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IN THIS ISSUE

RESEARCH PAPERS

Workplace environment for nurses and healthcare assistants in residential aged care facilities in New Zealand

Evaluating the efficacy and impact of the Nursing and Midwifery Exchange Program

Pressure injury point prevalence: state wide survey to identify variability in Western Australia

Side effects of chemotherapy in children with cancer: effects of nursing training administered to caregivers

SCHOLARLY PAPER

Exploring life history methodology in chronic illness: a study in Relapsing Remitting Multiple Sclerosis

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ISSN 1447-4328

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Indexing

The AJAN is indexed in the CINAHL (Cumulative Index to Nursing and Allied Health Literature) Database, Current Contents, International Nursing Index, UnCover, University Microfilms, British Nursing Index, Medline, Australasian Medical Index and TOC Premier.

PRODUCTION

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June 2019 - August 2019 Volume 36 Issue 4

CONTENTS

RESEARCH PAPERS

Workplace environment for nurses and healthcare assistants in residential age care facilities in New Zealand Joerg Kussmaul, Kathy Peri, Michal Boyd	6
Evaluating the efficacy and impact of the Nursing and Midwifery Exchange Program: a study protocol Amy-Louise Byrne, Clare Harvey, Adele Baldwin, Brody Heritage, Diane Chamberlain, Elspeth Wood	18
Pressure injury point prevalence: state-wide survey to identify variability in Western Australian hospitals Dr Chantal Ferguson, Kathryn Crouchley, Louise Mason, Dr Jenny Prentice, Dr Amanda Ling	28
Side effects of chemotherapy in children with cancer: effects of nursing training administered to caregivers Zeynep Uzun, Sibel Kucuk	37
SCHOLARLY PAPERS	
Exploring life history methodology in chronic illness: a study in Relapsing Remitting Multiple Sclerosis Therese Burke, Joanna Patching	45

AUSTRALIAN JOURNAL OF ADVANCED NURSING REVIEW PANEL: AUSTRALIA

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Workplace environment for nurses and healthcare assistants in residential aged care facilities in New Zealand

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Conflict of Interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

KEYWORDS

Residential Aged Care Facility, environmental, noise, temperature, humidity, lighting

ABSTRACT

Objective

Continuous work under environmental and thermal discomfort such as cold, heat, and dim light has the potential to affect the health of nurses and healthcare assistants working in Residential Aged Care Facilities (RACF). The resulting health issues to workers from exposure to thermal discomfort include fatigue, concentration difficulty and work-related diseases such as cold and muscle tensions. Consequently, this often leads to higher labour absenteeism due to sick-leave which in turn correlates to poor nursing care quality for residents. This research investigated environmental factors which are temperature, humidity, noise, and lighting in nurse offices and resident lounges in RACFs in New Zealand and compared them with international standards.

Design

Quantitative study approach.

Setting

Seventeen Residential Aged Care Facilities (RACF) participated in this study, which were categorised in stand-alone (S-RACF), chain (C-RACF), and religious and charitable (RC-RACF) providers. The environmental measurements were conducted for 24 hours in the nurse offices and 12 hours in resident lounges.

Results

The findings demonstrated that the environmental factors, noise and humidity level met international standards predominately, but temperature and lighting levels failed to comply in nursing offices and resident lounges in RACF.

Conclusion

These findings indicate that nurses and healthcare assistants are working in environmental conditions that partially impedes the health and safety of nursing staff, and could affect their nursing care performance adversely for residents in RACF.

INTRODUCTION AND LITERATURE REVIEW

The World Health Organization (WHO) and the International Labour Organization (ILO) describe a workplace as a place surrounded by leadership engagement, worker involvement, common ethics, and culture. This means a workplace consists of a physical work environment, for instance, lighting, temperature, noise, and humidity. Working conditions are associated with work atmosphere, communication styles, job satisfaction, payment, training opportunities, work organisation, workload and stress factors (ILO 2019a; WHO 2010).

Research into occupational health and safety and related fields such as medicine is being conducted, and as a result, there are several environmental standards workplaces and working conditions published, for instance, for offices. These standards consist of definitions, measurement parameters, and recommendations to achieve healthy and safe workplaces and working conditions (ILO 2019b; Federal Institute for Occupational Safety and Health 2015, 2013, 2011, 2010a, 2010b; Accident Compensation Corporation 2010).

Temperature and humidity are significant factors in the well-being and health of employees at the workplace (Federal Institute for Occupational Safety and Health 2010a). The temperature in offices should be between 20 degrees Celsius and 22 degrees Celsius. However, it should not exceed more than 26 degrees Celsius unless the outside air temperature is higher and sun prevention measures are implemented to reduce the air temperature (Department of Labour Occupational and Safety and Health Service 2017; Federal Institute for Occupational Safety and Health 2010a, 2015). For a healthy and comfortable work environment, the physical correlation between the room temperature and the humidity level is essential (Safe Work Australia 2011). Humidity levels at the workplace should be between 40 and 60% because more than 70% humidity stimulates the growth of moulds and fungi (Department of Labour and Occupational Safety and Health Service 2017; Federal Institute for Occupational Safety and Health 2013). People who are sensitive or immunosuppressed could develop headaches, fatigue and concentration disorders. In many cases, if people are exposed to an unhealthy environment for too long, they could develop breathing difficulties and frequent coughing. Also, they can be more prone to respiratory tract related diseases (Canadian Centre for Occupational Health and Safety 2019).

Noise is another essential well-being factor at workplaces. Sound, measured in decibels (dBA), is a vibration that spreads in waves from the noise source. Loud sound equates to a high decibel level. In the workplace, the sound sources are often mixed, such as direct noise at the workstation, indirect noise from the background, and reflected noise (U.S. Department of Transportation 2017; Accident Compensation Corporation 2010). Sound with a decibel level of over 60 dBA is perceived as loud by the majority of people. Continuous loud noise is stressful for the human body and can cause illness and permanent hearing damage. Other adverse effects are fatigue, nervousness, tenseness, isolation and impairment of the performance (World Health Organization 2019; Swiss Federal Office for the Environment 2018; Federal Ministry for the Environment, Nature, Conservation, Building, and Nuclear Safety 2014).

The required level of lighting, measured in lux, correlates with the fundamental work activities, specific hazards and the work environment, for instance: natural or artificial light conditions, contrast, reflections or the transition of natural light over the day. The minimum recommended illumination level for simple work activities, for example, welcoming visitors in an entrance hall or waiting room, is approximately 150 lux and for regular or moderately easy work, and 250 lux should be provided, for instance, for food preparation. There are 300 to 400 lux suggested for low-risk work activities such as common office tasks. The nursing offices should have at least 500 lux and 500 to 1000 Lux are suggested for high-risk nursing activities such as dealing with excretion, human liquids or infectious instruments or with pointed, sharp, moving or hot instrument (ILO 2014; Federal Institute for Occupational Safety and Health 2011; Safe Work Australia 2011).

Employment is considered as health-promoting for an individual's well-being, but on the other side, it also can be pathogenic in an adverse work environment (Williams 2018). The correlation between the working environment and conditions and worker's health is in the interest of occupational science. Previous research has shown that continuous work under thermal discomfort has the potential to affect the health of nurses and healthcare assistants severely with resulting health issues such as fatigue, concentration difficulty, and colds (ILO 2019b; Department of Labour and Occupational Safety and Health Service 2017). As a consequence, this often leads to higher labour absenteeism due to sick-leave which correlates with poor nursing care quality for residents (Castle and Ferguson-Rome 2015; North et al 2013).

There is little knowledge on whether RACFs meet environmental standards for workplaces for nurses and healthcare assistants. This research assumes that the environmental workplace conditions for nursing staff in the nursing offices and resident lounges meet international standards. The research aims at developing a fundamental understanding of environmental related workplace condition for nursing staff in RACFs based on noise, temperature, humidity, and lighting.

STUDY DESIGN

This quantitative investigation in nursing offices and resident lounges in RACFs is part of a mixed method research with a sequential explanatory design to answer whether optimal workplace health, safety and working conditions in RACFs promote high-quality nursing care for residents.

PARTICIPANTS

The quantitative research was implemented in the Greater Auckland Region because more than a third of New Zealand's population lives there (Statistics New Zealand 2013). The three District Health Boards (DHB), Auckland, Waitemata, and Counties Manukau, organise and fund health care services in this area. In total, 183 RACFs with an average of 55 beds per facility provided long-term nursing care services for dependent and older people during the study time (Ministry of Health 2016). The managers of the RACFs in the defined research field received an invitation letter to participate voluntarily in the study based on a randomised list generated by a computer between September 2016 and January 2017. The sample size of this study comprised a total of 17 (1,022 residential beds) out of 183 RACFs (9,777 residential beds) from the determined research field. The RACFs are categorised in stand-alone (7 facilities), chain (6 facilities), and religious and charitable (4 facilities) RACFs (Ministry of Health, 2016).

ETHICS APPROVAL

This study is approved by the University of Auckland Human Participants Ethics Committee on 12 July 2016.

METHOD

The technical measurements were conducted in nurse offices (24-hour period measurement) and resident lounges (12-hour period investigation) in the participating RACFs between September 2016 to March 2017. One set of recording instruments were placed in a box which was located on the main desk in the nurse offices and the second one on a table in the resident lounges. The nursing staff and residents were informed at a prior staff meeting and the data collection day about the purpose of the instrument containers and advised not to touch, move, and unplug it. After the instruments were activated, they recorded autonomously.

The validity and reliability of measurement instruments that were purchased for this study undertaking are ensured by the manufacturer (PCE Instruments UK Ltd). The devices used for the environmental measurements and recordings are listed in table 1.

Table 1: Overview Technical Environmental Measurements and Pedometer Instruments

Environmental Indicator	Instrument	Measurement Intervals	Measurement Place
Temperature	PCE- HT110	Every minute	
Humidity			Nurse Offices,
Noise	PCE-322	Every ten seconds	Resident Lounges
Lighting	PCE-174	Every minute	

The recorded data was directly exported from the instruments to a Windows Excel 2016 sheet. After the data cleaning, a descriptive statistics analysis was conducted.

FINDINGS

Noise Results

Figure 1: Noise Levels in the Nursing Offices of all RACFs (n=17)

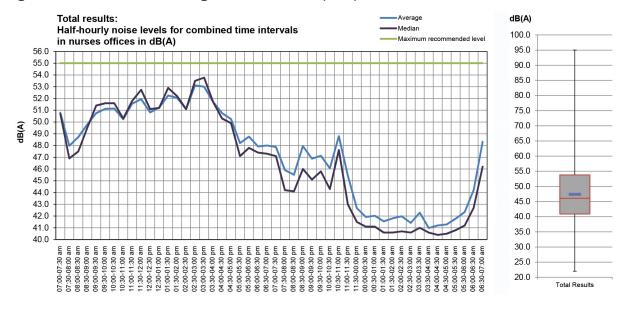
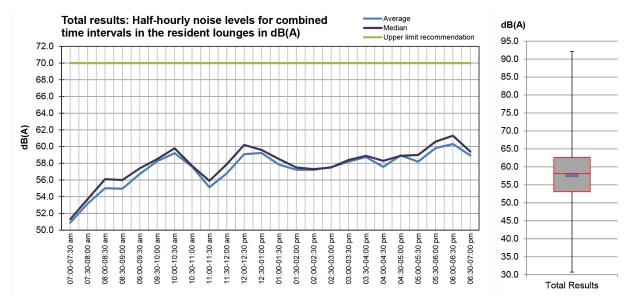


Figure 2: Noise Levels in the Resident Lounges of all participating RACFs (n=17)



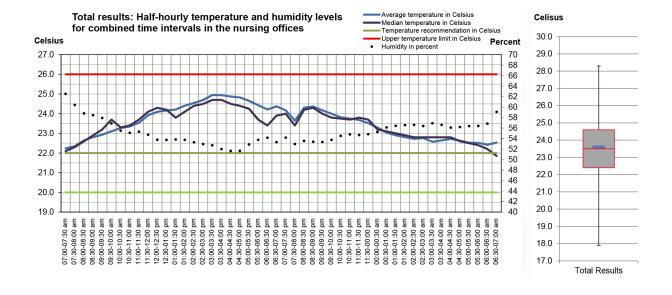
In the 24-hour investigation period of noise in nursing offices, the average of 47 dB(A) and median of 46 dB(A) indicated a fairly quiet to a recommended level for the individual perception of noise. Also, in the 12-hour examination period in resident lounges, a normal level for the individual perception of noise within an average and median of 58 dB(A) was detected.

The noise volumes in nursing offices can be categorised as day-time (7am to 5.30pm), evening (5.30 pm to 11pm), and night-time (11pm to 7am) based on similar ranges of dB(A) levels. This means that the approximate average and median noise volumes during day-time ranged between 47 dB(A) and 54 dB(A), in the evening from 44 to 48 dB(A), and in the night-time 40 to 42 dB(A). The investigated time for noise volumes in resident lounges can be classified in the morning (7am to 12.30pm), and afternoon (12.30pm to 7pm). The noise volumes ranged from 51 to 60 dB(A) in the morning and between 60 to 61 dB(A) in the afternoon. The recommended noise limits of 55 dB(A) for offices and 70 dB(A) for resident lounges were not reached throughout the measurement periods. However, single volume measurement points peaked briefly up to 95 dB(A) (Federal Insitute of Occupational Safety and Health 2010b).

Taking all measurement points into account, the noise volumes were within the recommendation and under the maximum limit for offices for 20.57 hours (86% of a day) and in resident lounges for 10.02 hours (83% of 12 hours). In the comparison of the S-RACF, C-RACF, and RC-RACF providers results showed that noise levels were comparable in each noise category except for small and insignificant differences. The average and median noise measurements in nursing offices and resident lounges of all RACF complied with international environmental standards (Federal Insitute of Occupational Safety and Health 2010b).

Temperature and Humidity Results

Figure 3: Temperature and Humidity Results of the Nursing Offices of all RACFs (n=17)



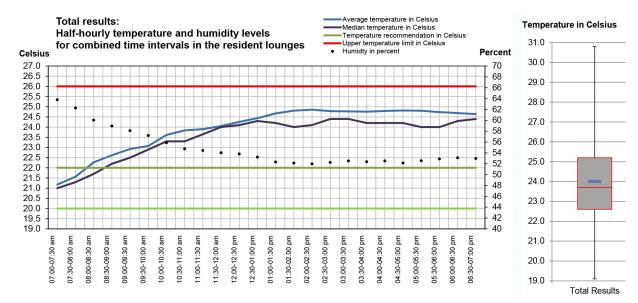


Figure 4: Temperature and Humidity Results in the Resident Lounges of all RACFs (n=17)

The temperature results in nursing offices in the 24-hour examination timeframe demonstrated an average of 23.6 degrees Celsius and a median of 23.5 degrees Celsius. The average temperature levels were continuously higher than the environmental recommendation from 20 to 22 degrees Celsius. The average humidity in nursing offices was 55% and within the recommended parameters of between 40% and 60%. Similar results were found for the temperature conditions in resident lounges during the 12-hour examination. The average temperature was 24 degrees Celsius, and the median was 23.7 degrees Celsius. Apart from two hours in the morning, the average temperature was always higher than the recommended environmental standards. The maximum temperature was measured at 30.8 degrees Celsius. The average humidity in the living room was 55% and met the recommended standards likewise (Department of Labour and Occupational Safety and Health Service 2017; Federal Insitute of Occupational Safety and Health 2013, 2010a).

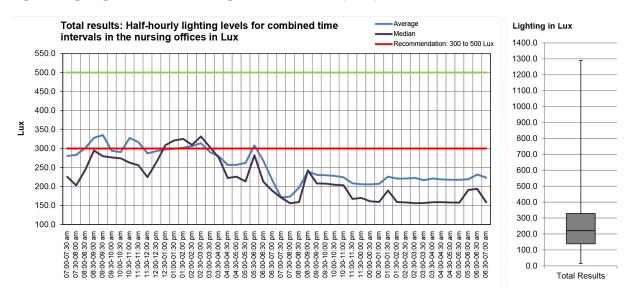
The temperature conditions in nursing offices can be categorised in 'day-time' (7am to 8.30pm) and 'night-time' (8.30pm am to 7am). During the day the average temperature was between 23 to 25 degrees Celsius and at night-time from 22 to 24 degrees Celsius. Single temperature measure points were higher than the upper temperature limit of 26 up to 2.3 degrees Celsius. The temperature recordings in resident lounges can be classified in 'morning' (7am to 1.30pm) and 'afternoon' (1.30pm to 7pm). In the morning the average temperature was 21 to 24 degrees Celsius while in the afternoon it was from 22 to 25 degrees Celsius. Single temperature measurements reach higher levels to a maximum of 30.8 degrees Celsius momentarily at times.

To summarise, the average temperature was within the environmental recommendation in offices for 3.51 hours (15% of a day) and in resident lounges for 1.5 hours (13% of 12 hours). The humidity levels in nursing offices were complied with environmental safety recommendations for 15.63 hours (65% of a day) and in resident lounges for 7.62 hours (64% of 12 hours).

In a comparison of the average exposition to temperature and humidity in nursing offices between S-RACF, C-RACF, and RC-RACF providers the findings demonstrated only moderate differences. In nursing offices and resident lounges, the temperature was predominately too high for more than three-quarters of the investigated time-frame, and only rudimentary met international environmental standards. The humidity levels in both areas complied with international standards approximately during two-thirds of the examined period (Department of Labour and Occupational Safety and Health Service 2017; Federal Insitute of Occupational Safety and Health 2013, 2010a).

Lighting Results





The lighting results in nursing offices in the 24-hour examination timeframe provided an average of 254 Lux and a median of 203 Lux. During the day the average and median light intensity reached the minimum recommended lighting of 300 Lux occasionally (Office work and low-risk nursing activities). At night the lighting condition was continuously under this level which also means that the recommended level of 500 Lux for high-risk nursing activities was not achieved (Federal Institute for Occupational Safety and Health 2015, 2011; International Labour Organization, 2014). The lighting condition can be separated in 'day-time' (7am to 6pm) and 'night-time' (6pm to 7am). During the hours of daylight, the average and median light was between 200 and 320 Lux. From early evening to morning the lighting levels were from 150 to 225 Lux. For a brief period, single lighting measure points could reach higher levels up to 1290 Lux.

The average and median lighting conditions were within the environmental recommendation for offices and low-risk nursing activities for 3.75 hours, (16% of a day) and 1.78 hours (7% of a day) for high-risk activities. In a comparison of the environmental lighting conditions in nursing offices across all RACF providers, the RC-RACF provided longest exposure of almost 18 hours to low levels of 0 to 300 lux. The C-RACF provider results were similar to the average levels in each lighting category. The lighting exposure of the S-RACF provider was under the average for each lighting level category.

In summary, the lighting situation in the nursing offices was almost throughout lower than the minimum lighting level recommendation for low and high-risk nursing activities according to the environmental standards (Federal Institute for Occupational Safety and Health 2015, 2011; ILO 2014).

STRENGTHS AND LIMITATIONS

One source of weakness of the technical measurements which could have affected the results was that the environmental instruments were occasionally unplugged, covered or moved by nursing staff and residents. This interference occurred despite attached signs on the container which contained the meters and prior verbal notice. Overall, the negative impact on the complete data was 13.6% (200,225 out of 1,468,800 measurement points) of missing noise values, 13.2% (3238 out of 24,480 measurement points) of missing temperature and humidity values, and 29% (212,680 out of 734,400 measurement points) of missing lighting values. Almost 30 per cent of the lighting values in nursing offices were missing. The reason for that was the

13

high number of measurement errors of the PCE Light-Meter-Instrument compared to the other environmental meters produced by the same company. The display of the light measurement instrument did not indicate any malfunction during the inspections rounds by the researcher. The missing data might be related to connection faults between the measurement sensor and integrated software of the PCE Light-Meter-Instrument. In order to develop reliable results based on valid measurements, a control calculation approach was implemented. No deviations for both methods were identified.

The PCE Noise-Meter-Instrument has an appearance similar to a microphone. It could be assumed that this optic caused nursing staff to hesitate to speak in a normal voice volume in fear of verbal recordings. This would result in lower noise results. However, the noise measurement results show no corresponding influences.

Also, it could be argued that the time of the year and changing weather conditions could compromise the temperature, humidity, and lighting results. However, this conclusion was not substantial because the environmental standards must be met regardless of seasonal weather conditions as per international environmental standards (Federal Institute for Occupational Safety and Health 2015, 2013, 2011, 2010b, 2010a).

DISCUSSION

The development of healthy and safe workplaces and working conditions is challenging due to their complex nature and a high number of influencing risk factors such as work culture, work organisation, and environmental conditions (ILO 2014; WHO 2010, 1994). The physical parameters for measuring the work environment such as noise, temperature, humidity, and lighting have been investigated comprehensively, and robust standards are developed (ILO 2014; Federal Institute for Occupational Safety and Health 2016, 2015, 2013, 2011, 2010a, 2010b; Accident Compensation Corporation 2010). Those standards are promoted on a macro-level by the WHO and national governments. On a micro-level, health and safety standards are implemented by management and health and safety representatives of organisations (ILO 2019b; WHO, 2010, 1994).

The noise findings of this research conducted in nursing offices and resident lounges in RACF complied with environmental standards. This result can be explained that nursing offices are usually restricted to nursing staff only with work-related conversation as the common noise source. On the other hand, nurses and healthcare assistants spend a considerable amount of time in the resident's rooms for treatment purposes and confidential conversations (Mallidou et al 2013). It seems that noise volumes in resident rooms do not affect the volume in nursing offices.

The noise results in resident lounges presented slightly higher volume levels than in nursing offices. One of the likely causes for the marginal higher noise levels in resident lounges is the gathering of residents and visitors to spent time together and take part in activities (Rindel 2012). These findings are typical when people meet and hold conversations (Federal Ministry for the Environment, Nature, Conservation, Building, and Nuclear Safety 2014; Accident Compensation Corporation 2010). However, even the higher noise levels in the resident lounges compared to the nursing offices were within the parameters of the recommended standards. There were no significant differences between RACF providers (Federal Institute for Occupational Safety and Health 2015, 2010b). This means that nursing staff in RACF was not exposed to health risks based on noise volumes. However, this research provides findings of the noise levels but not the type of noises. Further studies need to be carried out in order to develop an understanding of what types of noise in RACF can be stressful and how they affect the health and well-being of nurses and healthcare assistants.

14

The temperature in the nursing offices and resident lounges were too warm and barely met the recommended levels. One possible explanation for this finding in nursing offices might be that the rooms were often small and packed with of equipment, devices, and folders (Federal Institute of Occupational Health and Safety 2018; VGB 2018). Nurses and healthcare assistants working in the office releasing heat through their bodies and computers, printers, and fridges which are generating hot air increase the temperature further (VGB 2018; Marieb and Hoehn 2007).

Limited air circulation could also hinder the maintenance of cooler room temperature. Working in too hot rooms can lead to symptoms such as fatigue, and concentration problems, and diseases, for instance, a cold and conjunctivitis (Wittig-Goetz and Rundagel 2018; Department of Labour and Occupational Safety and Health Service 2017).

Even though average humidity levels in nursing offices and resident lounges were in accordance with environmental standards for two-thirds of the investigated period, there are hours in which the humidity was not within the recommended range. One reason behind this discrepancy could be non-insulated building structure and single-glazed windows. Another major influence can be poor air circulation (Canadian Centre for Occupational Health and Safety 2019; Federal Institute for Occupational Safety and Health 2013).

The type of RACF provider was not related to the humidity results. According to these findings, nursing staff should not physically experience headaches, fatigue and concentration disorders because of either excessively high or low humidity levels (Canadian Centre for Occupational Health and Safety 2019; Department of Labour and Occupational Safety and Health Service 2017; Federal Institute for Occupational Safety and Health 2013).

The lighting situations in the nursing offices did not meet environmental recommendations. This outcome can be due to offices lacking windows or their windows are inappropriately small. The number of light sources and their intensity in a room has a major influence on the lighting conditions (ILO 2014; Safe Work Australia 2011).

The lighting related findings of this study differed greatly between the RACF provider. Even the results between the facilities per RACF group were different and it seems that the lighting situations are strongly related to single RACF. This means that the nursing staff is facing health and safety risks such as eyestrain, fatigue, headaches, muscle tensions, and stress when they implement activities such as dealing with body fluids, body waste, and contaminated objects (VGB 2018; Federal Institute for Occupational Safety and Health 2015, 2011; ILO 2014).

The scope of this study is limited to four environmental factors. For a better understanding of how environmental related hazards affects nursing staff, some fragments are missing, for example, room air speed, air quality, and odours.

In order to develop a better understanding of how occupational-related hazards affect nursing staff, more insights into some fragments, such as room air speed, air quality, and personal perception of odour, are to be sought after.

CONCLUSION

This research investigated environmental workplace parameters which are noise, temperature, humidity, and lighting in RACFs and provided a comparison with international environmental standards.

The findings have identified that the noise levels in nursing offices and resident lounges of all participating RACFs complied with international environmental standards (Federal Institute for Occupational Safety and Health 2015, 2010b). The temperature in nursing offices and resident lounges were predominately too high and met international environmental standards just to a limited extent. The humidity levels were aligned

with international standards for approximately two-thirds of the respective examined period (Department of Labour and Occupational Safety and Health Service 2017; Federal Institute for Occupational Safety and Health 2015, 2013). The lighting situations in the nursing offices were predominately lower than the recommended minimum. This is a risk and an impediment to the implementation of nursing activities (Federal Institute for Occupational Safety and Health 2015, 2011; ILO 2014).

In other words, nurses and healthcare assistants are working in partially suboptimal environmental conditions which in turn could affect their health and nursing care performance for residents adversely (WHO 2019; Castle and Ferguson-Rome 2015; Woods 2015; North et al 2013). However, the individual environmental perception could differ from international standards and recommendations, for example, employees who are sweating excessively over 18 degree Celsius room temperature and workers who suffer from diseases such as hormone imbalance who prefer a cooler working space. This means that it may not be possible to meet recommended standards for workplaces as well as staff expectation at the same time (Department of Labour and Occupational Safety and Health Service, 2017).

The findings will be of interest to RACF employers and organisations who are committed to the provision of providing healthy and safe workplaces for nursing staff. It also contributes to the health sciences and enable a better understanding of the environmental workplace situation in RACF. Continued efforts are needed to generate a well-being environment at the workplace for nurses and healthcare workers in order to provide high-quality nursing care for residents in RACFs.

RECOMMENDATION

The results of this research demonstrated an environmental health and safety risk at workplaces for nursing staff in RACF. To minimise or avoid completely health-related risks at the workplaces a systematic approach is recommended. This includes the identification of relevant environmental standards, risk assessment, implementation of preventive actions, and evaluation of the effectiveness of those measures (WorkSafe New Zealand 2017; Johnson 2002; Deming 1986). At the same time, the workers' voice should be taken into consideration because they have a profound experience and awareness of potential risks at their workstation (WorkSafe New Zealand 2017). After identification of a potential health and safety risk, for example, throughout a workplace risk assessment, the preferred measure is to eliminate the hazard source, for instance, placing printers, copiers and other unnecessary electrical equipment not in nursing offices (Bux 2006). If this is not possible, then actions should be implemented to minimise the risk which includes structural changes such as, determining the optimal place for the light source and changing the location of the workstation, and providing personal safety equipment, such as disposable gloves, aprons, and masks (ILO 2014; Safe Work Australia, 2011).

The implemented preventive actions should be evaluated regularly. If the result is not sufficient according to the recommended standards, then a re-assessment of the workplace situation and environment should be conducted inclusive the implementation of further preventive actions (WorkSafe New Zealand 2017; Johnson 2002; Deming 1986).

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17

Evaluating the efficacy and impact of the Nursing and Midwifery Exchange Program: a study protocol

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KEY WORDS

rural, remote, exchange, workforce, nurse, midwifery

ABSTRACT

Objective

The following research protocol evaluates the Queensland Health Nursing and Midwifery Exchange Program (NMEP) and evaluates how exposure to diverse clinical settings, may impact the nursing and midwifery workforce on individual and organisational levels.

Design

This protocol details a mixed methodology allowing for both quantitative and qualitative data. The study is being undertaken in three stages; a survey of the participating nurses and midwives; a systematic review; and a Delphi study with an expert review group.

Setting

The study is a Queensland wide study across rural/remote, regional and metropolitan locations.

Subjects

This study will follow approximately 70 nurses and midwives employed by Queensland Health from diverse areas and streams at various stages within their clinical career.

Interventions

Nurses and Midwives participate in a three or six-month professional exchange to a rural/remote or metropolitan location.

Main outcome measure(s)

This study will evaluate the impact and sustainability of the NMEP program through measurement of burnout, job embeddedness, job strain, job satisfaction and attrition through a series of surveys. In addition to this, a systematic review and Delphi with executive experts will be conducted to consider a future pathway/model for nursing and midwifery exchange.

Results

This study has commenced and will be completed September of 2019.

Conclusion

The NMEP program is one novel approach to nursing and midwifery workforce concerns and looks to present excellent opportunities for the crossover of skills and ideas related to clinical, professional and service integration between metropolitan and rural practice.

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Conflicts of Interest and Course of Funding

The authors declare no conflicts of interest. This project is funded by the Office of the Chief Nursing and Midwifery Officer, Queensland Health, through the sponsor, South West Hospital and Health Service. This research is not subject to results-dependant funding or veto of publication by the sponsor.

INTRODUCTION

Global concerns about current and impending nursing workforce shortages have necessitated innovative strategic approaches that incorporate a revision of cost allocations and a shift in service management. The complexities associated with these shortages include an ageing workforce, increasing patient acuity and escalating costs of care provision (Hudspeth 2016; Sherman et al 2013; Productivity Commission 2005). The pressures of cost and space associated with acute hospital admissions have placed an increasing focus on community services in an attempt to reduce unnecessary and avoidable admissions (Australian Health Minister's Advisory Council 2017). This has compounded existing challenges related to health service provision in areas geographically removed from major metropolitan centres, where the difficulties associated with recruitment and retention of the workforce and access to services require special consideration. In Australia, just under half of the nursing workforce is over the age of 45 years, of which only 8.2% are located in community settings (Australian Institute of Health and Welfare 2013). Rural and remote nursing and midwifery is not identified in these statistics, although work undertaken by Rural Health West (2014) showed that there was a ratio of one nurse per 150 to 500 population in rural and remote areas.

Community nursing, an area which rural/remote nurses work collaboratively across, is of particular importance to health service provision as it supports home care and hospital avoidance. In spite of this knowledge, community nursing is largely invisible, and is not seen as an attractive career choice because of its generalist nature (Gray et al 2011; Kennedy et al 2008). Exposure to living in regional, rural and remote areas is therefore fundamental to attracting a suitable nursing workforce. It is a well-known fact that nurses who have grown up in, or have clinical experience in a particular region, are more likely to engage with it, and return to it for work. Moreover, preparing nurses to deal with the diversity of care and the challenges of rural and remote life is not always adequate (Francis et al 2016) and detailed consideration must be given to providing opportunities for nurses at all levels to develop the necessary understandings.

This research study builds on work that is currently being undertaken in Queensland Health, to develop strategies that support early transition into specialty practice, professional development and the encouragement of life-long learning including experience in rural and remote health (Fox et al 2015). One such project is the Nursing and Midwifery Exchange Program (NMEP). NMEP was conceived in the South West Hospital and Health Service (SWHHS), developed in partnership with the Office of the Chief Nursing and Midwifery Officer, in response to continued nursing and midwifery recruitment, retention and professional development difficulties. NMEP commenced in August 2017 and will run until June 2019. NMEP was designed to be an innovative, low risk opportunity for nurses and midwives to engage in professional exposure to different geographic locations and clinical environments within a supportive and nurturing framework.

BACKGROUND

Nurses working in rural and remote locations may be generalist in nature with primary and preventative healthcare as core business. However, they need to be able to transition quickly to acute and emergency nursing as situations demand, often in the absence of support from medical and other nursing staff. Thus, in addition to their usual scope of practice, rural and remote nurses take on additional skills and tasks, accepting significant additional responsibility for the welfare of their patients (Knight et al 2016).

For rural/remote localities, considerations for access, environment, lifestyle and isolation, complicate the health services ability to recruit, retain and maintain nurses with the broad repertoire of skill required to provide safe and effective services (Productivity Commission 2005). The complex nature of rural and remote nursing can lead to increased work pressures, stress and burnout. Burnout is a real and prevalent issue for nurses, often leading to increased staff turnover and sick days, all factors that can spill over to clinical practice effectiveness resulting in patient dissatisfaction and potential patient safety concerns (Hegney et al 2014). Mitigating factors of the nursing work experience, such as the degree of embeddedness and job satisfaction perceived by nurses, have been identified as potential approaches to reducing nurse turnover (Reitz and Anderson 2011; Cohen 2006; Holtom and O'Neill 2004). Embeddedness, a construct that refers to a constellation of fit perceptions, social ties, and elements that would be sacrificed upon leaving a job (Lee et al 2004), has demonstrated relevance to the retention strategies directed towards rural nurses specifically (Chandra 2010). Preventative strategies to mitigate these concerns include engaging the current workforce through innovation and building capacity and capability in graduate and early career nurses (Health Workforce Australia 2012). Feeling valued is a significant factor in how nurses respond to workplace pressures. Therefore, the importance of supporting isolated staff through workplace incentives, professional development, education and ongoing learning opportunities cannot be excluded from strategic planning (Mbemba et al 2013).

AIMS OF THE STUDY

The aims of this study are to evaluate the efficacy and sustainability of NMEP and to develop a formal pathway for ongoing implementation across the health services. To do this, we want to explore the perceptions of the exchange program, as viewed by the nurses and midwives who have taken part in the exchange program; we want to identify if there are similar models that have been trialled in other countries and settings; and gain a consensus from the managers of health services as to what they view as a sustainable model.

The original NMEP concept centred on a reciprocal relationship between rural/remote and metropolitan nurses and midwives, fostering the cross translation of skills and experiences. The core concept was designed around exposure to different areas with the hypothesis that exposure could lead to future recruitment. The program was developed through a state-wide steering committee of nursing leaders from rural/remote and metropolitan health services, aiming to build a more sustainable nursing and midwifery workforce through the collective strength of the state's resources. Candidates are matched with a partner, typically one rural nurse/midwife with one metropolitan nurse/midwife, and a swap of substantive positions is facilitated. The timeframe for the exchange may be either a period of three or six months. Rural/remote nurses have the opportunity to expand their skills and experience through exposure to higher acuity services and reduced hospital length of stay. The metropolitan nurses are able to expand their skills in rural continuity of care, Indigenous health services and 'rural generalist' nursing. The anticipated outcomes are for each cohort to develop skills that will support ongoing learning and professional development; improve networking, communication and collaboration between health services; and foster leadership and mentorship across diverse practice locations. While rural/remote exposure is important to improve recruitment, the relationship between metropolitan exposure for current rural/remote staff and retention to their rural/remote locations is also considered within the context of this study.

RESEARCH QUESTIONS

- 1. Can exposure to clinical practice in alternate settings change future employment intentions as viewed by the nurses and midwives?
- 2. Is there evidence of:
 - a) increased job satisfaction, and reduced burnout and job strain, amongst nurses and midwives who have completed an exchange placement?
 - b) self-reported confidence in relation to clinical and professional practice?
 - c) job and community embeddedness in practice?
- 3. Is NMEP financially sustainable in the long-term?
- 4. What is a sustainable model for NMEP, as viewed by experts?

METHODOLOGY

To facilitate inclusion of the variables the project uses a mixed methodology within a pragmatic research framework (Onwuegbuzie and Leech 2005). It allows for a systematic approach to exploring meanings in context and to examining "constructivist formulations, particularly those that theorize the role of agents in the creation of meanings, practices, structures, and institutions through their speech acts and communicative interactions (Duffy 2008, pp. 168). Pragmatic analysis allows for both qualitative and quantitative paradigms to be combined in a way that allows for the analysis of social phenomena, in real world situations that have not been fully explored.

The study is being undertaken in three stages; a survey of the participating nurses and midwives; a systematic review; and a Delphi study inviting executive directors of nursing to be a part of an expert review group (table 1).

Stage 1 - This stage has commenced and will run over 18 months (Completion September 2019). The survey consists of a series of questionnaires that address burnout, well-being, embeddedness, and job satisfaction, alongside questions rating nurses' and midwives' NMEP experience, with free text space to discuss their views of the program. The survey consists of the 12 item version General Health Questionnaire [GHQ-12] (Goldberg et al 1997), a short measure of turnover and attrition intentions adapted from Jaros (1997; Heritage et al 2018), the Short Burnout Measure (Malach-Pines 2005), the Abridged Job in General (Russell et al 2004) to measure job satisfaction, the community and workplace embeddedness measures of Lee et al (2004), and items generated by the authors specific to the NMEP project, which includes demographics such as place of employment, place of exchange, experience, age and education levels. The GHQ-12 has demonstrated good utility as a screening tool for minor psychological disturbance (e.g., anxiety) in general non-clinical populations (Goldberg et al 1997). Heritage et al (2018) have previously demonstrated acceptable reliability and use as outcome variables for both the job-based and occupation-based turnover measures (a = .82, a = .86, respectively) adapted from Jaros (1997). Malach-Pines (2005) has similarly demonstrated good evidence of reliability (a = .85-.92 across samples) and convergent validity with related burnout measures for the Short Burnout Measure. The Abridged Job in General has been previously demonstrated as a robust measure of global job satisfaction with adequate reliability and validity evidence by Russell et al (2004). Lee et al.'s (2004) job/community embeddedness measures have similarly demonstrated evidence of adequate reliability and validity (e.g., relationships with turnover intent).

Table 1: Research process

Desearch stage	Data collection	Inclusions / Evolusions	Analysis
	Survey on job strain, turnover intention, embeddedness, burnout, job satisfaction, and perceptions of NMEP. Analysis will determine whether or not there is a change to the way nurses perceive their work and if any of the above parameters have altered as a result of the exchange experience.	Inclusions/Exclusions Inclusions: Nurses and midwives employed by Queensland Health and involved in NMEP. Exclusions: Nurses not employed by Queensland Health and not involved in NMEP.	Two sets of analyses will be conducted: Comparative analyses between exchange participants and nonexchange nurses on the study's measures (job satisfaction, job strain, embeddedness, burnout, and turnover intention) via MANCOVA will be conducted, following checks for analysis data assumption compliance. This analysis will provide pilot cross-sectional results on the differing facets of the cohorts on these variables, without placing undue burden on the non-exchange nurses to complete longitudinal measurement. The second set of analyses will be within-subject generalised linear mixed model analyses of the exchange program nurses, and whether their change in turnover intention over time is attributable to their perceived level of job satisfaction, job strain, burnout, and embeddedness at the pre/during/post/follow-up measurement periods.
Stage 2 – Systematic review	Search focuses on rural and remote recruitment and retention of nurses and midwives across UK, Australia, New Zealand, United States of America and Canada. Focus on types on gaps and common themes within this area.	As per PROSPERO registration	The systematic review will follow the international guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (PRISMA, 2018) and the Joanna Briggs Institute (Joanna Briggs Institute, 2014) approach for systematic reviews. Full details of the overall search strategy for the project can be found in the research protocol and will be registered with the International Prospective Register of Systematic Reviews (PROSPERO).
Stage 3 – Delphi with experts	Series of survey and interviews rounds to develop a consensus on a draft policy for the roll out of NMEP.	Inclusions: Executive directors of nursing and midwifery employed by Queensland Health and involved in NMEP. Exclusions: Executive directors of nursing and midwifery not employed by Queensland Health and not involved in NMEP.	A series of surveys will be sent out, followed by a final interview conducted over ZOOM™ in which the draft policy will be shared, and specific questions related to the model posed to a group of nursing managers

Stage 2 – A systematic review is underway which will explore similar models that have been trialled and/or are in practice and the context around current rural remote recruitment, retention and practice gaps. The search will include the United States of America, United Kingdom, New Zealand, Australia and Canada. The outcome of this stage will be to develop a model for NMEP based on the early analysis of data (first 6 months) from the surveys and the data synthesis from the review. This will be used as a baseline for the development of a draft model.

Stage 3 - A four round Delphi technique inquiry method will gather input from a draft model informed by the initial data analysis of the Stage 1 surveys and the outcomes of the systematic review. It will require feedback from a consenting panel of executive directors of nursing experts from Queensland Health. The first round Delphi questionnaires thus comprise a combination of open and closed questions using Survey Monkey™. Where closed questions are used, asking panellists to specifically rate through a 5-point Likert system some component of the NMEP formal pathway; panellists will be asked to explain their opinions. The second-round questionnaire will ask further questions on new issues that emerge from responses to previous open questions, plus iterated closed questions. Feedback on the opinions of panellists on the first two rounds along with summaries of the written arguments given by panellists will pre-empt Round 3, a consultative consensus meeting through as online meeting platform to allow discussion and debate of synthesised themes and agreement for further modelling. Comments, recordings, transcripts, and notes will be collated by the Delphi moderators, who are two of the researchers chosen for this purpose. Upon completing the analysis of the third round, we will merge the predictive statements into patterns based on common themes. Data will be thematically analysed to develop sub-themes around purpose, process, enablers, and evaluating outcome and impact of a NMEP formal pathway. Round 4 consists of a survey where synthesized themes will be incorporated into a Likert-type scale, and the expert panel participants will be asked to validate responses. Participants will be asked to rate statements, which will be both positively and negatively formulated, using a five-point Likert scale, effectively re-ranking components from strongly disagree (1) to strongly agree (5), with the option to include comments if desired. The standardised mean, median, as well as the interquartile range of all answers, will be computed. When statements meet more stringent criteria (IQR of ≤1 instead of ≤2); this will be regarded as strong consensus (Franklin et al 2007).

RECRUITMENT

Stage 1 – Nurses and midwives who have participated in the exchange program and are employed by Queensland Health. Over the period of the program, there will be an estimated 70 nurses and midwives who will have been involved in the exchange program. Participants will be provided with an information sheet at the beginning of their placement, on which is a link to an online anonymous survey. They will be invited to complete the survey four times, on commencement of the exchange; midway through the exchange; at the end of the exchange and three months post-exchange.

To better understand the impact of NMEP, a comparative cohort of nurses and midwives is included. This cohort consists of participants from health services involved in the exchange, but whom have not undertaken exchange themselves. Typically, these nurses/midwives' wards or services have seen someone engage in the program, hence being exposed to the program philosophy, but the nurses in the comparative group have not engaged in exchange themselves. They will be invited to complete the survey once only. Depending on sample size adequacy, *t*-tests with alpha corrections to account for multiple family-wise comparisons, or a multivariate analysis of variance that accounts for sociodemographic covariates (MANCOVA) will be conducted to examine differences between the NMEP participants and the comparison group. The outcome variables that will be compared are job satisfaction, job strain, burnout, embeddedness, and turnover intention.

The surveys for both groups are voluntary and submission of the survey is consent to participate. Ethical approval was provided by the academic institution conducting the surveys.

Stage 3 – Executive directors of nursing from 16 Queensland health services participating in the exchange program will be invited to participate in a Delphi Study round in which they will be asked to consider and comment on a draft policy for NMEP.

Ethical approval was provided by the Darling Downs Human Research Ethic Committee (HREC).

Data collection and analysis

The overview of data collection and analysis is outlined in table 1.

The survey uses a collection of questionnaires that support the review and analysis of the nurses/midwives' perceptions of the program related to job satisfaction, embeddedness (table 2), in addition to demographic questions and free text for participants to provide their views of the program. Analysis via generalised linear mixed models will be used to examine the unique variance in job-related turnover intentions, and profession-based attrition intentions, explained by the predictors outlined prior. This approach will allow for time-related change in these relationships to be examined without the stricter data requirements of comparable repeated-measures ANOVA-based approaches.

Table 2: Questionnaires used in the Survey

Construct Measured	Name of Measure	Description
Demographic questions	Related to age, location, experience	Establishment of context in normal practice
Questions related to NMEP experience	Questions aimed at finding out how well the exchange program worked for the participant (Likert scale and free text)	Questions aimed at collecting data related to the efficacy of the exchange program
Burnout	Burnout Measure -Short Version (Malach-Pines 2005)	10-item version of the original 21-item scale. Example item: 'Difficulties sleeping'.
Job Strain	General Health Questionnaire (Goldberg & William, 1988)	A 12-item measure that captures general psychological distress using a 4-point Likert Scale. Example item: 'Felt constantly under strain'.
Job Satisfaction	Abridged Job in General (Russell et al 2004)	8-item scale, a short version of the previous Job in General Scale.
Job and Community Embeddedness	Job Embeddedness Measure (Lee et al 2004)	Questions that examine the Fit, Links, and Sacrifice elements that contribute to the construct of embeddedness, reflected by both job-based and community-based factors. Example item: 'I feel like I am a good match for this organisation'.
Attrition	Three-item Turnover Intention Scale (Jaros 1997)	Three items using a five-point Likert scale measures how often respondents consider leaving their occupation, and likelihood of leaving their occupation in the future. Example item: 'How likely is it that you would leave your organisation in the next year?

Thematic analysis will be used to draw out the common themes that are found across all data sets (Braun and Clarke 2006). The focus of this will be to examine alternatives around a sustainable exchange program, using both peer reviewed literature and the views of nurses and midwives, and nursing managers.

The Delphi, a structured communication technique initially developed as a systematic, interactive forecasting method comprising a combination of open and closed questions with mixed methods analysis, allows for a series of rounds that support the refinement of a draft document. Experts in the field are used to provide discussion and the exploration of ideas based on expert knowledge and experience (O'Keefe et al 2012).

Content analysis is divided into three phases: pre-analysis; the exploration of the material, and the treatment of the results; inference and interpretation.

Validity and rigour

In terms of the quantitative analyses, generalised linear mixed models used to examine time-related change is a rigorous approach that allows for greater flexibility in the data assumptions in comparison to the traditional ANOVA-based approaches (e.g. data non-normality and missingness is tolerated to a greater degree (Heck et al 2014)). Repeated measures designs are additionally better representative of the relationship between predictor/outcome variables by safeguarding against traditional flaws in cross-sectional research (e.g., regression to the mean). While we acknowledge that the between groups comparisons (i.e. NMEP participants and non-participants) are limited to cross-sectional inferences, this analysis provides the basis for future comparisons across these participant groups that would benefit from future longitudinal analysis, the latter of which falls outside of the data-collection scope of the current investigation.

In terms of the qualitative analyses, thematic analysis will allow for the inclusion of participant perceptions against questions posed in the survey. Jagd (2011) argues that any organisation "is a space intersected by a multitude of disputes, critiques, disagreements and attempts to produce fragile local agreements" (pp. 345). Participants will reflexively justify and explain their situation within it, and it is this reflexivity that allows for the ordering of themes within the commentaries provided throughout the survey, ordered into predetermined themes such as job security and satisfaction; job and community embeddedness; and burnout and compassion fatigue.

LIMITATIONS

This project was developed in two stages.

The first stage was a stand-alone project that set out to review the perceptions of nurses and midwives who had participated in NMEP. The exchanges are staggered across the program period between August 2017 and June 2019. This review was always going to have small numbers because of the limited number of placements available in rural and remote regions. Because the staffing compliment is small, it is not feasible to take away more than one experienced rural nurse/midwife at any one time, as it would leave the service at risk in relation to the skills mix of the staffing compliment. Although the service will have a metropolitan based nurse in exchange, as (Francis et al 2016) noted in their study, the probability of that nurse/midwife having the experience and necessary skills to deal with the additional lifespan issues in the rural context is small. This is in spite of careful selection in each exchange taking place.

Shortly after commencement, a request was made to have a procedure developed for ongoing roll out of NMEP by December 2018. This necessitated a systematic review to support the procedure development, in the light of the fact that the surveys of those involved with an exchange will not be complete. Ongoing opportunity though NMEP or a similar program is encouraging, as it supports recruitment and retention in the rural and

remote regions of the state. It does however mean that a systematic review is essential to support ongoing procedures around exposure and exchange, in light of the fact that the surveys of those involved within an exchange may not be complete.

CONCLUSION

This project started out reviewing the perceptions and experiences of a cohort of nurses and midwives who have been involved in a state-wide exchange program to experience different context of practice between rural and metropolitan regions. It was the brainchild of one rural health service to support recruitment of staff to the region and to offer the opportunity of expanding nursing/midwifery workforce professional and clinical skills by spending time in a metropolitan service. What has transpired is the state government seeing this as an opportunity to develop a formal exchange program to support recruitment, retention and opportunities for ongoing professional and clinical learning for their nursing and midwifery workforce across the state. The program is novel and looks to present excellent opportunities for the crossover of skills and ideas related to clinical, professional and service integration between metropolitan and rural practice. Health services are best positioned to identify and understand the specific challenges to providing quality healthcare in their unique settings. Further, the economic pressures of contemporary health care demand cost effective measures to address these challenges.

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Pressure injury point prevalence: state-wide survey to identify variability in Western Australian hospitals

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ACKNOWLEDGEMENTS

Patients and staff at participating hospitals across Western Australia and the Western Australia Department of Health; Annie Chacha-Gan (Project Manager, Department of Health); Wounds West – staff and resources; WA Pressure Injury Prevention Network

KEYWORDS

pressure injury, prevalence, risk factor, survey

ABSTRACT

Objective

A point prevalence survey was conducted across Western Australia to monitor adherence to national safety and quality health service standards, and to create baseline data on which to improve. The study identified significant areas for targeted interventions.

Design

A state-wide point prevalence survey of patients and their medical records.

Setting

Public hospitals in Western Australia (WA).

Subjects

Data was collected from 2,281 inpatients.

Main outcome measure(s)

The aim of the study was to determine pressure injury prevalence and characteristics, adherence to guidelines, significant related factors and their attributable burdens.

Results

8.7% of patients had pressure injuries. 6.3% were hospital-acquired (HAPIs). Over 1,000 HAPIs per year were attributed to being older, a long-term patient, having acute renal failure or volume depletion. 65% of patients had a skin inspection; less likely in birthing mothers and long-term patients. 70% of patients were screened with a risk assessment tool. 36% of patients were identified as at risk of a pressure injury; and of these, 71% had prevention plans in place. One third of all adults with HAPIs were not identified as at risk using current practices.

Conclusion

The prevalence and characteristics of pressure injuries and HAPIs was comparable with prior state-wide results. The survey identified variations in rates of: skin inspections, using risk assessment tools; and applying plans for those at risk of pressure injuries. Multivariable logistic regression identified areas for improvement: the main groups at risk of pressure injuries; and patient groups with lower rates of skin inspections and screening.

INTRODUCTION

Pressure injuries are frequent and largely preventable injuries of the skin and subcutaneous tissue that increase morbidity and mortality (National Pressure Ulcer Panel et al 2014). Pressure injuries significantly reduce quality of life, increase length of stay in hospital and cost approximately 1.9% of all public hospital expenditure (Nguyen et al 2015). There has been substantial research to support improved clinical practice to ameliorate pressure injuries, such as the development of the International Prevention and Treatment of Pressure Ulcers: Clinical Practice Guidelines.

The Australian Commission on Safety and Quality in Health Care (ACSQHC) introduced National Safety and Quality Health Service Standards and include guidelines to prevent and manage pressure injuries (ACSQHC 2012). In relation to these standards, a multi-focused point prevalence survey was conducted to assess the current situation in Western Australia (WA). Prior surveys had been conducted and the rate of HAPIs in 2011 was 6.3%, a 17% increase since 2009 (Mulligan et al 2011). Subsequently, state-wide pressure injury prevention strategies were implemented and this current survey would determine rates, proportion related to medical devices, and using multivariable logistic regression determine factors associated with HAPIs and gaps in screening.

The aim of the study was to determine the prevalence and characteristics of pressure injuries and to use logistic regression to determine significant factors associated with HAPIs and adherence to guidelines, in order to identify areas where improvements can be made.

METHOD

Participation

Hospitals were included in the audit if they had at least 40 acute and/or subacute beds and admitted public patients. Accordingly, 14 metropolitan and 6 regional hospitals throughout the state were included in the study. Participants included multiday-stay public in-patients from acute and subacute wards in the hospitals on survey days in May 2014. Exclusions: dialysis patients, mental health wards, unqualified newborns, hospital in the home, and day surgery/procedure patients.

Ethics approval: The study attained ethical approval from the Department of Health Human Research Ethics Committee (#12/2014).

Audit tool and data collection

The project methodology was built on previous wound prevalence surveys (Mulligan et al 2011; Prentice et al 2009). Qualitative and quantitative data were collected by over 400 surveyors who attended educational sessions and passed a competency test. Each audit was conducted by a hospital-based clinician with an external surveyor.

Survey teams examined medical records for each patient. In addition, a full body skin inspection was conducted on consenting patients. The pressure injury audit tool consisted of the following elements:

- 1. The presence and details of pre-existing and hospital-acquired pressure injuries from the medical records and/or on inspection of the participants' skin.
- 2. Determination of whether patients had a skin inspection for pressure injuries within 8 hours of presentation.
- 3. Documented use of a validated pressure injury risk assessment tool (Braden scale©, Braden Q or Western Australian Health Glamorgan Pressure Injury Tool) within 8 hours of presentation.

- 4. If at risk, whether preventative measures and a management plan had been implemented.
- 5. Whether the patient/carers had been involved in pressure injury prevention or management discussions.
- 6. If the patient had one or more pressure injuries the following were recorded:
 - a. location of the pressure injury(s)
 - b. whether it was hospital acquired or present on admission
 - c. whether it was medical device related
 - d. classification by stage
 - e. if preventative equipment was in place
 - f. if a management plan was in place.

Data analysis

Data analysis included testing the statistical significance of differences between groups using the Pearson's Chi-squared test for categorical data. Data was supplemented using data linkage to extract previous diagnoses and admissions, and the Australian Bureau of Statistics data on socio-economic status and hospital accessibility. Univariable and multivariable logistic regression models were fitted to test for significantly different outcome percentages between hospitals and patient characteristics. Odds rations (ORs) were obtained from the models to compare outcomes against the reference hospital (hospital 11 – with the largest group of audited patients). Attributable burden was calculated for an annual basis to estimate the number of patients potentially affected by any significant factors.

FINDINGS

Participants

Of the 3,181 patients who were hospitalised on the day of the pressure injury audits, 2,288 consented to having a skin inspection (table 1). Data for seven patients was missing, leaving a final cohort of 2,281 patients (71.7%). Paediatric patients were significantly less likely to consent to a skin inspection than adults, OR=0.5 (95% CI: 0.4-0.8).

Slightly more females (52%) than males (47.8%) participated in the audit, and just under half of all participants were aged 65 years or older (49%). The majority of hospitals were from the Perth metropolitan area (14 of 20 hospitals), which also comprised 91% of the final patient cohort.

Pressure injuries

Overall, 8.7% of patients (207 patients) were identified as having at least one pre-existing or hospital-acquired pressure injury (HAPI).

6.3% (142) of patients had one or more HAPIs (table 2). The prevalence of HAPIs ranged from 0-11% across the 20 hospitals. Nearly three quarters of patients (73%) had only one HAPI, with a further 17% (25 patients) having two pressure injuries and 9% (13 patients) having three pressure injuries.

The frequency of having at least one HAPI was approximately three times greater for older adults compared with young adults and adults, and five times greater than for children.

Table 1: Patient and hospital characteristics, point prevalence survey

Patient demographics	patients	%
Total number of patients admitted on survey day	3,181	100.0
Patients consenting to having a skin inspection	2,288	71.9
Sex		
Female	1,191	52.2
Male	1,090	47.8
Age group		
Child (0 to 15yrs)	214	9.4
Young adult (16 to 24yrs)	120	5.3
Adult (25-64yrs)	825	36.2
Older adult (65yrs and over)	1,122	49.2
Total	2,281	100.0
Hospital location		
Metropolitan hospitals (14)	2,073	90.9
Regional hospitals (6)	208	9.1
Total	2,281	100.0

Table 2: Characteristics of pressure injuries, point prevalence survey

Characteristics	Number of patients	Percentage of patients
Pressure injuries		
Patient does not have a PI	2,074	91.3
Patient has one or more PIs	198	8.7
Patient has one or more HAPIs	142	6.3
HAPIs by age group		
Child (0 to 15 years)	4	1.9
Young adult (16 to 24 years)	4	3.4
Adult (25 to 64 years)	28	3.4
Older adult (65 years and over)	106	9.9
Hospital location of patients with HAPI		
Metropolitan	131	6.5
Country	11	5.4
Number of HAPIs		
Patients with one	104	73.2
Patients with two	25	17.6
Patients with three	13	9.2
Three most common locations		
Sacrum	43	24.9
Buttock	21	12.1
Heel	21	12.1
Risk assessment for pressure injuries		
Skin inspection undertaken within 8 hours of presentation	1,483	65.2
Screened with a risk assessment tool within 8 hours of presentation	1,596	70.3
Identified as at risk of developing a pressure injury	711	36.6
If at risk, management plan in place (N=711)	507	71.3
If at risk, patients (or carer) input into a management plan (N=711)	310	44.3
Medical device related pressure injury	49	18

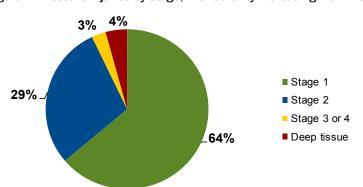


Figure 1: Pressure injuries by stage, with severity increasing from 1 to 4, or deep tissue.

HAPIs were staged using the National Pressure Ulcer Advisory Panel (2016) pressure injury definitions. The majority of HAPIs were assessed as stage 1 (64%) or stage 2 (29%), 3% were stage 3 or 4, and a further 4% were suspected deep tissue pressure injuries (no HAPIs were unstageable pressure injuries) (figure 1).

The percentage of patients with at least one HAPI was significantly higher than the average percentage of HAPIs found within this survey in two distinct populations: older adults (9.9%) and in patients with a stay of six or more days (9.9%).

Conversely, the percentage of patients with at least one HAPI was significantly lower than the percentage of HAPIs found within this survey in the adult population (3.4%); paediatrics (1.9%); and patients with a length of stay between zero and five days (3.5%).

Using a multivariable logistic model of the probability of a patient having at least one HAPI, older adult patients were significantly more likely to have at least one HAPI than adults, OR = 2.4 (95% confidence interval, CI: 1.5-3.7). Similarly, patients with a stay of six or more days were significantly more likely to have at least one HAPI than patients with a stay of between zero and five days, OR = 2.2 (CI: 1.5-3.2). Patients with an additional diagnosis of acute renal failure were significantly more likely to have at least one HAPI than patients without that diagnosis, OR = 2.6 (CI: 1.7-4.2), and similarly for patients with an additional diagnosis of volume depletion, OR = 2.5 (CI: 1.5-4.1).

The estimated burden attributable for each significant risk factor was calculated (table 3). The table shows the estimated annual change in the number of individuals with at least one HAPI when the risk factor is absent from the population. For example, the presence of at least one HAPI among an estimated 1,505 individuals each year can be attributed to being an older adult (>65yrs) as opposed to being adult (25-64yrs). This corresponds to 5% (3-8%) of the estimated annual number of older adult hospitalisations in all WA hospitals examined.

Table 3: Multivariate logistic model of the probability of a patient having at least one HAPI and the estimated attributable burden if applied to the annual number of patients in Western Australia.

Patient Characteristic	Reference Group	Adjusted OR (LCI, UCI)	Change in the number of patients with the outcome (LCI, UCI)	Annual change in the number of patients with the outcome (LCI, UCI)	Annual change as a percentage of the estimated annual number of patients with the risk factor (LCI, UCI)
Older adults	Adults	2.4 (1.6, 3.7)	-58 (-84, -29)	-1505 (-2186, -761)	-5 (-8, -3)
Stay 6+ days	Stay 0-5 days	2.2 (1.5, 3.2)	-48 (-69, -26)	-752 (-1076, -405)	-5 (-8, -3)
Acute renal failure	-	2.6 (1.7, 4.2)	-20 (-31, -10)	-369 (-565, -180)	-11 (-18, -6)
Volume depletion	-	2.5 (1.5, 4.1)	-14 (-23, -5)	-277 (-457, -101)	-10 (-17, -4)

In addition, 18% (49) of pressure injuries were identified as medical device related and the cases were distributed across most hospitals.

Prevention strategies were in place for the majority of patients, with bed and/or chair support surfaces to prevent pressure injuries in use, and over 400 adjunct devices in use, such as limb elevator or foam wedges.

Risk Assessment

The audit identified differences in patient care processes across the hospitals.

Documented evidence of a full body skin inspection within 8 hours of presentation (65%).

A larger proportion of patients from metropolitan (65.9%) than regional (58.5%) WA hospitals had the evidence of a skin inspection within 8 hours of presentation (p=0.03). At the individual hospital level, rates of assessment ranged from 38.8% to 90% (p<0.01). A multivariable logistic regression model of the probability of having documented evidence of an initial skin inspection was fitted. This identified that patients staying over 6 days and adults having single, live births, were significantly less likely to have documented evidence of an initial skin inspection. The attributable burden of these factors is estimated in table 4.

Table 4: Multivariable logistic model of the probability of a patient having documented evidence of a skin inspection conducted within 8 hours of presentation. Odds ratios and 95% confidence intervals.

Patient Characteristic	Reference Group	Adjusted Odds ratio (OR) and confidence intervals	Estimated annual change in the number of patients with the outcome	Estimated annual change in the number of patients with the outcome	Estimated annual change as a percentage of the estimated annual number of patients with the risk factor
Length of stay: 6+ days	LCA 0-5 days	0.6 (0.5-0.7)	99 (58-142)	1562 (914-2228)	8 (5-12)
Additional diagnosis: adults with single live birth	-	0.1 (0.07-0.16)	87 (74-100)	6691 (5685-7666)	47 (40-54)

Patients with documented use of pressure injury risk assessment tool within 8 hours of presentation.

Use of a pressure injury assessment tool within 8 hours of presentation was documented for 70% of patients (Table 2), ranging from 42% to 95% across the 20 hospitals, (p<0.01). Risk assessments were conducted on a larger proportion of males (73%) than females (67.8%), p=0.01. In addition, larger proportions of adults (67.4%) and older adults (76.9%), were assessed compared with children and young adults (both 55%), p<0.01.

Patients identified as at risk of developing a pressure injury

Of the 1,945 patients who were risk assessed for pressure injuries, 36.6% were found to be at risk of developing a pressure injury. Almost half of children (49.6%) and older adults (45.5%) assessed were identified as being at risk, compared with one fifth of young adults (19.8%) and one quarter of adults (22.8%). There was significant variation at the hospital level with proportions of at risk patients ranging from 10% to 61.4% (p<0.01).

All children and young adults who had one or more HAPIs were identified as being at risk, while only two thirds of adults (62.5%) and older adults (66.4%) with HAPI's were identified as at risk.

The majority of patients (92%) were assessed with the Braden scale. To determine the accuracy in this population the prediction values were calculated (table 5). Screening sensitivity was 63.4% for patients aged 65 years and over compared with 100% for patients aged 16 to 24 years.

Table 5: HAPI prevalence and respective prediction of pressure injuries using the Braden Scale.

Age groups	patients screened	HAPIs	Rate	Sens 1	Spec 2	PPV 3	NPV 4
Young adults (16 to 24 yrs)	70	3	4.3	100.0	82.1	20.0	100.0
Adults (25 to 64 yrs)	574	21	3.7	66.7	78.3	10.4	98.4
Older adults (65 yrs and over)	798	71	8.9	63.4	94.3	13.2	94.3
All ages 16 yrs and over	1442	95	6.6	65.3	68.2	12.6	96.5

Sensitivity, 2. Specificity, 3. Positive predictive value, 4. Negative predictive value

Patients identified as at risk who have a pressure injury prevention and management plan insitu

Over two thirds (71.3%) of patients who were deemed at risk of developing a pressure injury had a bedside pressure injury management plan. The proportions of at risk patients who had a plan did not differ significantly by age, sex or hospital location (metropolitan or regional). At the individual hospital level, the rates of at risk patients who had a bedside plan ranged from 54% to 100%.

Limitations of the study include: data was collected from a large number of surveyors recruited across WA Health with varying levels of clinical and audit experience; the preventative strategies which were in place for pressure areas were reviewed on management plans but not necessarily viewed in practice at the time of the survey. To mitigate this a number of data verification steps were applied both on the day and during the data entry, including entries being double checked.

DISCUSSION

Early last decade, prevalence estimates for pressure injuries for in-patients in acute and subacute health care facilities in Australia ranged from 5.6-48.4% (mean 25.5%) and 29-38.5% in New Zealand (Australian Wound Management Association 2012). In 2003, Victoria reported a state-wide prevalence of 26.5%, of which two thirds were HAPIs. Following the introduction of a number of interventions the prevalence of pressure injuries declined to 17.6% (Victoria Health 2006). The prevalence of HAPIs in Queensland subsequently declined from 12.4% (2008) to 4% (2012) (Miles et al 2013).

This surveys rates for HAPIs (6.3%) remains unchanged from a previous survey in 2011 (Mulligan et al 2011). The survey had identified a 17.5% increase in the prevalence of HAPIs compared with 2009. State-wide prevention and management strategies were subsequently implemented in accordance with the national standards. This surveys prevalence of HAPI was slightly above New South Wales rates (2015: 6% and 2016: 5.3%), and over two times higher than for Queensland (2014: 3%) (Coyer et al 2017; Clinical Excellence Commission 2016; Clinical Excellence Commission 2015).

Jull et al (2016) reported an average prevalence rate of 6.3% for HAPIs over a three-year period between 2012-13 and 2014-15 in New Zealand. Over 97% of their patients were reported to have stage 1 or 2 HAPIs, which is higher than in this survey (93%).

This survey found that HAPIs were significantly higher amongst adults aged 65 years and older and longer stay patients; this would be consistent with decreased mobility associated with advanced age and extended bed rest (Rondinelli et al 2018; Coleman et al 2013). The main sites of pressure injuries were consistent with the most frequent sites reported in the literature. With the use of logistic regression to identify key risk factors

patients with additional diagnoses of either acute renal failure or volume depletion were also significantly more likely to have pressure injuries. Impaired renal function is associated with poor wound healing and comorbidities increasing the risk of pressure injuries, and volume depletion also reduces skin turgor (Maroz and Simman 2013). This identifies a group of patients whom it may be important to ensure pressure injury strategies are in place. Table 3 estimates the attributable burden of each significant risk factor for pressure injuries. By identifying the factors with high numbers of patients affected, interventions can be focused to potentially prevent hundreds of pressure injuries.

In addition, increased focus on prevention in patients with medical devices is required. 18% (49) of the pressure injuries were identified as being medical device related. This is within the range from published studies of 12%-35% (Dyer 2015; Black et al 2010), in which medical device related pressure injuries are not always considered as preventable. Whilst the risk factors for developing a medical device related pressure injuries are the same as for traditional pressure injuries, medical devices increase the risk of a pressure injury by more than 2.4 times (Black et al 2010) and develop faster than traditional pressure injuries - often on the face and head region, linked with tubing and masks (Kayser et al 2018).

The literature identifies the value of early assessment and prevention (National Pressure Ulcer Panel 2014). This current survey highlighted variations in rates of skin inspections and the use of a pressure injury risk assessment tool within the first 8 hours of presentation. Documented skin inspection rates by hospital ranged from 38 to 90%, and the use of a risk assessment tool ranged from 42 to 95% by hospital. Long-term patients were significantly less likely to have a documented initial skin inspection. The reason for this could not be identified, and needs further investigation.

The odds ratio of a patient having documented evidence of an initial skin inspection were almost ten times lower for birthing mothers. Both groups are at risk of pressure injuries due to reduced mobility and the use of anaesthesia in some birthing mothers (Milne et al 2009; Prior 2002).

This audit identified gaps in practices: just over two thirds of patients (70.3%) were reviewed with a pressure injury risk assessment tool within 8 hours of presentation; and of those identified at risk, 71.3% had a pressure injury management plan in place. In comparison, in New South Wales only 58% of patients had a risk assessment within 8 hours of presentation to a hospital or community nursing service and 44% of patients with a pressure injury were reported to have a wound management plan (Clinical Excellence Commission 2015). This wide variation in rates between hospitals for all of the measures highlights hospital wide differences in adherence to best practice.

The main risk assessment tool used (92.3%) was the Braden Scale for predicting pressure injuries. 36% of patients were identified as at risk. This is considerably different to surveys across New South Wales, with rates of 65% (Clinical Excellence Commission 2016; Clinical Excellence Commission 2015). The Braden scale in this audit was found to have 65% sensitivity, in contrast to other studies with 83% (Chen et al 2017). Only two thirds of adults (62.5%) and older adults (66.4%) with HAPI's were identified as at risk, therefore, one third of adults who develop pressure injuries are not being detected with current screening tools in this population. This may relate to either the tool or its application, or a combination of these factors.

CONCLUSION

The overall prevalence of pressure injuries and HAPIs for WA was comparable to previous state surveys and higher than published for other Australian states. The analysis of compliance with the national standards revealed variability in clinical practice across the 20 hospitals. Significantly higher rates of pressure injuries were found in: the elderly; long-term patients; patients with acute renal failure; or volume depletion.

The audit findings also showed that although pressure injury risk assessment tools were being used, the outcome of these assessments was not always being translated into management plans. Subsequently, the importance of ensuring that high risk groups are reviewed, processes support expertise in the application of skin assessments, is vital to reduce preventable HAPIs.

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Side effects of chemotherapy in children with cancer: effects of nursing training administered to caregivers

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KEY WORDS

caregiver, chemotherapy, child, education, nurse

ABSTRACT

Objective

The present study aimed to assess the consequences of providing nursing training to caregivers of children with cancer on the side effects associated with chemotherapy.

Design

The present study used a pre-test-post-test experimental design.

Setting

The study was conducted in a paediatric hematological oncology hospital in Ankara, Turkey

Subiects

This study was conducted with 40 caregivers responsible for looking after child patients, all of which had been recently diagnosed with cancer, but who had not started chemotherapy.

Primary argument

The knowledge scores of the caregivers on issues related to infection and bleeding risk, nutrition and oral care and total scores were significantly higher than their pre-test scores before undergoing training (p<0.05).

Conclusion

Planned training on the problems that may arise due to the side effects of chemotherapy was found to be effective in increasing the knowledge level of caregivers. The authors suggest that training in this subject should be provided before initiating a chemotherapy program, before the occurrence of side effects, and visual and written materials should be used.

INTRODUCTION

Chemotherapy for the treatment of cancer is associated with a wide range of side effects (Carelle et al 2002; De Boer-Dennert et al 1997; Griffin et al 1993). A multidisciplinary approach that involves nurses and other healthcare personnel is recommended for the management of cancer treatment processes and potential complications, and the importance of the caregiver responsible for the care of the child has been emphasised (Kutulu et al 2007; Holm et al 2003).

Patients must be prepared, and training must be provided by the attending nurse before initiating a chemotherapy program (Aranda et al 2012). As caregivers bear the primary responsibility for looking after the child, they should be trained in the prevention, detection and control of side effects associated with the chemotherapy (Kutlu et al 2007). The most significant symptoms and side effects seen in cancer patients could be prevented or minimised through effective and conscious nursing interventions and training programs (Aslan et al 2006). It has, however, been reported that the requirements of the patient are not sufficiently fulfilled despite the patients and their caregivers being given training from the nurses and other healthcare personnel on the side effects of chemotherapy (Aranda et al 2012; Kutlu et al 2007). Training programs that detail the possible side effects of chemotherapy in paediatric cancer patients, as well as preventive measures, may contribute to symptom control.

METHODS

Single-group pre-test-post-test experimental design was planned between 1 December 2014 and 1 December 2015 at a paediatric hematological oncology hospital located in the city center of Ankara. This study aims to assess the consequences of providing nursing training to the caregivers of children with cancer on the side effects associated with chemotherapy.

Participants

This study was conducted after obtaining the voluntary consent of the caregivers responsible for looking after child patients, all of which had been recently diagnosed with cancer, but who had not started chemotherapy and who were not terminally ill.

Study Sample

The study sample comprised the caregivers of 60 children with cancer who were admitted to the study center for cancer therapy during the study period. Twenty caregivers were excluded from this study as they did not fall within the study limitations. Consequently, the final study sample comprised 40 caregivers.

Ethical Considerations

Before starting this study, the ethical approval (Ankara Pediatric Oncology and Hematology Training and Research Hospital: 30.03.2015/2015-007) and the informed consent of the caregivers were obtained.

Research Hypothesis

The provision of planned nursing training on the side effects of chemotherapy provided to caregivers of hospitalised children undergoing chemotherapy can be considered effective.

Limitations

Recent diagnosis of cancer, no previous chemotherapy course, the exclusion of terminally ill patients and the voluntary participation of caregivers were the limitations of this study.

Preparation of the Training Manual

The training manual was compiled into two sections. The first section provided explanations of cancer, the chemotherapy process, the side effects of the drugs and the administration of chemotherapy, and contained

a total of seven explanatory diagrams. Details were given on the risks of infection and bleeding associated with chemotherapy, nutritional principles and oral care practices, as well as important considerations, which were explained with a total of 21 explanatory diagrams. The Training Manual was printed using the Arial 14 point font, and bold text was used in key sections to attract attention. The text was supported by explanatory color diagrams. The manual comprised 24 pages of A3-sized paper.

Provision of Training

Training was provided during a single-session face-to-face interview that lasted for 50-60 minutes in a separate room at the clinic, two weeks before the initiation of chemotherapy. Only one caregiver underwent training on a single day.

Before beginning the training session, the training manual was explained and handed to the caregiver for review. Each component of the training was explained practically (using an oral care set, port reservoir, port needle), and the caregiver participated actively in the hands-on training.

Data Collection

Data and sociodemographic characteristics were collected using a caregiver interview questionnaire that contained 52 closed-end questions related to chemotherapy, infection risk, bleeding risk, nutrition and oral care. The pre-test was performed immediately before the training session, and the post-test was performed one month after the training of the relevant caregiver, using a caregiver interview questionnaire. Before starting this study, a preliminary study was conducted with five caregivers with similar characteristics to the study group.

Data Analysis

The statistical analysis included mean, number, percentage, Kruskal Wallis test, Wilcoxon test and in paired comparisons. A Bonferroni test was used with median (interquartile range: IQR), minimum and maximum values, and the level of statistical significance was set at p<0.05 (IBM SPSS Statistics 21.0 [IBM Corp. Released 2012. IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY: IBM Corp.] and MS-Excel 2007).

Expected and correct responses given by the caregivers before and after training were coded as 2.5 points, and incorrect and irrelevant responses were coded as 0 points, and a knowledge score was then calculated for each caregiver from the results. The significance of the difference in knowledge scores before and after training was evaluated.

RESULTS

Of the children with cancer, 52.5% were male, 40% were aged 1-5 years, 27.5% were aged 6-10 years, 22.5% were aged 11-15 years, and 10% were aged 16-17 years; 37.5% had AML, 27.5% had ALL, 25% had CML, and 10% had neuroblastoma radiocarcinoma.

All caregivers were female, 32.5% were aged 25–30 years, 47.5% were aged 31–36 years, and 20% were aged 37 years and older; 72.5% were primary school graduates, 20% were high school graduates, and 7.5% were undergraduate or postgraduate students; 85% were housewives, 15% were employed, 95% were the patients mother, 5% were the patients sister, and 15% had another family member with cancer (table 1).

Table 1: Sociodemografic features of caregivers and children with cancer (n=40)

CAREGIVER	n	%
Age		
25-30	13	32.5
31-36	19	47.5
25-30	13	32.5
37 and upper	8	20.0
Education		
Primary school	29	72.5
High school	8	20
Undergraduate	2	5.0
Postgraduate	1	2.5
Profession		
Employed	6	15.0
Housewives	34	85.0
Relationship to child		
Mother	38	95.0
Elder sister	2	5.0
CHILDREN WITH CANCER		
Gender		
Female	19	47.5
Male	21	52.5
Age		
1-5	16	40.0
6-10	11	27.5
11-15	9	22.5
16 -17	4	10.0
Diagnosis		
ALL	11	27.5
AML	15	37.5
CML	10	25.0
Neuroblastoma, radiocarcinoma	4	10.0

The knowledge scores of the caregivers on issues related to infection and bleeding risk, nutrition and oral care and total scores were significantly higher than their pre-test scores before undergoing training (p<0.05) (table 2).

Table 2: The correct answers and knowledge scores of caregivers after and before education (n=40)

Education subjects	Before education		After education		
	Correct answer (n)	Score	Correct answer (n)	Score	
Infection Risk					
Using mask	40	100	40	100	
Ventilation of room	39	97.5	40	100	
Taking baths every other day	34	85	40	100	
Changing the bed linen	27	67.5	40	100	
Separating personal items	26	65	40	100	
Bathroom / toilet cleaning	26	65	40	100	
Ironing of clothes	17	42.5	40	100	
Reporting of IV/port catheter changes	26	65	40	100	
Hand washing	25	62.5	40	100	
Proper hand washing	26	65	39	97.5	
Do not enter other patient rooms	32	32	39	97.5	
Do not accept visitors	23	23	39	97.5	
Choosing the right toy	8	20	39	97.5	
Chaning clothes when return from outside the hospital	25	15	36	90	
Total		805		1380	
Bleeding risk					
Do not bath glove	22	55	40	100	
Using moisturizer after bathing	20	50	40	100	
Daily gaita follow-up	24	60	40	100	
Keeping the bed locked	22	55	40	100	
Do not toothbrush	14	35	39	97.5	
Report changes in the body (bruise, redness, etc.)	24	60	39	97.5	
Do not give foods that can cause oral irritation	20	50	38	95	
Report blood presence in urine / stool	20	50	38	95	
Observing changes in the anal region	21	52.5	37	92.5	
Learning thrombocyte value before procedures that can disrupt skin integrity	16	40	35	87.5	
Total		507.5		965	
Nutrition					
Reporting when undernutrition	18	45	40	100	
Often and often, little by little eating	19	47.5	39	97.5	
Reporting factors influencing eating	23	57.5	39	97.5	
Report diarrhea / constipation	22	55	39	97.5	
Consumption of plenty of water	9	22.5	39	97.5	
Fruit washing right	5	12.5	39	97.5	
Fruit-feeding with the knowledge of the health team	2	5	38	95	
Do not buy ready food	18	45	36	90	
Total		290		772.5	

Oral care				
Observation of mouth and oral mucosa	1	2.5	40	100
Time for oral care	1	2.5	39	97.5
Swallowing the fungostat while oral care	2	5.0	39	97.5
Making oral care within half an hour after eating	1	2.5	39	97.5
Using mouthwash in oral care	0	0.0	38	95
Make the mouthwash for 30 seconds	1	2.5	38	95
Do not give food / drink for 30 minutes after oral	0	0.0	37	92.5
care				
Reporting when oral care can not be done	0	0.0	35	87.5
Total		15		762.5
FINAL TOTAL		1617.5		3880

Table 3: The knowledge scores of the caregivers about infection risk, bleeding risk, nutrition and oral care before and after education.

Education subjects	Median score			Test	
	Before education	After education	Z*	р	
Infection Risk	23.7 (7.5)	35.0 (7.5)	5.182	0.001	
Bleeding Risk	12.5 (10.0)	25.0 (7.5)	5.385	0.001	
Nutrition	7.5 (10.0)	20.0 (0.0)	5.533	0.001	
Oral care	0.0 (0.0)	20.0 (0.0)	5.785	0.001	
Total	43.7 (19.4)	100 (5.0)	5.514	0.001	

^{*} Wilcoxon test

DISCUSSION

Neutropenia is a common side effect of cancer therapy (Lustberg 2012). Compliance with hand and general hygiene principles in neutropenic areas (WHO; Gencer 2008), wearing face masks (Raad et al 2002) and providing easily disinfectable toys available in childrens rooms (Randle et al 2006) are recommended approaches to reduce infection rates. Isolation is another means of preventing infections, and has been reported to be successful in the prevention of nosocomial infections (Ostrowsky et al 2001). Invasive interventions and the presence of an indwelling IV/port catheter increase the risk of infection (Lustberg 2012) and it is important to provide training in catheter care to families (Gordon et al 2003). The rooms of patients with neutropenia must be arranged in accordance with hygiene principles, and particular measures must be put in place, such as limiting the number of visitors (Gonderen et al 2009). Providing training to caregivers in infection risks increased the level of knowledge in all sections, particularly on isolation and toy selection, and the training proved to be effective (table 1, table 2).

Chemotherapeutic drugs may predispose to bleeding by decreasing the platelet count. It was suggested that preventing the patient from engaging in activities in which there is a risk of soft tissue injury, using a soft toothbrush, avoiding the use of nail clippers and the monitoring of bleeding are recommended during periods when the patient has a low platelet count (Can 2005). The knowledge scores of the caregivers on bleeding risk increased in all training sections (table 1), and the difference between the scores before and after training was statistically significant (table 2). Findings suggest that increasing the knowledge level of caregivers on bleeding risks and prevention and protection measures may facilitate the protection of the child.

Nutritional problems may have unfavorable consequences in cancer patients (Andreyev et al 1998), and chemotherapy may affect the child's nutritional status by causing nausea, vomiting, taste changes and diarrhea (Can 2005). Furthermore, 66 % of children experience fluid volume deficit, although fluid resuscitation is important in the treatment (Gonderen et al 2009). Although no relationship has been identified between a neutropenic diet and infection (DeMille et al 2006; Wilson 2002), a neutropenic diet is administered in most hospitals when a patient is undergoing chemotherapy (Jubelirer 2011). Certain rules are applied in the center associated with the present study which the caregivers and children are asked to comply with.

A significant increase in awareness in all training sections has been noted after training, particularly on the consumption of plenty of water, washing, and eating fruit, which was relatively unknown before training (table 1). The difference between the scores before and after training were statistically significant (table 2).

Oral complications may occur in children within 1–2 weeks after initiating a chemotherapy program (Chen et al 2004). Following oral care protocols during courses of chemotherapy has been reported to reduce incidences of mucositis (McGuire et al 2006; Chen et al 2004). A daily check of the oral mucosa (Harris 1980) and oral care at night (Sweeney et al 1995) are recommended. Oral care is important for the prevention of mucositis, pain, loss of taste and difficulty in swallowing (Kıkınc 2012), however informing the caregivers about correct oral care practices is important to prevent complications, as the child will be unable to perform these activities unattended.

The knowledge level of the caregivers on oral care was low before training but showed a significant increase after training. Of all the training sections, the most remarkable increase was noted in the oral care segment. Before the training, caregivers had little knowledge about oral care solutions, the time required to avoid consumption of food/beverages after oral care and informing the healthcare team when mouth care is not performed. These were training themes, the level of knowledge was higher after the training (table 1). This was thought to be related to the chemotherapy having not commenced, and that caregivers had not performed oral care. The difference between the oral care scores before and after training was statistically significant (table 2).

The findings showed that training proved to be effective in all training subjects, and that the level of knowledge and the knowledge scores increased after training (table 1). A significant difference was noted between the scores before and after training (table 2).

CONCLUSION

Planned nursing training on the problems that may arise as side effects of chemotherapy was found to be effective in increasing the knowledge level of caregivers. The authors suggest that training in this subject should be provided before initiating a chemotherapy program, before the occurrence of side effects, and visual and written materials should be used. The knowledge levels of nurses working in paediatric oncology clinics regarding the side effects of chemotherapy should be increased, and the training should be provided by the specialist nurses.

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Exploring life history methodology in chronic illness: a study in Relapsing Remitting Multiple Sclerosis

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Acknowledgement: Therese Burke was the recipient of support through an Australian Government Research Training Program Scholarship as a PhD candidate at Notre Dame University, Australia for this research study.

KEY WORDS

Relapsing Remitting Multiple Sclerosis, chronic illness, lived experience, life history, ethnography

ABSTRACT

Objective

The aim of this study was to gain insights into the lived experience of a chronic disease, Relapsing Remitting Multiple Sclerosis (RRMS). Selecting the most effective methodology to reflect the life span proved challenging. However, the life history approach proved to be a data-rich methodology for this study and is explored in detail in this paper as a qualitative nursing tool.

Setting

This study recruited participants through a state based Multiple Sclerosis organisation in the community.

Subjects

Thirteen participants living with RRMS were purposively recruited, ten female and three male, to discuss their lived experience. Participants were from diverse backgrounds and were at various stages of disease progression.

Primary argument

Ethnography and life history is an under-utilised methodology in nursing research. However, the life history approach was used effectively to collect data to explore the life trajectory of living with a chronic illness. Semi-structured interviews and Braun and Clarke's (2006) method of thematic data analysis ensured a systematic, robust exploration of the lived experience of RRMS. The study developed eight key themes and over 70 subthemes, providing clarity into the experience of living with RRMS.

Conclusion

Employing the life history approach to living with RRMS reflected the ebbs and flows of life, themes intertwining and changing positions of importance according to life events, whether directly or indirectly related to RRMS. Life history proved to be an effective method to gain a greater understanding of chronic illness and although often overlooked in nursing research, may represent an excellent methodology choice for nurse researchers working in other areas of chronic illness.

INTRODUCTION

Multiple Sclerosis (MS) is a progressive inflammatory disease of the central nervous system (CNS) with the most common form of MS at diagnosis being RRMS, affecting 85% of people living globally with the disease (Compston and Coles 2008). Recent data from Multiple Sclerosis Research Australia (MSRA) suggests that there may be 25,600 people living in Australia with MS (MSRA 2018). RRMS is characterised by unpredictable relapses (exacerbations or attacks), which usually last several weeks before the individual returns to baseline functioning (Lublin et al 2014). There is currently no curative treatment for RRMS, although recently there have been major advances in more efficacious treatments called disease modifying therapies (DMTs) to control relapses and possibly prevent future disability (Stuve and Racke 2016). Aside from a highly variable disease state and multitude of possible neurological symptoms, MS can also cause numerous secondary and tertiary effects. Issues may develop in highly personal areas of intimacy and sexuality, mental health, relationships and employment.

Although there exists an abundance of literature examining many different aspects of MS and MS symptoms, there is a paucity of literature exploring the whole life experience of living with MS, and more specifically, RRMS. The aim of this study was to gain insights and understanding into the lived experience of RRMS, so that nurses may have a deeper understanding of the patient experience and be able to plan and adjust their nursing care accordingly. To address these specific aims, the study sought to answer the research question "What is the experience of living with Relapsing Remitting Multiple Sclerosis?"

Exploring the literature for a suitable method for data collection and later data analysis that would span as much of the life trajectory as possible proved challenging. Using a qualitative approach to understand the experience of living with RRMS would ensure the participant remained at the centre of the research process, and their lived experience the focus of the research. However, beyond that, there were very few studies (especially in recent times), which replicated methods in data collection and analysis in the speciality of MS. The aim of this paper is to explore life history as an interesting and effective methodology for qualitative nursing research in chronic illness. Full study results from the research have been published elsewhere (Burke 2019).

The study most alike the current study in terms of participant numbers and focus (Miller 1997) was published prior to any disease modifying therapies being available and reflected a completely different prognosis than in modern times. Miller's (1997) study asked 10 participants living with RRMS "What is it like for you living with RRMS?". Hermeneutic phenomenology was used to analyse the transcripts and 12 themes were developed to describe the experiences of living with RRMS including the importance of social networks, coping with RRMS, control, uncertainty and conflict. Miller's (1997) study however, only concentrated on the present time of living with their illness, not the entire life trajectory, posing questions as to whether previous life events influenced this chronic illness and vice versa.

Other studies have used various methodologies in phenomenology to explore single cases of women living with RRMS (Fawcett and Lucas 2006; Finlay 2003), or most recently a study exploring the life world of six young women living with RRMS (Beshears 2010). However, the focus of the research was centred on the present time, and no male participants were included in the studies. There was only one narrative found in the literature review for the current study which explored living with MS using a life history approach (de Chesnay et al 2008). This short narrative presented an abbreviated story to teach others about overcoming obstacles in chronic illness (de Chesnay et al 2008).

DISCUSSION

Choosing a research methodology for the current study

The research question in the current study required a methodology that would gain deep, rich insights and understanding of the experience of living with RRMS. In seeking to understand and interpret meaning within context, the study also sought to be inductive (develop findings directly from the study data) and to seek both patterns and differences in data. The individual voices were important to hear, as well as the group voice of the entire data set. Finding individual meaning and understanding in stories from patients is fundamental to the caring and compassionate culture of nursing, and something nurses strive for in daily practice (Munhall 2012). Additionally, nurses are often attracted to qualitative research as they value the richness of deep understanding and the perspective of the individual living with chronic illness. Finding a data collection method which considered the people living with RRMS as the experts (Windle 2011) was also important to consider as a component of the ontology and epistemology beliefs underpinning the current study.

Ethnography methodology

Ethnography is a research methodology which involves the process of learning about people by learning from them (Roper and Shapira 2000) and has its historical roots embedded in social and cultural anthropology (Holloway and Todres 2003). The goals of ethnography are to describe, interpret and understand characteristics of a particular social setting, taking into consideration the diversity and multiplicity of voices from key informants, the experts who have rich knowledge of the subject under research (Holloway and Todres 2003). Essentially key informants who represent the culture under study discuss their lives, so that others can better understand the culture (de Chesnay 2014). Ethnography has a place in health research, particularly with its focus on the emic, or the patient perspective (Morse 2012), being holistic, contextual and reflexive (Boyle 1994).

Ethnography takes on many forms and has been adapted for use in different settings, depending on the goals of the research. Early ethnographers spent long amounts of time in the field, known as 'fieldwork', getting to know the study participant/s and encouraging them to share their life stories, often forming personal relationships in the process (de Chesnay 2014). Often in recent times, economic and time constraints are considered to inhibit such long encounters between researchers and study participant/s, especially in the field of nursing. In keeping with the important aspects of traditional ethnography (insights, understanding and culture), focused ethnography developed, wherein researchers attempt to learn about certain conditions by asking about the experiences of those living with the condition (de Chesnay 2014; Cruz and Higginbottom 2013).

Life history as a form of focused ethnography

The life history is a "retrospective account by the individual of his or her life in whole or part, in written or oral form, that has been elicited or prompted by another person" (Watson and Watson-Franke 1985, pp.2). This involves a person choosing to tell about the life he or she has lived, told as completely and honestly as possible (Atkinson 1998). The terms life history and life story are sometimes used interchangeably (Plummer 2001), but there is a subtle difference. Life history is defined as the life account told by a person to the researcher (de Chesnay 2014) whilst life story is the narrative analysis created of the person's life from the life history told to the study researcher (Atkinson 1998). Focused ethnography, in particular life history, has recently become more popular in health research generally, as it is an effective method to gain information from a culture that may not necessarily have direct contact with one another (Morse 2012), as is often the case with people living with a chronic illness.

Life history in nursing

Life history in general is an underused methodology in nursing, but is perfectly suited to the profession, as nurses have always valued the stories and insights patients are able to provide to improve understanding of their world (de Chesnay 2014). Hagemaster (1992) advocated the use of life history in nursing research, and although still developing, more nurse researchers have used life history over the last two decades to investigate social, psychological and illness inspired phenomenon. Nursing studies using focused ethnography have been used to explore illness in homeless youth (Ensign and Bell 2004), investigate health in immigrant adolescents (Garcia and Saewyc 2007), explore recovery from eating disorders (Patching and Lawler 2009), report the experiences of community mental health nurses (Spiers and Wood 2010) and to examine the experiences of a rare chronic health condition, lymphangioleiomyomatosis (Haylen 2015; Haylen and Fisher 2014).

Given its ability to provide a comprehensive holistic examination of the subjective life experience, the life history approach was chosen as the most appropriate design for the current study, for the purpose of identifying important themes experienced by individual people living with RRMS, which may also be experienced by their peers in similar situations (Field and Morse 1985). A great advantage of life history is that it retains the whole individual story and locates it in a wider social, cultural and historical moment (Plummer 2001). Life history examines events and how they impact individuals and their life trajectory, revealing turning points, epiphanies and transformations that may occur over the course of the life living with disease (Haylen and Fisher 2014). It also provides a way of understanding the meaning of illness and how this meaning might change over time.

Using life history in researching chronic illness reflects the complexity of the human experience it is examining (de Chesnay 2014), presenting an ideal methodology to gain insights and understanding. Being less time consuming than traditional ethnography, focused ethnography in the form of life history, is more practical for most nurse researchers. However, there are challenges inherent in using this methodology, including deeply personal narratives which may affect the researcher/s emotionally, and the fact that the interviews and follow-up can be time consuming and prolonged.

Conceptualising life history in the current study

As suggested by de Chesnay and Fisher (2014), the purpose of the life history is to collect a focused history around a disease to document the story of each participant, but being careful not to frame this within a broader ethnography of all people living with a disease. The life history approach in the current study reflected the cultural and social contexts of each participant, allowing them to approach their life history in any way they chose, not necessarily in chronological order or centred only on their RRMS diagnosis. Interestingly, many participants talked of other events in their lives being just as pivotal or more so, than their RRMS illness diagnosis. Others revealed life events and happenings which later played a significant part in coping with their chronic illness.

In life history, the researcher and the participant come together as collaborators, composing and constructing a story (Atkinson, 1998). This was consistent with the ontology and epistemology of the current study with a strong focus on the emic (patient) perspective. Fostering a good relationship between the researcher and study participant is important in life history research, as it involves establishing a close relationship between the two (Plummer 2001). Developing a trusting environment and good rapport early in the process is essential to a successful study outcome.

Life history and study methods

Study participants were purposively recruited through a local, state based MS organisation using a flyer to contact the researcher if people living with RRMS were interested in participating in the study. Fourteen people expressed interest and requested further information, thirteen people were subsequently enrolled into the study and interviewed, and one person declined further involvement without giving a reason. Study recruitment followed the natural preponderance of RRMS, with ten females and three males agreeing to be interviewed. Participants were asked to choose a pseudonym for the study process to protect their identity and any potentially identifiable information (about significant others and health care professionals) was removed from the study transcripts. Approval for the research was obtained from the University of Notre Dame Human Research Ethics Committee (reference number 016002) with particular attention to participant confidentiality and managing potential distress to participants recalling past life events.

Semi-structured interviews have the purpose of obtaining descriptions of the life world of the participant with respect to interpreting the meaning of the described phenomena (Kvale and Brinkmann 2007), making it especially suited to life history research. Semi-structured interviews have some pre-defined questions built-in to the interview, however the researcher is also permitted to probe further and ask additional questions as the participant responds, often leading to the collection of powerful data in the form of insights, experiences and perceptions (Peters and Halcomb 2015). Semi-structured interviews were the chosen data collection method for the life history approach, performed in person and individually, with just the researcher and study participant present.

Interviews were performed at a location of the participant's choosing, and mostly occurred in the home of the participant and less commonly in a public location such as a park or café. At the commencement of the interview, participants were provided with a verbal overview of the study, outlining the study aims. Each participant was then invited to tell their life history, in any order they wished, and covering anything they wished to, with particular thought to the question "What is the experience of living with RRMS?". This consistent approach ensured the information gathered was rich and participant centred. Although predominately unstructured in nature, the interviews were categorized as semi-structured for two reasons. Firstly, reflection questions were provided to study participants a week prior to the interview to give some direction to the information that was sought. Secondly, the RRMS component of the research question gave particular direction about the topic to be explored as part of the interview.

Reflexivity in the study as a component of ethnography

Reflexivity fits into the wider perspective of ontology and epistemology (Berger 2015) examining the role of the researcher in the generation and construction of knowledge and assisting the researcher to act without bias (Holloway and Galvin 2016). Unlike quantitative research where an objective stance is necessary, in qualitative research the active role of the researcher is valued and appreciated as an important research tool (Braun and Clarke 2013). However, it is important that the researcher makes visible personal reflexivity as a form of quality control within the research (Braun and Clarke 2013), where the aim is for "empathic neutrality" (Ormston et al 2014).

The majority of study participants had been cared for by an MS Nurse as part of their life journey with RRMS, with the MS Nurse valued by participants for their skills, knowledge and support. Belonging to the 'MS Nurse club' most likely held some definite benefits for the principal researcher in terms of rapport and trust, gaining instant entry into their life-world. Participants felt comfortable to discuss any issue they wished disclosing insights into sensitive issues, such as parenting, sexuality, relationships, hopelessness, mental health, compromised care and fear. This enabled new understanding into living with RRMS and exposure of concepts

that have been reported infrequently, or have not been reported at all in the specialty. Additionally, having an understanding of the symptoms of MS (particularly participant fatigue) helped to manage the interviews by organising breaks and rest when necessary.

At times, the life history interviews contained highly emotive content and there was difficulty for the principal researcher to disengage from the data, with vulnerable feelings surfacing as interview transcripts were re-listened to and re-read many times as the thematic analysis progressed. Several of the interviews were emotionally intense, some participants had suffered neglected childhoods or had been subjected to tragedy, and others suffered mistreatment by health professionals. Constantly re-living these discussions to develop codes and themes often invoked sad and heart-rending emotions for the researchers. However, an earlier article by Tanner (2009) exploring experiences listening to sad situations during qualitative doctoral work proved very helpful in facilitating an effective mental health plan for the study researchers during this process.

Life history and the study findings

As a chronic illness, the life journey of RRMS takes many twists and turns; it is never a linear journey, but rather one of continual flux, which is mainly due to the innate unpredictability and uncertainty that comes with the diagnosis of RRMS. This is also the case for many other forms of chronic illness. The great advantage of using the life history approach is that it reflects the entire life journey; with and without disease. Using this process uncovered many aspects of each participant's life, which may have had an impact on their later journey with RRMS. In particular, many participants described events in childhood, which gave rise to their later development of resilience, such as childhood neglect, other illness and migration from non-English speaking countries. This resilience was then helpful to the study participants in later life, drawing on coping skills to help them through the difficult and challenging times of RRMS. The process of telling the life history to the researcher also helped participants to understand themselves in a different way, with many participants openly recognising their achievements in overcoming difficulty and challenge.

Study themes were developed from the data, with eight key themes telling the story of living with RRMS as a chronic illness over the life span. Commencing with "Piecing Together the Puzzle" of symptoms at the beginning of the RRMS journey in the years prior to and during diagnosis, followed by "(Re)defining ME now that I have RRMS" and coping with the diagnosis, "Battling the Demons" that followed diagnosis, relapses and symptoms, for some the experiences of "Surplus Suffering" from others, and negotiating "High (In) visibility" of the symptoms. Eventually study participants were able to gain control by "Taming the Beast", learning "The DMT Dance" managing their medications and side effects, and ultimately "Holding Hands with Hope", expressing hope and practising purposeful positivity. Although presented theme by theme in a logical succession, the study findings did not always follow in sequence and definitely did not always "end up" with hope and positivity. Instead, the eight key themes intermingled with each other to reflect the ebb and flow of life. They tell the story of possible stops along the life journey of RRMS and the constant moving backwards and forwards when negotiating and managing living with a chronic illness. Nurses involved in all areas of nursing care from community, surgical care, other medical specialities, emergency, midwifery and mental health may encounter patients living with MS and benefit from insights into understanding the journey of patients to plan care which is patient centred, individualised and holistic. Specific clinical recommendations have been published elsewhere to comprehensively address specific areas of care (Burke 2019). The nurse can also experience greater job satisfaction and fulfilment with a deeper understanding and insight into illness.

As noted life history author Plummer (2001, pp.7) reflects, "life is in fluctual praxis, always in flow and ever messy." Using ethnographic methodology, and the life history method in particular, to uncover the study themes worked skilfully with the "messy" life trajectory of RRMS, a chronic but unpredictable disease. Additionally,

the inclusion of subthemes in the data analysis gave the added ability to "drill down" even further into each theme, identifying more specific features of a theme under the same central organising concept, but with subtle differences. This helped to give the study findings more structure and subsequently guided the development of recommendations for clinical practice (Burke 2019).

CONCLUSION

Using life history methodology to explore the lived experience of a chronic illness gave this study much more emotion and insight than would have been achieved by simply asking pre-determined interview questions in a structured format, or by presenting participants with a survey or questionnaire of topics that the researchers felt were important. Instead, life histories flowed naturally for the study participants, forming stories and presenting an abundance and wide range of themes.

Life history gives voice to the ordinary members of a culture as they cope on a daily basis with the joys and challenges of life (de Chesnay and Fisher 2014), and was embraced by thirteen participants living with RRMS in the current study. The use of this focused ethnographic methodology worked cleverly with the ebbs and flows of living with a chronic illness, to reveal many themes and subthemes exploring the lived experience of RRMS. As RRMS is most commonly diagnosed in young adults, it represents a long period of time to live with a chronic illness. Using the life history approach generated rich and detailed data about the experiences of living with RRMS and unearthed some extraordinary insights, which subsequently led to the development of clinical recommendations for nursing practice. This under-used ethnographic methodology could be very useful to consider in other nursing studies researching chronic illness in the future.

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