family member's wishes for EOL care and felt unprepared for the decisions they were asked to make close to their family member's death. Very few families were aware of the concepts of advance care planning or had discussed the goals of care approach with the treating doctor. Advance care planning has been shown to be an effective approach for improving communication between

patients who are dying, their families and health professionals (Brinkman-Stoppelenburg et al 2014). An advance care plan (ACP) is the plan for future health and personal care whereby a person's values, beliefs and preferences are made known so they can guide clinical decision making at a future time when that person cannot make or communicate their decisions because they no longer have capacity (Detering et al 2010). An ACP can provide clarity for health professionals who provide treatment and services and for family members who may be involved in the decision-making (Brinkman-Stoppelenburg et al 2014).

The quality of the care and support experienced by NOK and their dying family member varied considerably. While some NOK were happy with the care provided, others perceived their family member did not receive basic care and was not treated with respect or dignity. Similar findings in which health professionals stopped engaging with the dying person's clinical needs in acute settings, almost as though these needs were no longer relevant, have been previously reported (Neuberger et al 2013). Most medical and nursing staff are motivated to provide quality care, however, factors such as feeling under-prepared and under-educated strongly influence the cultures and attitudes towards caring for dying patients (Aleksandric and Hanson 2010). Caring for the dying is important and doing it well requires health professionals to have high-level skills in clinical care, compassion and communication.

Family members also expressed the need for support and follow-up after their relative's death. Some family members reported significant grief resulting in negative consequences for their health. The detrimental effects of long-term, unresolved grief are well documented (Fauri et al 2000). In the palliative care setting it is well recognised that care does not end until the family has been supported with their grief responses and those with complicated grief responses have been helped to get care (Street et al 2004). Further work is needed to explore the availability and quality of bereavement services in acute settings, particularly in rural areas.

## **LIMITATIONS**

This study explored the experiences of 12 family members in one hospital in regional Australia. The findings are local and particular to the area, however, may be relevant to similar hospitals in similar rural/regional settings. As the sample size is small it is not clear that findings are representative of the experiences of family members of people who have died in this rural setting. The use of family members as patient proxies, while providing a limited understanding of patient experience, still provides important information on the quality of EOL care in this setting.

## **IMPLICATIONS FOR CLINICAL PRACTICE**

This study identified key actions for nurses and doctors in providing a best practice approach to caring for the dying person. Firstly, allowing families time to prepare for their loved ones death by identifying that the person is dying and family as soon as possible. Families need to be involved in the conversations, and have information, including prognosis, explained to them. Clinicians should be sensitive, use plain language and avoid euphemisms, with follow up to ensure the family understands. Secondly, there is potential for ambiguity and uncertainty at the end of life. Clinicians should explain the prognosis and that the dying process varies between individuals. This must be honestly and openly acknowledged, and discussed with patients, substitute decision-makers, families and carers. Finally, families of people who are dying also need care from the treating team, both during the dying process and following the death. There is a need to ensure there is support for the family with their grief responses and to identify those that are at risk of complicated grief.

In order to address these priorities all members of the interdisciplinary team should receive education and training to prepare them for having conversations about EOL care (Australian Commission on Safety and

Quality in Health Care 2014). Results from this study have informed an EOL framework, providing guidance and direction for staff at a large regional health service, for the delivery of best practice EOL care.

## CONCLUSIONS

Families are seeking guidance from health professionals for their role in end of life care for their dying relative. End of life care planning in acute hospitals needs to incorporate strategies, such as health professional communication skills training and advance care planning, to ensure end of life discussions take place. These discussions need to take into account the preferences of both the patient and their family and provide guidance for them through the dying process.

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# Pilot study: how Sydney community nurses identified food security, and student nurse focus group perceptions

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## KEY WORDS

Food security, food insecurity, community health, community health nurse (CHN)

## ABSTRACT

### Objectives

This paper aims to discuss and explore food security in the context of community health nursing, to provide insight about how frontline workers may identify whether their client is food secure.

### Design

A qualitative descriptive design pilot study, using questionnaire and unstructured interviews.

### Setting

Community health services across Sydney.

### Subject

How community health nurses identify whether their client is food secure.

### Method

Three community health nurses were interviewed and their responses recorded. Two student nurses participated in a focus group during professional work experience in community health.

### Findings/Results

Although community health nurses claim they can identify whether their clients are food (in)secure, it remains unclear how they operationalise this claim, and indeed if they do, what the outcome may be for their clients' health determinants.

### Primary argument

To raise awareness and stimulate discussion about food security as a social determinant of health, and whether community nurses have a role identifying client food security.

### Conclusion

Food (in)security is increasingly recognised as a social determinant of health, with evidence that the prevalence of food insecurity is increasing in Australia. It is acknowledged that community health nurses have established professional relationships with their clients, and that food insecurity may be identified through formal and informal means.

A more open discussion is required about food (in)security and potential ways in which it may be discussed in non-judgemental, sensitive ways. Further investigation is required to interview community health nurses, in the context of their relationships with clients, how they establish whether food security is occurring and being maintained.

## INTRODUCTION

Food insecurity, an important Social Determinant of Health associated with poor health outcomes (Wilkinson and Marmot 2006) has been identified as a significant Australian public health issue at national and state levels (Nolan et al 2006; NSW Centre for Public Health Nutrition 2003). It has been shown that food insecurity affects physical, mental and emotional health and well-being of families and individuals (Foodbank 2016). While food insecurity may be perceived to be more prevalent in developing countries, it has been identified as a growing problem in Australia.

Community health nurses, at the forefront of providing health care during each stage of the life cycle, are pivotal in assessing client need and making appropriate referrals across many dimensions. They are in a key position to identify food insecurity with clients, including families with children, following childbirth, the elderly, those with chronic and complex health care needs, and from other vulnerable groups.

This qualitative, descriptive pilot study aimed to discuss and explore current methods used by community health nurses to identify food (in)security in their clients, and the role of nurses. It also aimed to gain insight into how nursing students during work experience on community placements perceive and understand food insecurity.

Student nurses, as beginning nurses are expected to develop skills in critical thinking and evidence-based practice to prepare them for professional practice. They learn within complex policy and education frameworks as well as professional experience programs in order to integrate theory with practice. During community practice experience, nursing students develop knowledge and skills while working under the supervision of an experienced CHN, accompanying them on home visits and working in community clinics.

## LITERATURE REVIEW, FINDINGS AND GAPS

A literature search was conducted via UTAS Library using nursing and midwifery databases to search nursing and allied health articles. Key words 'food security'; 'food insecurity'; 'community health' and 'Australia' were used, searching peer reviewed articles in English, in abstract from 2008-2014. Only relevant full texts were selected: eleven articles via CINAHL, and three of twenty articles via Medline PubMed. Articles in English, from Australia, United States of America and United Kingdom were selected, because of similarities between demographics of clients, education of health workers, and studies in food (in)security. The literature searches revealed a body of current literature pertaining to food security in Australia, mainly among lower income groups (Rosier 2011; Innes-Hughes et al 2010; Nolan et al 2006).

The Physical Activity and Nutrition Obesity Research Group (PANORG) (Innes-Hughes et al 2010) discussed the USDA food security tool (Bickel et al 2000) its use in the National Nutrition Survey and NSW Population Health Survey and noted the "absence of measurement of food insecurity for reasons other than financial constraints, such as limited mobility, illness, mental illness or social isolation". PANORG (Innes-Hughes et al 2010) reported that community level reporting of food insecurity is neither widely discussed nor commonplace in Australia, and suggested further research to collect information about people experiencing food insecurity be conducted to add to the overall knowledge about food security in NSW.

CHNs undertake comprehensive psycho social, physical and functional assessments of clients, using documents based on NSW Health guidelines (Sydney District Nursing Assessment Tool, Community Health Nursing Assessment 2014; NSW Department of Health Supporting Families Early Package 2009) to gather comprehensive information about clients' lifestyle, health history and personal care needs, upon which care planning and referrals are based. A preliminary review of existing psycho-social and physical assessment

tools and documentation currently in use reveals there are no specific inquiries related to food security with regards to whether the client and/or family can afford adequate food to sustain a healthy life, or whether they have enough food. It is unclear from the literature reviewed how CHNs working in community health settings in Sydney determine specifically if their clients are food secure.

Searches for professional CHN organisations undertaken through NSW Nurses and Midwives Association, revealed fewer professional organisations compared with other nurse speciality organisations, which is interesting in a climate of increasing emphasis of community based care (HealthOne, NSW Health 2006; Brookes et al 2004).

Consequently Koch (cited in Brookes 2004) claims that CHNs “have escaped scholarly scrutiny, and their voice has been weak in nursing matters”. A fair proportion of research utilised in community health practice is ‘applied’ research in the context of clinical care and outcomes, and research relevant to CHNs tends to focus on health and well-being in ageing populations (Arbon and Cusack 2011) thereby excluding other vulnerable groups. Brookes (2004) found “there were conflicting role expectations” between health care sectors, and identified “underutilisation and untapped potential of the role of community health nurses”.

## **BACKGROUND**

Food security is achieved when all people at all times have physical and economic access to sufficient, safe and nutritious food to meet dietary needs and food preferences for an active and healthy life (Food and Agriculture Organisation 1996). Yet food insecurity may be hidden in our communities (Sydney Food Fairness Alliance 2007).

In the context of this study, “food insecurity” is defined as not being able to afford enough food or enough of the right food, and can involve clients worrying about food running out, cutting meal sizes, missing meals and experiencing hunger pains (Anglicare 2012). In NSW, 6.2 per cent of households had ‘run out of food and could not afford to buy more’ in the previous 12 months (NSW Child Health Survey 2001).

Children and older persons are most at risk from poor nutrition, and food insecurity may contribute to poorer health outcomes (Russell et al 2014). Relatively high levels of food insecurity have been identified in pockets of low income among South West Sydney residents (Nolan et al 2006).

The Foodbank Report (2016), based on data analysed by Deloitte Access Economics, stated that one in six Australians reported they had experienced food insecurity at least once over the last twelve months, and that over 644,000 people now receive food relief each month, 33% of whom are children. The report noted an 8% increase in the number of people seeking food relief during 2015.

Food insecurity is of particular relevance to frontline community nurses who interact with vulnerable groups such as young families and the elderly because food insecurity is generally associated with poorer health. Some adverse health outcomes attributed to food insecurity might include risk of poor health, developmental or behavioural problems in children (Ramsey et al 2011) which may affect their academic achievement, poor wound healing in adults (Australian Wound Management Association 2009), while over consumption of energy dense low nutritional foods is known to result in obesity (Innes-Hughes et al 2010).

Community health care sits within a primary health framework, based on the primary health care principles that encompass early intervention, health promotion, illness prevention, health management and client education (Baum 1998). Community health care is provided amid societal and healthcare change by skilled CHNs who work within a broad framework to sustain and improve health in the community (Van Loon 2011).

The Solid Facts (Wilkinson and Marmot 2006) outlines key aspects of people's living, work and lifestyle conditions, the social determinants of health (SDH) which have a powerful influence on health and well-being. The SDH include the social gradient, early life, stress, food and social exclusion.

## **METHOD**

This study is a qualitative study using a descriptive design. Three community health nurses, working at community health centres in south west and south Sydney were interviewed by the author by phone, and their responses recorded. The three CHNs were asked if they use specific questions to inquire whether their clients are food secure. A focus group was held with two University of Tasmania (UTAS) nursing students during professional work experience (PEP) in the community. The students discussed their perceptions of food insecurity, how it is identified by community nurses, and whether they observed CHNs using specific questions to inquire whether their clients are food secure. The interviews were recorded and transcribed.

Ethics approval was received for this project.

## **RESULTS**

It was found that CHNs may use informal processes to identify food insecurity. However, it remains unclear how they specifically identify whether their clients are food insecure in this context, and indeed if they do, what the outcome may be in terms of social determinants.

Two CHNs replied that they do not make a specific inquiry regarding food insecurity. One CHN replied that RNs do not ask specifically about food insecurity, however use the SAFE START psychosocial assessment questions pertaining to major stressors in the last 12 months 'such as financial problems' or 'other serious worries'. CHNs also ask specific questions regarding client's type of diet, recent weight loss, and functional assessments may be undertaken to assess a client's ability to shop and prepare food. An instrument such as the Malnutrition Screening Tool (MST) may be used to assess client's recent weight loss and loss of appetite was rarely used. The student nurses were familiar with the MST through studies at university, however, they did not observe its use by the CHN in the community.

It has been said that CHNs may use 'intuit' or observe whether the availability of food in the fridge (pers. com CHN, 2007). They do this by taking cues from the client's responses to questions, for example, about financial matters, and by observing the availability of food in the client's home, for example the presence of fruit and vegetables. The CHN may take the opportunity to make a cup of tea for the client, and note whether there is fresh milk in the fridge.

The focus group held with two UTAS students discussed their perceptions of food security while working under the supervision of experienced CHN.

The students discussed the importance of good nutrition for general physical and mental well-being, healthy weight and wound healing and identified barriers to food security relevant to the clients they encountered in the community. The students perceived that CHNs readily identified food insecurity but they could not specifically articulate how this was operationalised.

Themes emerged including access to shops, transport, awareness of nutrition and cooking skills, availability of adequate food preparation area and storage, clutter, social isolation, income, and how food needs may be interpreted by others shopping on behalf of the client. The students observed that some clients declined Meals on Wheels or assistance, preferring their own food choices and/or to maintain independence. While many clients lived in comfortable housing and were food secure, they observed some clients in poor living

conditions, a lack of fresh fruit and vegetables, some lived on 2 minute noodles, sugary drinks, while others had plenty of food, but the wrong type, for example baklava and tea.

The students did not observe CHNs asking the question “In the last 12 months, were there any times that you or your family ran out of food, and could not afford to buy more?” However, the students observed CHNs asking diet related questions regarding type of diet, recent weight loss, what the client may have for dinner that night, and conducting a functional assessment to assess client ability to shop and prepare food. The students perceived that the CHN observed food availability in clients’ homes informally, by observing the availability of food (in fridge and on benches). The students acknowledged there may be stigma associated with not having food in the house, and they felt it may be insensitive to inquire or probe, particularly among some cultures.

The UTAS students perceived that establishing therapeutic relationship between the CHN and client was paramount, and that CHNs possess skills to elicit and observe clients’ needs. The students also observed that CHNs have great understanding and knowledge about the needs of their client, with capacity to identify those needs. The students perceived that CHNs use informal means, and skills of intuition to assess the needs of their clients. This may link to ‘hidden practice’. However, they suggested that CHN could be provided with further education to enhance skills and assist them to further explore and elicit food insecurity with their clients in the community.

The students discussed ways in which to introduce a more open discussion about food security with clients for example by disclosing that as a student they had ‘run out of food and sought help’, and relating good nutrition, a balanced diet with family wellness, and improved wound healing.

## DISCUSSION

Themes emerged related to social determinants (SDH) such as access, transport, education, isolation, housing, while further sub-themes emerged including therapeutic communication skills, education of nurses, and that CHN use a range of methods to explore client well-being and needs to assist recovery and maintain health.

Generally among those involved in this pilot, the CHN did not make specific inquiries regarding food security, or inquire whether “In the last 12 months, were there any times that you or your family ran out of food, and could not afford to buy more?”. It may be that CHN identify food insecurity by using other means including observation, ‘hidden practice’, ‘intuition’, indirectly through other formal assessments and eliciting information based on cues.

The student nurses acknowledged that ‘food insecurity’ is not commonly discussed, and they held reservations that it may be perceived by clients as ‘intrusive’ to ask directly whether there was sufficient food at home, while acknowledging the CHN should be comfortable to inquire in a respectful way, and make necessary referrals.

A preliminary review of existing psycho-social and physical assessment tools and documentation currently in use reveals there are no specific inquiries related to food security with regards to whether the client and/or family can afford adequate food to sustain a healthy life, or whether they have enough food. It is unclear from the literature reviewed how CHNs working in community health settings in Sydney determine specifically if their clients are food (in)secure.

Searches for professional CHN organisations undertaken through NSW Nurses and Midwives Association, revealed fewer professional organisations compared with other nurse speciality organisations, which is interesting in a climate of increasing emphasis of community based care (HealthOne, NSW Health 2006; Brookes et al 2004).

Consequently Koch (cited in Brookes 2004) claims that CHNs “have escaped scholarly scrutiny, (and) their voice has been weak in nursing matters”. A fair proportion of research utilised in community health practice is ‘applied’ research in the context of clinical care and outcomes, and research relevant to CHN tends to focus on health and well-being in ageing populations (Arbon and Cusack 2011) thereby excluding other vulnerable groups. Brookes (2004) found “there were conflicting role expectations” between health care sectors, and identified “underutilisation and untapped potential of the role of community health nurses”.

## CONCLUSION

This project investigated how food security, as a key Social Determinant of Health is explored and identified, and how this process is perceived. Gaining further knowledge and understanding of current assessment processes, and how nursing students perceive this process, and depending on what is revealed, may provide opportunity to influence future education of nurses, CHN and community nursing practices.

The investigations in this study indicate that the subject of food security, how it is identified and explored by community nurses working in Sydney has not been investigated in this context before. Formal identification of food insecurity appears to be in the domain of dietitians in community and public health nutrition, community services, emergency food aid, and on preliminary investigation, appears to be outside the domain of CHN.

Yet CHN are at the forefront of providing complex and diverse care in the community, in an increasingly complex health system (Brookes et al 2004). Whether the skills of CHN’s are under-utilised with regards to identification of food insecurity among their clients in the community is unclear. In the context of this study, it remains unclear who else would formally assess client food insecurity, whether there are conflicting role expectations between health care workers and sectors, and whether there is untapped potential regarding the role of community health nurses.

On preliminary investigation, the question, “In the last 12 months, were there any times that you or your family ran out of food, and couldn’t afford to buy more?” (NSW Health, NSW Population Health Survey 2008; ABS, National Nutrition Survey 1995) is not asked by CHNs. This single item question is very specific to determine basic level of food security, while limited, (Russell et al 2014) may provide baseline information to better assess client/family need, consider appropriate interventions and referrals. Innes Hughes (2010) reported that community level reporting of food insecurity is neither widely discussed nor commonplace, and recommended that further research to collect information about people experiencing food insecurity be conducted to add to the overall knowledge about food security in NSW.

CHNs are in a key position to assess need, identify food insecurity with their clients, including young families, vulnerable groups, and the aged to consider intervention strategies and make appropriate referrals to improve health. It is undisputed that CHNs may identify food insecurity through formal and informal interactions with clients, and make appropriate referrals.

## RECOMMENDATIONS

Further inquiries are required to investigate how Food Security as a key Social Determinant of Health is determined by professional CHNs working in Sydney, particularly as food insecurity is increasing. CHNs working at the frontline with young families, vulnerable groups and the aged are in a key position to contribute to this research, and development of strategies to influence practice and improve the health and well-being of their clients.

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# Osteoporosis treatment preferences and satisfaction in postmenopausal women: Denosumab compared with oral bisphosphonates

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## KEYWORDS

osteoporosis treatment, bisphosphonates, Denosumab, adherence, satisfactions.

## ABSTRACT

### **Aim**

This paper aims to investigate whether Denosumab is more effective in promoting adherence and satisfaction than oral bisphosphonates in the treatment of osteoporosis in postmenopausal women.

### **Methods**

Electronic database - MEDLINE, PubMed, CINAHL, Wiley online Library, ProQuest Nursing and Allied Health), free text engines Google Scholar and Findit@Flinders and reference lists of retrieved papers were searched according to the inclusion and exclusion criteria. Twelve studies were ultimately selected.

### **Primary argument**

The author analyses and critically appraises literature comparing two common osteoporotic medications: oral bisphosphonates and subcutaneous Denosumab in view of patients' preferences and satisfaction. Findings from this review could provide suggestions for developing frameworks in clinical practice, identify strategies to improve patient adherence to treatment and develop policies promoting active patient involvement in treatment decision-making.

### **Results**

Following thematic organisation of the studies, four major themes emerged: patient's view on attributes on osteoporotic medications; patient satisfaction and preferences in oral bisphosphonates compared to Denosumab; adherence to treatment with oral bisphosphonates compared to Denosumab; and practice implications.

### **Conclusion**

Findings from reviewed studies favor Denosumab over oral bisphosphonates as the preferred long-term treatment in postmenopausal women. Patients have a greater satisfaction with less frequent dosing, mode of administration and side effects of Denosumab.

## INTRODUCTION

Osteoporosis is a severe and chronic condition with significant physical and emotional concerns including increased risks of fragility fractures, hospitalisation and often surgery needs, chronic pain and high mortality rates (Perry and Downey 2011). It causes a tremendous burden on people affected by the disease, their families, as well as the health and social care system (Ebeling et al 2013). Numerous pharmacological agents are designed to slow disease progression and prevent complications with the effectiveness of some reported by many robust clinical trials (Conn et al 2015). However, studies have shown that 50-75% of patients treated with anti-osteoporotic medications have discontinued treatment within one year. This sub-optimal adherence rate and lack of persistence with prescribed treatment leads to a significant decrease (approximately 50%) in the effectiveness of these treatments (Rosen and Drezner 2015; Reynolds et al 2014), and consequently success in achieving therapeutic goals and successful control of osteoporosis (Cairolì et al 2015; Cheng et al 2013; Ziller et al 2012; Imaz et al 2010).

When making decisions regarding treatment options, in order to decrease the likelihood of failure, we must have a better understanding and knowledge of the reasons behind the non-adherence to treatments. Identifying the determinants could assist in clinical decision-making and development of guidelines and policies (Cairolì et al 2015; Laba 2014). According to Rabenda and Reginster (2010), the biggest barriers (most often reported by patients) in relation to discontinuing treatment are: inconvenience, complicated and strict medications dosing regime, and gastrointestinal side effects with oral therapy. However, since osteoporosis treatment is available in various forms, dosages, frequency of administration and regimens, medical practitioners and patients should choose the most appropriate, convenient and personalised treatment (Ward et al 2013; Barbosa et al 2012; Lee et al 2011).

## REVIEW OF THE LITERATURE

### Methodology

An integrative style of review was chosen as most appropriate to address the research question. An appraisal tool developed by McMaster University 'Critical Review Form for Quantitative Studies' was used to evaluate the retrieved articles (Law et al 1998). The review is organised thematically, allowing important findings from the research to be grouped into themes, followed by further discussion in terms of the topics covered.

### Search strategy

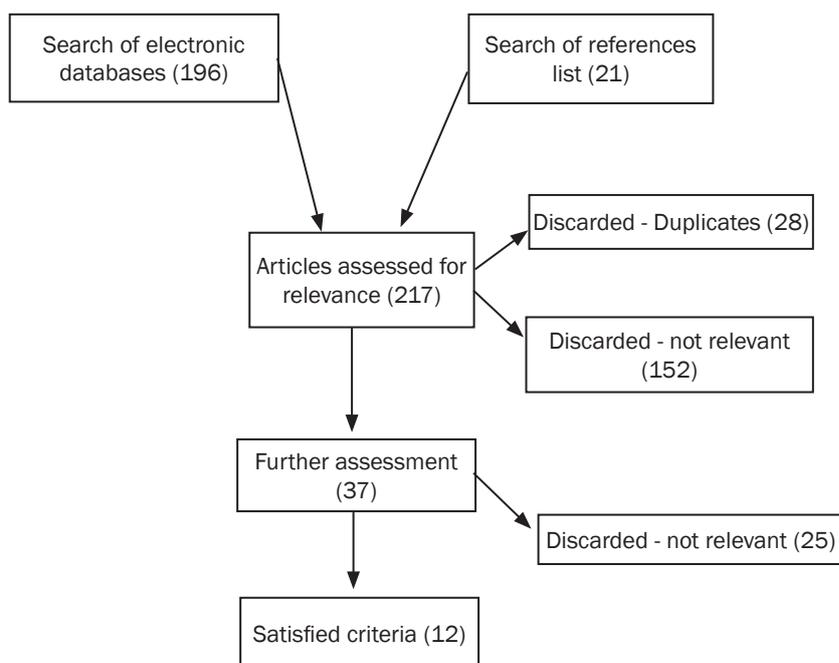
A comprehensive search of electronic databases including MEDLINE, PubMed, CINAHL, Wiley online Library, ProQuest Nursing and Allied Health, identified studies providing answers to the research question. Free text search engines such as Google Scholar and Findit@Flinders were extensively used to search through various sources and related publications. Additionally, reference lists of retrieved papers were scrutinised; primarily focusing on previously published systematic reviews and meta-analyses, which often cite important high quality papers. Both titles and subsequent abstracts were screened for eligibility. Only primary studies published in English, in full text, and between 2010 and 2015 were chosen where the articles' main focus was on comprising and reporting outcomes of adherence, preference and patient satisfaction with oral bisphosphonates as opposed to subcutaneous Denosumab. This review only includes studies with postmenopausal women - the largest osteoporosis prevalence group.

Systematic reviews, meta-analyses and other forms of reviews were excluded. Articles comparing cost effectiveness were also excluded, as this review focuses on patient views and opinions. Studies with participants living in aged care or health institutions were also excluded, as these medications are not self-administered, instead reliance is highly dependent on health care providers.

### Search outcome

Twelve articles met the inclusion and exclusion criteria and were selected for evaluation of strengths and weaknesses in view of answering the review question, as well as providing suggestions for possible benefits to clinical practice and improvement of treatment outcomes. All articles have a quantitative design, six are randomised clinical trials and six are cohort studies.

**Figure 1: Flow chart of literature search**



## RESULTS

All of the selected studies clearly indicated the research aim and used appropriate methodology to address the research question. Participant selection was appropriate to study design, which included large samples, carried out in accordance to ethical guidelines. All studies also provided clear statements of findings, research values and clinical practice relevance. Although randomised trials are highly ranked in the hierarchy of evidence (National Health and Medical Council (NHMRC) 2009), the five trials were open-label and not blinded, potentially leading to biased results. The majority of the studies had a clinical trial setting where third-party influence, willingness to participate in study or study design cannot rule-out selection biases. Freemantle et al (2012), Kendler et al (2011) and Kendler et al (2014) used the same sample in their studies therefore as independent studies their findings could provide significant research value, however in the context of this review they were considered as one source of evidence. All studies had short 1-2 years durations, which is potentially an inadequate period to evaluate adherence to treatment or patient's satisfaction for this chronic disease, which requires extended treatment.

### Summary of selected articles

A summary of the selected studies is presented in table 1.

Table 1: Summary of reviewed articles

Study	Aim	Sample	Method	Major findings	Strengths and limitations
Barrett-Connor et al (2011).	Association between treatment satisfaction and persistence with postmenopausal osteoporotic treatment.	2,405 postmenopausal women	Assessment of satisfaction using Treatment Satisfaction Questionnaire for Medication (TSQM).	Lower satisfaction with treatment increased risk of discontinuation. Effectiveness, side effects and convenience play important role in adherence to treatment.	Large sample, anonymous questionnaire, data from longitudinal study, primary care setting. Loss to follow up, self-reporting persistence.
Brown et al (2014).	Compare the effect on bone mineral density (BMD) and bone turnover in patients who switched therapy from bisphosphonates to denosumab.	1703 postmenopausal women.	Post-hoc analyses of 2 previously randomised, open-label, parallel-group studies.	Denosumab more effective in increasing BMD and reducing bone turnover.	Large sample, randomisation. Clinical trial compliance in real-world could be lower. Selection bias - participants willingness to be involved in study. Open-label study.
Freemantle et al (2012).	Provide final results of the DAPS (Denosumab Adherence Preference Satisfaction) 2 years study.	250 postmenopausal women.	Randomized, open-label, multicentre study; Crossover; used Preference & Satisfaction Questionnaire (PSQ).	Preference and satisfaction higher for denosumab than alendronate. 92.4% preferred injections over oral medications as more convenient, better mode and frequency of administration.	Randomisations, multicentre, frequent follow ups. Not a real-world setting.
Hadji et al (2015).	Evaluate denosumab-taking behaviour in routine practice.	1500 postmenopausal women from 4 European countries.	Interim analyses of multicenter, prospective, non-interventional study.	87.0-95.3% were persistent and 82.7-89.3% were adherent with treatment. Understanding patients and physicians factors influencing medications taking may improve persistence with treatment.	Large sample, multicentre, 4 health systems. Heterogeneity of clinics, physicians and participants. Participants and physicians willingness to participate in trials.
Hilgigsmann et al (2014).	Evaluation of preferences for Medications properties and how patients exchange these properties.	257 postmenopausal women.	Quantitative study Discrete Choice Experiment (DCE) survey: efficacy, side effect, mode, frequency, cost to patient.	Patients prefer higher efficacy lower cost and less frequent dosing regimens. Dislike GI side effects more than skin reaction or flu like symptoms; Willing to pay more and give up on efficacy for treatment mode.	Participants exposed to different types of treatment previously. Possible selection bias. Only common side effects included in questionnaires.
Kendler et al (2010).	Compare patient preference and satisfaction between denosumab and alendronate.	1,693 postmenopausal women.	Quantitative, international, randomised, double-blind, DECIDE and STAND; PSQ used.	Higher preference and satisfaction with less frequent treatment.	Large sample, international, randomised, double-blind, double-dummy, phase 3 head-to-head studies- Selection bias-participants willingness to be involve in study. Not real-world setting. Short duration of the study.

Kendler et al (2011).	Assess adherence to treatment with 6 monthly denosumab and weekly alendronate.	250 postmenopausal women from 25 centres.	Randomized, open-label, multicentre, crossover study; follow up at 6, 12, 18 and 24 months; Beliefs about Medications Questionnaire (BMQ).	Denosumab higher adherence, satisfaction and preference in dosing and route of administration routine compared to alendronate.	Randomisations, multicentre, frequent follow ups, equal exposure to 2 treatments, adequate length of study. Not a real-world setting.
Kendler et al (2014).	Analysis how adherence to treatment is influenced by participants belief in treatment, necessity of treatment, their concerns and preferences.	250 postmenopausal women from 25 centres.	Quantitative study Post-hoc analyses of two randomised, open-label studies; TSQM used with 4 domains: effectiveness, side effects, convenience, and global satisfaction.	Denosumab - greater necessity, preferences and adherences. Greater satisfaction with denosumab as more effective and convenient.	Randomisations, multicentre, frequent follow ups. Not real-world setting. Negative media reports for alendronate and positive for denosumab.
Palacios et al (2015).	Evaluate the treatment satisfaction when switching from bisphosphonates to denosumab.	1703 postmenopausal women.	Randomised, open-label, parallel-group study.	Greater satisfaction may improve adherence to treatment and consequently effectiveness of the therapy.	Randomisation, large sample. Post-hoc analysis, Open-label. Short 1 year study. Potential self-selection bias.
Roux et al. (2014).	Compare efficacy and safety of denosumab and risedronate.	870 postmenopausal women from 82 centres.	Questionnaire - efficacy, safety, convenience and direct cost to patient. MaxDiff analysis was used to determine preferences.	Denosumab is more effective and safer option when compared with risedronate.	Randomised, international, multicentre, large sample. Selection bias large numbers of exclusion. Open-label and short 1 year study. Clinical trial only.
Silverman et al (2013).	Assess weighting of osteoporotic medication attributes - safety, efficacy, cost and convenience.	367 postmenopausal women from 4 ethnic groups.	Multicentre, single arm, prospective, observational study. PSQ and BMQ used.	Efficacy and safety have higher attributes than cost and convenience.	Comprehensive questionnaire. Heterogeneity of participants. Not consistent with entering answers.
Silverman et al (2015).	To estimate persistence with denosumab treatment.	935 postmenopausal women.	Interim analyses after 12 months of 24 months study.	81.9% persistent at 12 months. High persistence with treatment have potential in improving treatment.	Prospective observational study, multicentre, real-world setting. Heterogeneity of clinics, physicians.

## MAJOR THEMES

Following thematic organisation of selected studies, four major themes emerged: patient's view on attributes of osteoporotic medications; patient's satisfaction and preferences in oral bisphosphonates compared to Denosumab; adherence to treatment in oral bisphosphonates compared to Denosumab; and implications to practice.

### **Theme 1: Patient's view on attributes on osteoporotic medications**

Five of the chosen studies evaluated the importance of osteoporotic medication attributes from the patient's perspective. 'Drug efficacy', 'safety', 'out-of-pocket cost', 'convenience' were key features selected by participants (Palacios et al 2015; Hiligsmann et al 2014; Silverman et al 2013; Barrett-Connor et al 2012; Freemantle et al 2012). Hiligsmann et al (2014), using a Discrete-Choice Experiment (DCE), asked patients to rank two types of medications in relation to these attributes and concluded that 'effectiveness', was the highest attribute and 'cost' was the lowest. A 'longer dosing regimen' was selected as more significant than 'the mode of administration', and 'gastrointestinal side effects' was the most troublesome. Similarly the results of a study by Silverman et al (2013) show that 'drug efficacy' is the most valued feature followed by 'safety', 'cost' and 'convenience' while also observing that medication ranking depended on age, education and income, but not on racial differences.

Barrett-Connor et al (2012) used the Treatment Satisfaction Questionnaire for Medication (TSQM). In their study, 'side effects' were classed as the most important attribute with 'global satisfaction' being the lowest. 'Side effects' were ranked as the highest trigger of discontinuing treatment, followed by 'inconvenience'. Palacios et al (2015) also used the TSQM tool, however their outcome revealed that 'side effects' were not the major contributor in choosing medication, with 'effectiveness' and 'convenience' valued higher. In most of the studies, the 'effectiveness' of medications was valued highest, followed by 'safety'. Other factors such as 'out-of-pocket cost' and 'convenience', which include mode and frequency of administration of medications, were ranked as important but not essential.

### **Theme 2: Patient's satisfaction and preference in oral bisphosphonates vs Denosumab**

Six of the studies from different countries and health care systems acknowledged patient satisfaction and their preferences to treatment as significant determinants when choosing osteoporosis treatment options (Palacios et al 2015; Hiligsmann et al 2014; Kendler et al 2014; Freemantle et al 2012; Kendler et al 2011; Kendler et al 2010). To evaluate patient satisfaction and preference, researchers used the Patients Satisfaction Questionnaire (PSQ), TSQM or the Belief in Medication Questionnaire (BMQ). The 'convenience and life style fit', 'mode of administration', 'dosing frequency' and 'drug related side effects' were revealed as the most influencing factors affecting participant's satisfaction level. Freemantle et al (2012) showed that 91% of participants were satisfied with injections while only 52% preferred oral medication for 'medications administration mode'. Similarly, 94% preferred injection and only 43% chose tablets in view of 'frequency of administrations'. Less frequent treatments were preferred as reported by Kendler et al (2010), revealing that 64% participants preferred bi-annual injections and 16% favoured weekly tablets. Approximately 20% of patients were indifferent to frequency.

Results from a study by Hiligsmann et al (2014) showed that a significant number of participants preferred bi-annual injections to weekly tablets but there were no noteworthy dissimilarities in preferences between bi-annual injections and monthly tablets, proving that less frequent treatment regimens were preferred. Patients often blame lifestyle inconvenience for discontinuing osteoporotic treatments (Kendler et al 2014). In all six studies, a bi-annual Denosumab injection was recognised as more convenient over oral bisphosphonates primarily due to the less frequent treatment requirements. Possibility of side effects related to treatment of

osteoporosis were of high concern which were also reported in all selected studies but according to Palacios et al (2015) it was not always crucial. Gastrointestinal side effects, often associated with oral bisphosphonates, were recognised as more troublesome than skin infections and flu-like symptoms sometimes associated with Denosumab (Hiligsmann et al 2014).

### **Theme 3: Adherence and persistence to treatment in oral bisphosphonates versus Denosumab**

Five of the selected papers examined factors influencing patient adherence to treatment (Kendler et al 2014; Barrett-Connor et al 2012; Freemantle et al 2012; Kendler et al 2011; Kendler et al 2010). Barrett-Connor et al (2012) and Kendler et al (2014) concluded that a patient's belief in the necessity of therapy and fear of possible side effects plays a significant role in treatment adherence; a higher degree of necessity with a lower degree of concern leads to better treatment adherence. In two widely recognised studies, DECIDE and STAND (Kendler et al 2010), patients were initiated or switched to therapy with Denosumab from oral bisphosphonates. The authors reported that persistence with treatment was high, above 90% and was very similar in both groups. Those results however could be overestimated, as all patients were closely monitored, possibly motivating them and consequently improving their adherence. Similarly, another study, DAPS, in which participants were randomly divided into two groups 'Alendronate' and 'Denosumab', showed that after the first year, adherence to Denosumab was considerably higher than to Alendronate; 87.3% and 76.6% respectively. Furthermore, after a crossover treatment, adherence to Denosumab increased to 92.5% and Alendronate dropped to 63.5% (Kendler et al 2014; Freemantle et al 2012; Kendler et al 2011).

Generally, high adherence to Denosumab was also confirmed in the study by Hajdi et al (2015) and Silverman et al (2015). The interim result of the non-interventional study in four European countries showed that 82.7-89.3% of women were adherent to being treated with Denosumab, because they received their second injection within the required time (Hajdi et al 2015). Similarly, 82% of postmenopausal women from a study by Silverman et al (2015) (Canada and USA), who were treated with Denosumab as a routine osteoporosis therapy, were persistent with their treatment, and obtained a second dose of the medication within six months. A significant advantage of both of these studies is that they were realistic real-world studies, minimising the likelihood of biases.

### **Theme 4: Practice Implications**

Findings from the reviewed studies highlight the importance of an individual's beliefs, preferences and satisfactions in clinical decision-making regarding treatments to improve osteoporosis care. This 'patient-centred care' or 'preference based care' approach suggested by researchers provides valuable evidence for health care providers and policy makers regarding which treatments and attributes are more respected and preferred, and emphasises that patients and doctors might have different opinions about treatment choices (Palacios et al 2015; Silverman et al 2015; Barrett-Connor et al 2012). A large body of evidence shows that patient preferences in regards to 'frequency regime' and 'mode of administration' must be taken into account to deliver personalised treatment and improve treatment outcome. Less frequent medications administration regime are viewed as more 'convenient' to fit into a patient's lifestyle therefore, bi-annual injections are preferred by many post-menopausal women with osteoporosis (Hadji et al 2015; Palacios et al 2015; Brown et al 2014; Hiligsmann et al 2014; Kendler et al 2014; Roux et al 2014 Silverman et al 2013; Freemantle et al 2012; Kendler et al 2011; Kendler et al 2010).

Injectable medications, like Denosumab, require additional health services but they also provide great opportunities for health care providers to communicate with patients, motivate them with treatment and directly assess treatment adherence (Freemantle et al 2012). Hiligsmann et al (2014) revealed that patients are willing to trade 'efficacy of treatment' and have 'out-of-pocket expenses' for their preferred choice.

Researchers also suggest that for patients who were non-adherent with weekly oral bisphosphonates, switching to monthly regime is not as effective as switching to Denosumab bi-annually (Palacios et al 2015; Brown et al 2014). Understanding the factors influencing patient adherence to treatment at the commencement of their therapy may significantly improve treatment outcomes (Hadji et al 2015; Kendler et al 2014). Consequently, there is a great need for increased research into methods of increasing patient's knowledge and awareness of different options available for them, assessing their preferences and techniques of reducing side effects (Palacios et al 2015; Kendler et al 2014; Barrett-Connor et al 2012).

## DISCUSSION

The purpose of this review is to explore available literature examining the effect of patient satisfaction and treatment preferences in relation to treating osteoporosis in postmenopausal women by comparing oral bisphosphonates and Denosumab. The findings support the existence of strong links between patient satisfactions and treatment adherence, also revealing that the main reasons for poor adherence are inconvenience, complicated dosing regime and side effects. The reviewed studies highlight the importance of personalised individual's choices, preferences and satisfactions in clinical decision-making regarding treatment to improve care (Hadji et al 2015; Palacios et al 2015; Silverman et al 2015; Freemantle et al 2012).

When comparing the two reviewed treatments, both have 'pros and cons'; oral bisphosphonates require a strict regime in order to achieve optimal effect and minimise the risk of side effects (Roux et al 2014) while administration of medication via injections often requires frequent visits to a clinic and can also be associated with pain and needle phobia (Kendler et al 2010). Patient safety was considered a significant treatment attribute and a common reason for discontinuing treatment (Cairoli et al 2015; Hiligsmann et al 2014; Barrett-Connor et al 2012). Possible gastrointestinal side effects from oral bisphosphonates are more bothersome than flu-like symptoms or skin infections from Denosumab (Hiligsmann et al 2014; Kendler et al 2014; Barbosa et al 2012).

Hiligsmann et al (2015) suggested that patient beliefs and preferences need to be addressed to improve medication adherence. Patient satisfaction plays a crucial role in treatment adherence; women who reported low satisfaction are 37% more likely to discontinue or switch the treatment than those who have a higher satisfaction (Palacios et al 2015). According to Barret-Connor et al (2012) this number may be even higher, up to 67%. Although those two factors are very important when choosing the best treatment option, other medication attributes such as effectiveness, safety and cost of treatment are also highly recognised by patients and may influence their decision (Cairoli et al 2015; Hiligsmann et al 2014; Kendler et al 2014; Freemantle et al 2012). According to current guidance and recommendations for treatment of osteoporosis in postmenopausal women, oral bisphosphonates are the first option because of their effectiveness, affordability and significant safety data (Rosen and Drezner 2015). However, our findings show that Denosumab, when compared with oral bisphosphonates, has been proven more effective in improving BMD in all routinely measured sites, significant reduction in bone turnover as well as in preventing fractures in numerous rigorous trials (Roux et al 2014; Recknor et al 2013; Sutton and Riche 2012). Although research shows that the cost of Denosumab is slightly higher than oral bisphosphonates, it is more beneficial in long-term practice because bi-annual injections provide better treatment adherence and optimisation (Parthan et al 2013; Barbosa et al 2012; Hiligsmann and Reginster 2011).

Randomisations, large samples, use of widely recognised tools in analyses of findings, and high relevance to practice are the most significant strengths of the reviewed studies. The main limitation discovered throughout the appraisal was diversity in design of studies, which could decrease transferability, or generalisability of the results. The majority of chosen studies were clinical trials potentially resulting in selection bias. Most

studies were open-label, participants were willing to be involved, understood the purpose and were aware that their adherence is monitored therefore their adherence to treatment might be higher. Moreover, participants had regular contacts with healthcare providers, which could be a motivational factor enhancing adherence. Additionally, cost of medications, travel expenses to clinics, follow-ups and diagnostic tests were all covered eliminating out-of-pocket expenses. Large diversity within participant's characteristics such as age, education, and socioeconomic status, cultural and ethnical differences, high and low fracture risk can be seen as both strengths and weaknesses.

Another significant limitation was the short duration of trials. All studies occurred over one or two years, therefore participants taking Denosumab bi-annually had only two treatment doses and were subsequently classified as adherent to treatment and treatment satisfaction was evaluated only on those two doses. The studies only focused on frequent but minor side effects, with rare but major adverse reactions omitted.

Further research using a well-designed observational study (prospective or retrospective cohort studies) and longitudinal studies would be beneficial in addressing patient satisfaction and adherence to treatment in real-world settings and potentially minimising bias (Gibson and Glennly 2012).

Despite limitations, the findings from this review may assist healthcare providers in better understanding the reasons for poor treatment adherence for osteoporosis and other chronic diseases. Usually, there is no single reason for discontinuing treatment therefore it would be unrealistic to believe that one intervention may resolve the problem and thus, strategies for improving adherence should be individualised (Rabenda and Reginster 2010). Fung and Spector (2010) emphasised the need for support and education for health practitioners and patients to ensure informed decision-making. They also advocated tailored treatment management to suit the specific patients' needs.

## CONCLUSION

Findings from these selected studies favor Denosumab over oral bisphosphonates as the preferred long-term treatment in postmenopausal women. Patients have a greater satisfaction with less frequent dosing as well as the mode of administration of Denosumab. Similarly, because oral bisphosphonates are more likely to cause troublesome side effects, patients were more satisfied with Denomusab than oral bisphosphonates. Thus, Denosumab has a high potential to improve adherence to treatment of osteoporosis in postmenopausal women. However, limited research in this field and insufficient studies in 'real-world' settings reduce the value of these outcomes. Therefore, further research is needed to provide more substantial evidence leading to informed practice recommendations.

However, and more significantly, selected studies highlight the importance of understanding an individual's personal beliefs, preferences and overall satisfaction when making clinical decisions regarding treatment choices. Medication-taking decisions should be rational and informed with good understanding of personal preferences. The single intervention, like prescribing Denosumab instead of oral bisphosphonates, will not alienate problems with low treatment adherence. Therefore, future interventions, guidelines and policies should encourage healthcare providers to customise treatment management to suit the individual patient and co-operate with all parties involved in the development of guidelines and recommendations to improve the effectiveness of treatment for osteoporosis.

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# Sporting injuries amongst children in Australia: a review of the literature

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## KEYWORDS

sporting, injuries, children, Australia

## ABSTRACT

### Objective

Sports and recreation promotes health benefits to the child's wellbeing but can also expose him or her to injury risks. Literature that explores sporting injuries amongst children in Australia with discussions about the paediatric nursing role is reviewed.

### Setting

Prevalence of sporting injuries within the Australian paediatric population.

### Sample

The search utilized medical search terms of 'Sporting injuries' 'Children' 'Paediatric/paediatric Nurses' in health related databases to locate literature published from 2007 until present. Australian based studies were preferable but not exclusive. Relevant sources through hand selection helped to develop a potential relationship between the frequency of sports injuries occurrences and the types of injuries being treated in hospital.

### Primary argument

Of the twenty-five papers chosen, nineteen were related to sports injuries while a further thirteen focussed specifically on children involved in sports and recreation. Data concerning children sustaining sports related injuries, particularly in Australia, is scarce and inconsistent with no literature found relating to the role of paediatric nurses. With a particular focus on spinal injuries sustained through sports and recreation, how the paediatric nurse is involved is identified.

### Conclusion

Further analysis on sporting injuries in children in Australia will help to gauge its health burden to the country to better understand this contemporary child safety concern.

## INTRODUCTION

Physical activity is essential in the healthy wellbeing of children as it brings a wide range of health benefits to support their growth and development (Richards 2015a). Sports are a popular form of physical activity that children engage in where involvement from a young age teaches them the importance of maintaining fitness that continues well into adulthood (Rossler et al 2014). However, participation in sports has its risks and raises concerns for the safety of the child, as it is a leading cause of injuries within the paediatric population (Richards 2015b). Sporting injuries are a major risk factor that deters families from allowing their children to be involved in certain sports with evidence suggesting that approximately 50% of incidents are preventable (Minuzzo et al 2009). While most injuries are minor, some are so severe they require immediate medical attention and extensive rehabilitation to overcome. Some sporting injuries potentially result in lifelong disabilities or even death. This paper will therefore review relevant literature on sporting injuries as a contemporary safety issue for children and address its impact on the child and family as well as community. The role of the paediatric nurse in caring for patients injured in sports is explored with particular focus on those who have sustained spine injuries.

Participating in sports extends beyond keeping children physically fit, it also helps develop social skills, to work as a team, aids in the regulation of emotions to perform under pressure and enhances self-esteem along with other health benefits (Loprinzi et al 2012). The Australia Bureau of Statistics (2013) states that in 2012, 1.7 million of the 2.8 million children aged 5-14 years old were involved in organised sports outside of school making up 60% of the population for that age range. In addition adolescents aged 15-17 years old are reported to have the highest participation rate in sports and recreation of 74% (Australian Bureau of Statistics 2015). Children participate in a variety of different sporting activities including basketball, rugby, equestrian and road motor sports but the most popular sports are swimming and soccer (Roy Morgan Research 2015). Keeping children active from a young age enables the pursuit of a healthy lifestyle that ultimately produces better health outcomes (Minuzzo et al 2009). Encouraging children to play sports is even a government initiative to help overcome childhood obesity, which is a growing epidemic in Australia (Commonwealth of Australia, 2010). Although children who engage in sporting activities have advantages in relation to their health, the risks involved should not be ignored because it poses a threat to their safety.

Children are potentially at a vulnerable risk of sporting injuries due to their physical and physiological processes of growth and development (Caine et al 2014). For example, in comparison to mature adult bones, children's developing bones are more cartilaginous resulting in injuries unique to their age group such as growth plate fractures and greenstick fractures (Shanmugam and Maffulli 2008). Studies have also highlighted that during the pubescent period, the occurrence of injuries increases (Caine et al 2014). This is because the rate at which certain muscles strengthen is not the same as other muscles leading to imbalance and instability. For example, anterior cruciate ligament tears are often seen in the adolescent female population. Children also participate in sport categorised by chronological age rather than weight divisions thus their structure, function, and performance can differ significantly. As a result, late maturing young athletes are at a disadvantage against their physically larger, yet of the same age, opponents. Furthermore due to their immature and underdeveloped coordination, skill, and perception, children's risk of sporting injuries may also increase (Schwebel and Brezusek 2014).

## METHODOLOGY

For the purposes of obtaining relevant literature on the topic Medical Subject Heading (MeSH) terms were employed with CINAHL, Medline, Pubmed & Informit chosen as the preferred databases for this review. Using Boolean search types, literature searches of the databases were conducted in three parts. The initial search

conducted utilised the MeSH terms of 'Sporting injuries' 'Children' 'Paediatric Nurses'. Results were then limited to a time frame of 2007 onwards to achieve more contemporary information. Studies from Australia were considered to gain more knowledge on the country's understanding of sporting injuries amongst the paediatric population. The overall number of journals was poor due to the lack of literature exploring the role of paediatric nurses. As a result, literature used in this review was hand selected based upon relevance to the topic, highlighting potential for links to be made between children involved in sporting injuries and the role of paediatric nurses.

Using MeSH terms 'sporting injuries', 'children' and 'paediatric/paediatric nursing' to locate literature in databases of choice was unsuccessful. Instead the literature used for analysis was not exclusive to sporting injuries in children but had relevance to the topic. Of the twenty-five papers selected and reviewed, nineteen are about sporting injuries, while thirteen focused on children involved in sports and recreation. Through thorough examination of databases, few studies relating to the epidemiology of sporting injuries amongst the paediatric population in Australia exist.

## DISCUSSION

Inconsistencies between the published literature makes it difficult to attain definite and clear figures to understand how much of an issue sporting injuries are to the safety of children. While 4.3% of individuals aged 18 years and younger visit the emergency department for sport related injuries in the United States of America each year, Australia does not have similar data to compare (Safe Kids Worldwide 2015). Reported injury rates varied between different studies due to the discrepancies in definition but also in the method of collecting and measuring injuries (Spinks and McClure 2007). It is acknowledged that different mechanisms of injuries usually took precedence over sports being the primary cause, which ultimately alters information ascertained for analysis. One study carried out in 2011 in Victorian hospitals highlights that poor documentation is also a contributing factor where the activity engaged at the time of injury is unspecified in 59% of cases presented to emergency departments (Clapperton 2012), though when it was written down, sports became the most commonly recorded activity. Updated statistics have replaced activity and place of injury with 'setting' where 9.3% in injuries are from sport settings. However again, it fails to clearly represent how often the cause of an injury is related to sports because children could have been at school, home or other locations while engaged in some form of sporting activity (Hayman et al 2017). While it is evident that sporting injuries do make up a proportion of presentations to emergency departments, facts and figures remain unclear. In response, determining its prevalence, particularly with children and how this impacts the Australian healthcare costs is difficult (Finch 2014).

Although children under the age of 15 are not included in the survey published by the Australian Institute of Health and Welfare in 2011-2012, it does provide some relevant information to better understand sporting injuries in this country. Based on the report, the number of individuals aged 15-17 years old who required hospitalisation as a result of sporting injuries was 5,770 (Kreisfeld et al 2014). It is found that most injuries sustained are from football of all codes; that is soccer, Aussie rules, rugby and touch football. Rather than suggesting how dangerous this type of sport is, it is a reflection of its popularity amongst the Australian population (Johnson 2014). While the number of those injured in wheeled motor sports was not as significant as football incidents, the proportion of injury to participant was the highest in comparison to the different sports people are involved in with a reported 3,500 hospitalisation for every 100,000 participants. Furthermore, in conjunction with cycling and equestrian sports, wheeled motor sports have higher proportions of severe injuries (Kreisfeld et al 2014). Given the fact that the data collection for this survey is only those children requiring hospitalisation and not including presentations to emergency departments or visits to a general

practitioner, the number of sporting injuries occurring is not represented as accurate and is most likely a gross underestimation.

The age of the child should also be taken into consideration when understanding sporting injuries. While sports participation often peaks among children and adolescents, certain injury risks are also associated with different age groups (Pointer 2014). For example, falls from playground equipment and drowning in swimming pools pose significant dangers to younger children whereas falls from skateboards accounted for 15% hospital admissions in children aged 10-14 years. The location, severity and diagnosis of sport injury also differ from age groups (Straccioni et al 2013). The study found injuries affecting the upper extremities, namely fractures, were common amongst young children aged 5-12 years while older children (13-17 years) tended to injure their chest, pelvis and spine more with soft tissue damage as a result of overuse as the root of cause.

Examining the incidences of children sustaining injuries from sports through accuracy and consistency in data collection is crucial. It helps to reflect on the effectiveness of current practices in protecting the paediatric population and raises public awareness (Finch and Clapperton 2012). One recent study from Victoria attempted to examine the burden of sporting injuries in children comparing the incidents to road traumas (Finch et al 2014). Findings concluded that within the 2004-2010 period, there was a significant increase in the frequency of children requiring hospital treatment as a result of sports while those involved in road accidents decreased. The health burden is also larger with more direct hospital costs, more admissions as well as longer years lived with disabilities. Similarly there has been a marked increase in the hospitalisation of children for sports related injuries in Canada (Fridman et al 2013). These results demonstrate that the burden of sporting injuries in children is growing in numbers and cost internationally. Nevertheless it also provides incentives to prioritise the need to implement sports injury preventative measures for the paediatric population.

Sporting injuries vary in severity. They can range from scrapes and bruises to head trauma and spinal cord injuries (Dunkin 2016). Common injuries often seen in the emergency departments include fractures and soft tissue injuries (Kreisfeld et al 2014; Fridman et al 2013). For those who require hospitalisation it is imperative that their injuries are managed appropriately to reduce long-term complications. A severe yet rare example is children with spinal cord injuries caused by sporting activities. The spine is central to the skeletal system supporting the head and surrounding the spinal cord which contains millions of nerve fibres used for communication between the brain and the rest of the body (Sansbury and Wilson 2015; Spinal Injuries Australia 2015). As the spinal cord lies within the vertebrae and is well protected, a considerable amount of trauma is required to cause injury. Therefore the mechanisms of injury in sports tend to be from collisions in rugby tackles, or a high fall off a motor cross bike. Trauma to the vertebral column includes fractures, dislocations and subluxations (Hung 2015). Such injuries to the vertebral column prevent correct alignment making the spine unstable. Further unguarded movement on the unstable spine can affect the spinal canal causing compression or overstretching of neural tissue within. This potentially leads to permanent damage to sensory or motor function. As a result suspected spine injuries are to be taken very seriously (Sydney Children's Hospital Network, 2012).

Certain areas of the vertebral column are less stable making them more susceptible to injury from severe flexion and twisting (Sansbury and Wilson 2015). The cervical vertebrae, which is the highest segment of the spine, is fractured most often and injury at this level causes extensive paralysis. The immediate response to spinal cord injury is known as diaschisis or spinal shock (Hung 2015). It is characterised by flaccid paralysis with tendon reflex losses below injury level, absence of somatic and visceral sensation and autonomic dysfunction

manifesting in hypotension, abnormal thermoregulation and loss of control over bladder and bowel. For the paediatric patient and family members a spinal cord injury is a life-changing event because in an instant the once full functioning and athletic child has become dependent and relies on mechanical ventilation to breathe. Providing emotional support for the family is detrimental as they may experience a sense of grief or loss during this time. However it is also important to remind families that this is only the initial stage where the extent and severity of damage cannot be established at first and improved function takes weeks or even months to occur when spinal shock resolves (Evans 2015).

## **THE ROLE OF THE PAEDIATRIC NURSE**

Improvement in the management of children with spinal cord injuries is a result of enhanced technology and surgical interventions as well as more extensive research into the complexity of the spinal cord and its neurological components (Sansbury and Wilson 2015). Paediatric nurses play a vital role when caring for a child who has sustained a spinal injury from sports. During the acute phase their primary role is to prevent further insult to the damaged spinal cord (Sydney Children's Hospital Network, 2012). Spinal precautions where the child requires a rigid neck collar must lie in supine position at all times and log rolled when transferred are essential to immobilise and stabilise the spine for optimal healing. Ensuring airway patency, preventing complications and maintaining function are priorities (Evans 2015). Furthermore, evaluating the extent of neurological damage early to establish a baseline helps to monitor the patient's neurological status. This entails Glasgow coma scale, assessing limb strength, neurovascular observations, and pupil response. Spinal cord injury has the potential to cause multiple impairments that reduces an individual's level of activity, participation and quality of life (Withers et al 2014). As nurses, it is therefore important to find a balance between instilling hope and helping the patient and family come to terms with reality when caring and communicating with them. While working within the multidisciplinary team, paediatric nurses liaise closely with different health professionals such as the occupational therapist, physiotherapist, social worker, psychologist and dietician to address the different aspects of the patient's life during their rehabilitation.

When the degree of damage is confirmed the goals become maximising motor function and minimising disabling effects of the pathological condition (Sansbury and Wilson 2015). The role of the paediatric nurse is to assist and educate family members in caring for their child independently in preparation for discharge back into the home environment. Progress may be slow at first, as the initial weeks require thorough explanation and demonstrations on performing tasks specifically to protect the spine. The following weeks involve supervising the caregiver- namely parents, in looking after their child appropriately. In the cases of adolescents who are deemed cognitively competent, self-care is promoted (Sydney Children's Hospital Network 2014). Supporting the child and family emotionally is just as crucial where an altered perception of body image as a result of their injury may occur and thus the paediatric nurse should acknowledge their frustration and openly discuss their situation. Eventually the aid of the paediatric nurse will become less over time as the family and the child builds confidence to perform tasks such as transferring, showering and pressure area care in a safe manner. When technique is assessed as correct and no concerns are raised after review from the treating team, the child will return home temporarily beginning with a few hours and gradually upgrading to staying overnight. The purpose of temporary leave from hospital care is to ease the transition back into everyday life with alterations made to the home to accommodate for the disabled child.

## **CONCLUSION**

In conclusion, sports and recreation is recognised to help children maintain a level of physical activity that will benefit their growth and development in a number of different ways. However the risks, namely sporting

injuries, compromise the safety of the child and adolescent. Injuries from sporting activities fall onto a spectrum of scrapes and bruises that have little effect on the child to extreme though rare cases of traumatic brain injury and spinal cord injuries, which result in lifelong disabilities or even fatality. Review of relevant literature concerning sporting injuries in children found there is a paucity of data in determining the prevalence of injuries or the impact on the individual, family and community. While injuries are the leading cause of disability and mortality amongst the paediatric population, more academic studies to address this issue are necessary to better understand the mechanism of injury. This will also raise public awareness to seek improvements on a local, state and even national level to keep children safe while participating in sports. Currently, paediatric nurses are treating children who have sustained sporting injuries rather than preventing them. With better surveillance of this safety issue, more can be done to reduce the risks and ease its health burden in Australia.

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