



Advancing the Science and Practice of Nursing

A collection of articles by Fellows of the Royal College of Nursing (UK) to celebrate the International Year of the Nurse and the Midwife 2020

NursingStandard

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One article, An enduring legacy: contributions of Royal College of Nursing Fellows to nursing science by Benton, Tierney, Watson and McCourt, has been subject to double-blind peer review

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Introduction

by Alison Tierney, Roger Watson, David Benton, Daniel Kelly, Michael Brown and Kath McCourt

The Royal College of Nursing (RCN) confers its highest award – a Fellowship – in recognition of exceptional commitment to advancing the science and practice of nursing and the improvement of health and patient care. The scheme was introduced in 1976 in the RCN's 60th year.

RCN Fellows can be practitioners, researchers, educationalists and leaders and they represent all sectors and levels of the profession, and all four countries of the UK.

Honorary Fellowships are also awarded. These are for nurses who are registered outside the UK or people who are not nurses, but who also have made a significant impact on nursing or health care. The full Fellowship is for members of the RCN who are registered nurses in the UK. A small number of Fellowships are awarded each year by a process of nomination and election. Including the awards announced in 2020, there are now 206 Fellows and 46 Honorary Fellows on the Roll of Honour.

Individually, RCN Fellows make ongoing contributions of various kinds to support the professional agenda of the College. The Fellows Coordinating Committee, currently chaired by Kath McCourt (FRCN 2008), is

the decision-making body for the group and it organises activities for the Fellows, including an annual meeting at RCN HQ in London.

However, for the wider College membership and the profession at large, the collective contribution of RCN Fellows to the advancement of nursing science and practice is not well known. So, as a way of celebrating the designation by the World Health Organization (WHO) of 2020 as The International Year of the Nurse and the Midwife, the Fellows Group has produced this collection of articles to illustrate some of their work. The articles highlight some of the many changes and achievements in nursing over the past 50 years.

Exemplary research and scholarship

The impetus for this project came from Jane Ball (FRCN 2019) at the annual meeting in November 2019 when the Fellows Group discussed what it might do to mark the year 2020. Jane suggested we should publicise the exemplary research and scholarship that can lead to the award of a Fellowship by reprinting a series of 20 notable papers that have been published by 20 Fellows over the years. However, the logistics of re-publishing papers can be tricky, and also would generate a large

volume of reading. So, instead, we decided to produce a collection of new, not-too-long, essay-style articles in which Fellows would offer a personal reflection on the influence and impact of one of their past publications, also offering their view of its impact and influence over time and its relevance to current and future challenges for nursing.

Contributors were asked to write in a personal and reflective style in the hope that this will engage readers and encourage their own assessment of the impact and ongoing relevance of Fellows' work.

Of course, not all of the activities of RCN Fellows end up in the form of published work and so this collection of articles does not represent the whole gamut and variety of their contributions to nursing practice, education, research and policy – and beyond. However, a wide range of topics are addressed across the 22 articles in the collection. A few of them are co-authored, so we have not ended up with the neat 20-20 equation that originally was envisaged, but near enough. There was no selection process and no formal peer review.

The idea was explained to Fellows in a circular email towards the end of last year and expressions of interest in contributing an article were invited. There was an enthusiastic response. The contributors were free to choose their underpinning publication – as long as it can be accessed online – and while most of the articles are based on a research or scholarly journal paper, a few are based on a book or a book chapter or a policy report.

Sense of pride

Each contributor was paired with one member of the team of Fellows that steered this project and they provided feedback on drafts and helped keep the work on track. The team comprised Alison Tierney (FRCN 1995), Roger Watson (FRCN 2009), David Benton (2003), Daniel Kelly (2016) and Michael Brown (2015). Kath McCourt (2008), as convenor of Fellows, chaired the team's meetings and kept the College up to date with progress as well as securing the assistance of Nursing Standard as publisher.

Much of the work was progressed during the months of the COVID-19 lockdown across the UK. Most of it anyway would have been done by email and we held our team meetings on Zoom. For some of us this project provided a welcome preoccupation during those 'stay at home' months of the lockdown but, for others, it made added demands to

professional or personal responsibilities that were heightened by the pandemic.

For all of us involved in any way with nursing, 2020 will be remembered with great sadness for all the lives lost, but also with an abiding sense of pride in how nurses stepped up to manage the crisis with such professionalism, compassion and courage.

In spite of preoccupation with the pandemic, the designation of 2020 as the International Year of the Nurse and the Midwife still calls for us to celebrate the wider value and achievements of nursing, and also to focus our minds on the challenges ahead.

New generation

These challenges have been highlighted through the global Nursing Now campaign and are set out in detail in the State of the World's Nursing report published in April by WHO. It is clear that the nursing profession has a crucial and central role to play if the sustainable development goals (SDGs) for global health are to be attained and if that so-far elusive concept of 'health for all' is to become a reality.

But progress is not inevitable; we need to create it ourselves. One of our hopes for this collection of articles is that these personal stories of work done by RCN Fellows will inspire newer members of the profession to see how ideas and ambitions to improve nursing can be taken forward and realised for it falls to each new generation to ensure the ongoing advancement of the science and practice of nursing for the coming years and decades.

We did think about collecting the articles together under themes but, in the end, we have decided to present them simply in a chronological sequence according to year of Fellowship award. Almost the entire span of the 40 years of the award scheme is represented.

The 22 articles are prefaced by a stand-alone paper, also being published in the regular issue of Nursing Standard, that reports the findings of a bibliometric analysis of the published work of the Fellows as a collective. This piece of work was initiated and led by David Benton, also involving other members of the team. We think this work clearly demonstrates that RCN Fellows are unequivocally making a contribution – an enduring legacy – that reflects the original intent of the award in advancing the art and science of nursing and the improvement of health care.

Why you should read this article:

- To familiarise yourself with the aims of the Royal College of Nursing (RCN) fellowship award
- To understand how bibliometrics can be used to analyse scholarly publications
- To recognise how RCN fellows have contributed to advancing the nursing profession and improving healthcare

An enduring legacy: contributions of Royal College of Nursing fellows to nursing science

by David Benton, Alison Tierney, Roger Watson and Kathleen McCourt

Citation

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Abstract

Background The Royal College of Nursing (RCN) initiated a fellowship programme in 1976 as a means of recognising outstanding registered nurses who have demonstrated a commitment to advancing the art and science of the profession and the improvement of healthcare.

Aim To conduct a bibliometric analysis of the scholarly output of RCN fellows, thereby documenting their coverage, connectivity and contribution to the indexed professional literature.

Method This study used a mixed-methods approach, analysing publicly available data to identify and report thematic and quantitative measures of the scholarship of fellows through the application of bibliometric analysis.

Results In total, 193 fellowships were awarded between the inception of the scheme in 1976 and 2019. Collectively, fellows have 9,336 publications indexed in Scopus and have accrued 131,408 citations resulting from 116,961 citing articles. Overall, 166 fellows produced one or more indexed articles. The 166 fellows engaged 9,908 co-authors in the production of this work from a total of 72 countries or territories. The work of the fellows covers 24 themes that include major healthcare priorities and a variety of clinical settings, as well as themes essential to the advancement of the nursing profession and the quality of services.

Conclusion While there are limitations to this study in terms of its coverage of the indexed database, it has established a useful baseline of the published scholarship contributions of RCN fellows. The contributions made reflect the original intent of the RCN fellowship award – to acknowledge nurses who have demonstrated a commitment to advancing the art and science of the profession and the improvement of healthcare.

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Keywords

audit, data collection, literature search, mixed methods, quantitative research, research, research methods, service improvement

Background

The Royal College of Nursing (RCN) in the UK initiated a fellowship programme in 1976 as a means of recognising outstanding registered nurses who have demonstrated a commitment to advancing the art and science of the profession and the improvement of healthcare. Fellowship of the RCN entitles recipients to use the post-nominal letters 'FRCN' and is the highest award that can be granted to RCN members (RCN 2020a). Recipients may work in clinical practice, or in the managerial, education, research or policy domains of nursing. In addition, the RCN also grants honorary fellowships to nurses who are registered outside of the UK, as well as non-nurses, for example clinicians who work with nurses on topics of mutual interest such as child health, and who have demonstrated a positive effect on nursing or healthcare.

Fellows often contribute to RCN policy debates or contribute by serving on various committees and taskforces, and by working on the production of a range of guidance documents. Additionally, since 1986, several of the fellows have contributed to the RCN's oral history collection by telling their life stories, which provide an insight into their personal experiences of nurse training and clinical skills, and which are stored digitally at the RCN archive in Edinburgh, Scotland (RCN 2020b).

While RCN fellowship is awarded for a wide range of contributions, many fellows regularly contribute to the literature. Some fellows – particularly those who are recognised for their clinical, managerial or policy contributions – produce guidelines or exemplars of best practice, or publish in the grey literature. However, up until this point, no systematic analysis of the corpus of published and indexed material has been conducted. As nurses around the world celebrate 2020 as the International Year of the Nurse and the Midwife, it seemed appropriate to distil the work of the RCN fellows to identify the quantity and breadth of their contribution.

Aim

To conduct a bibliometric analysis of the scholarly output of RCN fellows, thereby documenting their coverage, connectivity and contribution to the indexed professional literature.

Method

This study used a mixed-methods approach, analysing readily available data to identify and

report thematic and quantitative measures of the scholarship of RCN fellows through the application of bibliometric analysis. It was not the intention of this study to examine the specific and detailed output of individual fellows because this would require a more nuanced approach (Benton 2017).

Bibliometrics

Bibliometrics is a method used to analyse scholarly publications and identifies a range of characteristics, including the general themes contained within the published work and the existence or non-existence of collaborative networks of scholars, as well as a wide range of other measures (Ball 2017).

While bibliometrics has been used by information and library scientists for several years, it is only within the past decade that it has been used extensively by nurse researchers (Smith and Hazelton 2011). There is a wide range of measures both at an aggregate level of analysis (across the population of interest, in this case the fellows), and an individual level (the authors or specific fellows), that can be used to conduct bibliometric analysis. However, only aggregate metrics relevant to this study will be covered in detail in this article.

In the past, rudimentary analysis of individual scholarship has been conducted to quantify the output of nurse academics in the UK, Canada and Australia (Hack et al 2010, Thompson and Watson 2010, Hunt et al 2011). All of these previous studies have examined metrics relating to individuals, but this study encompasses general individual and population measures.

Data collection and analysis

The RCN maintains a roll of honour of fellows and honorary fellows. For the purpose of this study, the analysis was limited to individuals who have been awarded full fellowship of the college, with honorary fellows not included (RCN 2020c).

There are three potential aggregate sources that could be used to extract bibliometric data relating to the RCN fellows and the citation of their work – Scopus, Web of Science or Google Scholar. Of the three, Scopus has the most comprehensive coverage of nursing-related content, and although it requires individual scholars to ensure their entries are up to date, the authors selected it as the database of choice for extracting the necessary information.

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There are several challenges associated with indexing databases such as Scopus, including variations in the spelling of author names or institutional attribution (Jacso 2008, Hack et al 2010). Additionally, on occasion, work published by an author with a name similar to the author of interest can be misattributed, so careful data cleansing is necessary. While Scopus has the most comprehensive coverage of nursing content, it does not index all of the nursing material produced. Some journals and grey literature are not indexed in the Scopus database; therefore, the analysis presented in this article was an under-representation of the scientific contribution of fellows. Nevertheless, the study provides a valuable starting point.

The study focused on five variables of interest for each fellow – the total number of indexed publications, the number of citations received, the number of citing articles, the *h*-index (highly cited index) and the number of co-authors. Using the summary analysis function of Scopus, these five variables of interest were recorded in a tabular format for each fellow to calculate the basic aggregate statistics of median, average (mean) and maximum value for each variable.

The *h*-index was developed by Hirsch (2005) as a means of quantifying the aggregate effect of an individual's scholarship and is increasingly used in the academic sector to assess the output of researchers (Thompson and Watson 2010). The *h*-index is calculated based on both the number of articles published and the frequency of the citation, and is insensitive to the potentially distorting influence of a small number of highly cited works (Watson et al 2016).

Several authors have offered suggestions on the importance of either the number of citations that an article receives, or the *h*-index of the author as a means of identifying the most prolific and impactful scholars (Hack et al 2010, Thompson and Watson 2010). These authors have noted that the cut points (the numerical values that represent boundaries between categories) that determine what constitutes a 'good' number of citations or *h*-index may vary between disciplines, roles within the same discipline or even the subtopics being studied. One way to objectively assess such data is to use Jenks' natural breaks analysis, which identifies natural breaks in the data to ascertain if there are naturally occurring cut points (Jenks 1967, Moffitt 2019).

In addition to the descriptive statistics, multivariate cluster analysis was conducted to determine whether the fellows comprised a connected scholarship community (co-author analysis of authorship). To achieve this, the software package VOSviewer, which was developed at the University of Leiden in the Netherlands by van Eck and Waltman (2010), was used. This software examines the bibliographic data relating to each article and examines the co-authors of individual fellows. A visualisation of the co-authors' network is then displayed in the form of a cluster diagram, with individuals who regularly work with each other allocated to a colour-coded cluster. However, the physical location of an author is calculated based on the relationships between all authors and co-authors and consequently individuals can be 'stacked' on top of one another, resulting in only the uppermost author being visible on a printed image.

In large datasets such as the one used in this study, the consequence is that when a two-dimensional cluster diagram is displayed by the software, some authors' names are obscured by their peers. While it is not ideal that the visual representation of the co-authors' network obscures the work of some fellows at the expense of others, this is an inherent limitation of the software, because it seeks to present an overview of the fellows' collective work. When using the VOSviewer software, it is possible to zoom into and rotate the image to view a particular individual, but this will then obscure others.

The VOSviewer software also enables the frequency of co-authorship to be set. Callon et al (1983) stated that a minimum of three articles is sufficient to identify regular co-authorship. Furthermore, by examining the co-author's country of affiliation, the extent of any network of collaborators beyond the UK can also be displayed.

To ascertain the general themes associated with the work of the fellows, a co-occurrence analysis of author keywords was conducted. A co-occurrence analysis examines the keywords that the author has allocated to an article. The VOSviewer software examines the most frequently occurring keywords and clusters them together based on their co-occurrence within articles. As a result, clusters of commonly occurring keywords are generated, then mapped as an image. Closely related keywords are located near to each other and non-related words are located further apart. These keyword clusters can contain a

mixture of research methods, the populations being studied as well as the subject matter under investigation.

To summarise the content of the keyword clusters, each of them was reviewed independently by the authors of this article and a brief title and succinct description was generated for each cluster. Having completed this work independently, the authors compared their results and where there were differences in interpretation, these were discussed until agreement was reached.

After parsing the data to identify commonly occurring terms and the relationships between them, a visualisation of the relationship between the variable of interest is constructed and displayed by the VOSviewer software. The more related the concepts, authors, countries or keywords are to one another, the closer they are located on the visualisation. The more prolific a topic, author or country is, the larger the circle drawn on the mapped image. Connections marked by lines between the circles on the mapped image display the relationships between the variables being studied; the thicker these lines, the stronger the connection between the two variables.

Ethical approval

The study analysed data obtained from a publicly available database and used a secondary analysis of literature, therefore no ethical approval was required. However, for

the purposes of courtesy, RCN fellows were informed in advance that the analysis was being undertaken.

Results

RCN fellowships were awarded for the first time in 1976, with the number of fellowships awarded each year ranging from none in 2005, to 11 in 2014. Data from the list of 193 fellows (1976-2019) was extracted from Scopus on 12 January 2020. Collectively, the fellows had a total of 9,336 publications indexed in Scopus, which accrued 131,408 citations resulting from 116,961 citing articles. It was identified that 166 fellows produced one or more indexed articles, and they engaged 9,908 co-authors in the production of this work. Table 1 provides a synopsis of fellows' descriptive statistics calculated across the variables of interest (indexed publications, citations, citing articles, *h*-index and co-authors).

By applying Jenks' natural breaks analysis to the data set, using four progressive levels related to the fellows' productivity (entry level, well-established level, excellent level and exceptional level) (Hack et al 2010), numerical ranges were calculated based on grouping the data from all 193 fellows into four clusters for each of the five variables of interest. The Jenks' natural breaks analysis of fellows' indexed publications, aggregate citations, citing articles, *h*-index and co-authors is shown in Table 2.

Implications for practice

- The study identifies the current foci of the RCN fellows and for nurses with an interest in working in the areas detailed in Table 3, there is a clearly identified source of mentorship
- Nurses starting their journey in scholarship should examine the work of the fellows to identify topics that they may wish to study further or, through identifying gaps in the literature, find new areas of inquiry
- Bibliometrics is a versatile technique that can be used to explore groups of scholars or domains of practice and can offer valuable insights into the current state of the science, thereby providing direction for those wanting to undertake original research or consolidate findings through systematic reviews and meta-analysis

Table 1. Synopsis of fellows' descriptive statistics calculated across the variables of interest

	Indexed publications	Aggregate citations	Citing articles	<i>h</i> -index	Co-authors
Median	17	30	28	3	7
Average (mean)	48	681	606	7	51
Maximum value	632	16,289	12,708	57	1,071

Table 2. Jenks' natural breaks analysis of fellows' indexed publications, aggregate citations, citing articles, *h*-index and co-authors

Level of productivity	Indexed publications		Aggregate citations		Citing articles		<i>h</i> -index		Co-authors	
	Range	Number of fellows	Range	Number of fellows	Range	Number of fellows	Range	Number of fellows	Range	Number of fellows
Entry level	0-49	135	0-1,057	163	0-961	164	0-4	114	0-73	153
Well-established level	52-142	42	1,302-3,531	20	1,145-2,916	19	5-12	35	81-245	34
Excellent level	150-274	14	4,223-7,397	9	3,270-5,043	8	13-25	26	303-531	5
Exceptional level	470-632	2	16,289-16,289	1	12,228-12,708	2	26-57	18	1071-1071	1

Multivariate analysis

Figure 1 provides a mapping of the connections between fellows and their co-authors. Many of the co-authors are not fellows and, in some cases, come from disciplines other than nursing. As can be seen in Figure 1, this is a highly complex and connected map. Several fellows are prolific authors and have

Figure 1. Mapping of the connections between fellows and their co-authors

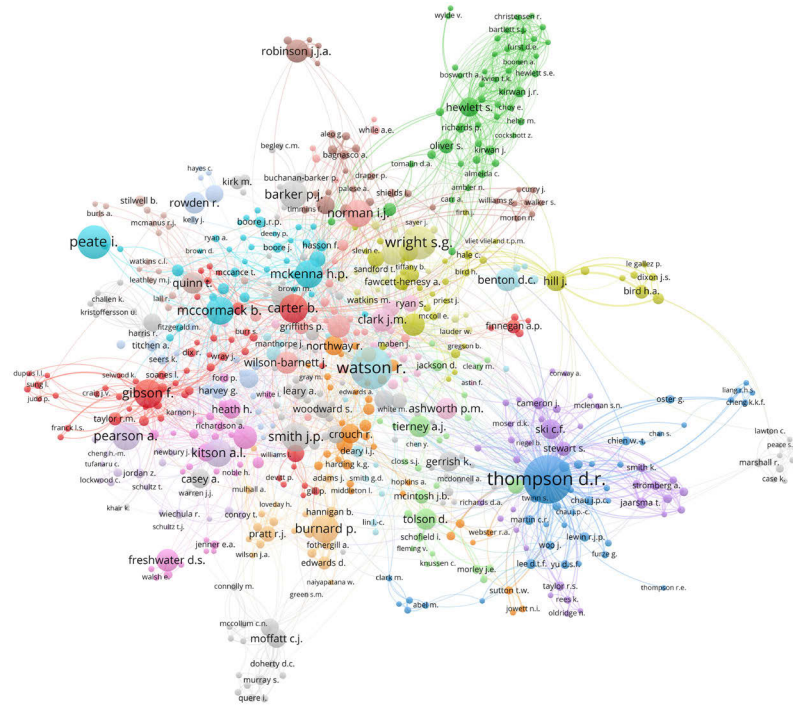
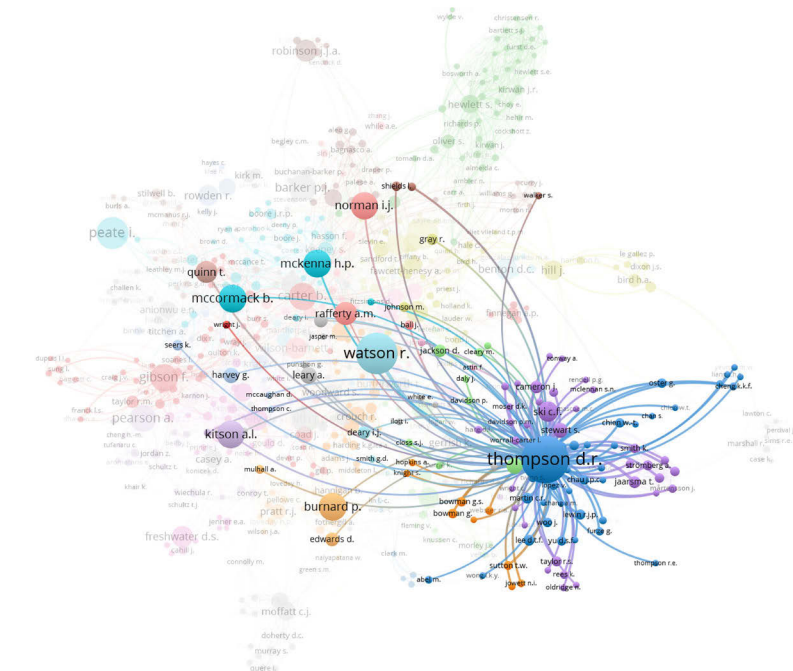


Figure 2. One-step co-author network of David Thompson's Scopus indexed work



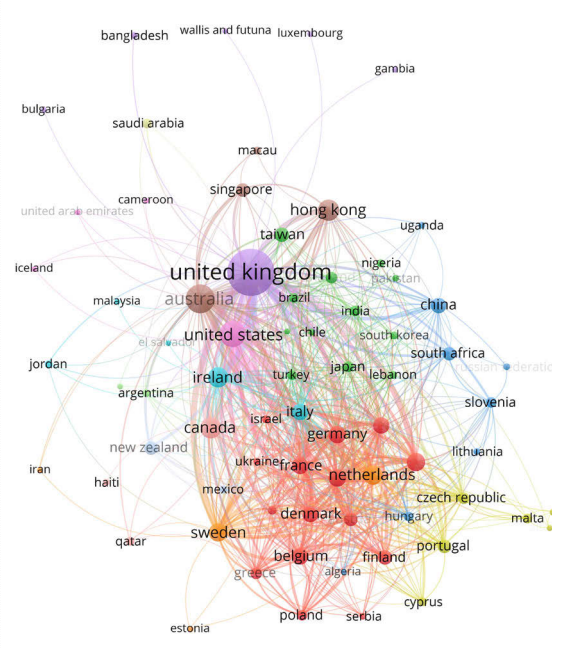
many co-authors. In this two-dimensional image, some fellows are obscured by having the data of other authors placed on top of their own data.

It was identified that the most prolific fellows are David Thompson and Roger Watson, but the larger circles show that there are a significant number of fellows who – over a period of just under 20 years on average – have contributed to nursing scholarship on multiple occasions.

To gain further insight and to visualise an individual fellow's one-step connections (those who the fellow is directly linked to through publishing activity), it is possible to use the VOSviewer software to identify a fellow's network of co-authors by clicking on their name, which will then detail their one-step network. For example, Figure 2 shows the one-step co-author network of David Thompson's Scopus indexed work. Authors who are part of the same cluster have the same colour and form a network that routinely works on related issues.

Co-authorship analysis of collaborations by country yielded a complex and diverse network of 72 country or territory connections. As can be seen from the co-authorship connections by country or territory shown in Figure 3, the most dominant countries or territories (those with the largest-sized circles) are the UK, Australia, the US, Hong Kong and Canada. There are also significant connections

Figure 3. Co-authorship connections by country or territory



to, and among, various European countries. Additionally, there are connections to Middle Eastern and Asian countries, Commonwealth member states, and even the Pacific Islands territory of Wallis and Futuna.

Figure 4 shows a co-occurrence analysis of the connectivity between 893 author-defined keywords that met the minimum frequency requirement of at least three occurrences. These are grouped into 24 keyword clusters comprising 10-67 terms per cluster. Due to the density and overlapping nature of the clusters, which limited the visibility of underlying terms, a detailed co-occurrence analysis of the clusters was conducted and is summarised in Table 3. Table 3 provides a brief title and succinct description of each of the keyword clusters from the co-occurrence analysis, which were derived from analysis of the terms included in each cluster.

Discussion

The *h*-index is a useful measure of publication productivity and impact that has been used to examine the work of nurse academics in the UK, Australia and Canada (Thompson and

Watson 2010, Hack et al 2010, McKenna et al 2018). Each of these studies have reported a set of descriptive measures such as mode, median and average score, and have offered suggestions as to how the *h*-index score or range of scores could be classified with relevance to the group being studied. For example, Hack et al (2010) undertook a citation analysis of research publications by Canadian nursing academics, and suggested that those with an *h*-index of 5-9 should be viewed as having a well-established publication record, those with an *h*-index of 10-14 an excellent record and those with an *h*-index of 15 or more an exceptional record.

This study, unlike the earlier work on academics by Thompson and Watson (2010), Hack et al (2010) and McKenna et al (2018), considered the entire population of fellows and – rather than using an undefined method of determining the cut points – used Jenks’ natural breaks analysis, allocating scores to one of four categories. In this study, the *h*-index level ranges identified for fellows were generally higher when compared with Thomson and Watson (2010) (entry level 0-4;

Figure 4. Co-occurrence analysis of the connectivity between 893 author-defined keywords

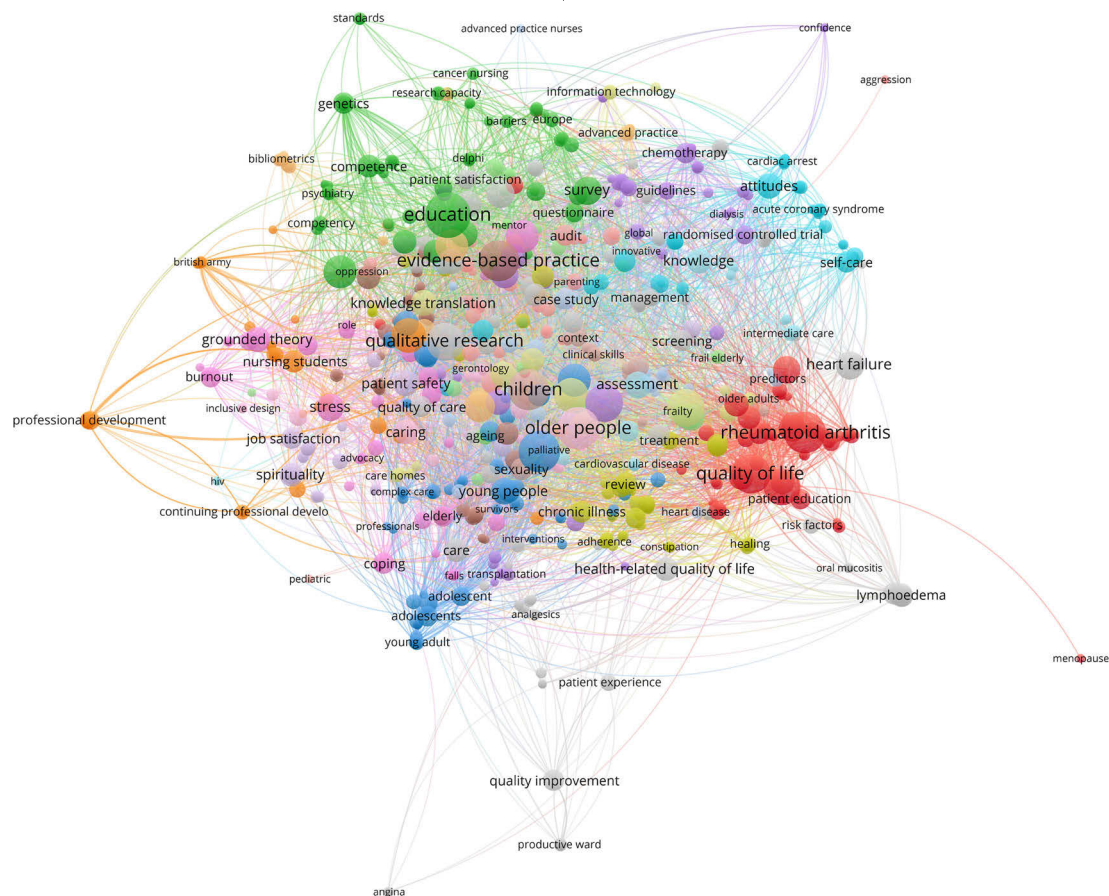


Table 3. Brief title and succinct descriptions of the keyword clusters from the co-occurrence analysis

Cluster number	Number of keywords	Brief title	Succinct description
1	67	Long-term and non-communicable disease	The management of lifestyle factors such as exercise and diet that can result in long-term and non-communicable disease that can be ameliorated by lifestyle changes
2	67	Professional education	The evidence and university-based programmes that develop research-informed clinical competence and critical thinking
3	60	Life-limiting child and adolescent care	The physical and psychological effects of serious life-limiting conditions on children, adolescents and their family members
4	56	Nurse-sensitive outcomes	The development and use of research-based guidelines to address common conditions that can affect activities of daily living and delay recovery
5	51	Evidence-based practice	The use of a range of approaches to optimise the delivery of care through specialist and advanced nursing practice
6	49	Acute cardiac event treatment	Physical and psychological emergency interventions and services available to support patients who experience acute cardiac events and their families
7	42	Transcultural nursing	The development and implementation of culturally competent practice and awareness of prevalent conditions prevalent in various ethnic groups
8	41	Fundamentals of nursing	The mechanisms used to identify, develop and refine fundamental nursing care and its theoretical basis
9	41	Psychological wellbeing	Factors, resulting potential issues and modes of intervention associated with disturbances in psychological wellbeing
10	38	Nursing policy interests	Diverse nursing policy interests covering the entire life course as well as clinical, managerial and educational-based themes
11	36	Measuring older person's functioning	The wide range of measurement instruments and techniques that can be used to assess the functional abilities of older people
12	34	Interpersonal abuse	Focuses on women and children who may be the subject of physical or psychological abuse and how this can be identified and addressed
13	32	Care of the older person	Physical and psychological issues and needs that are prevalent in the care of the older person
14	32	Factors leading to care left undone	Care setting and other factors to be considered in the delivery and prioritisation of interventions within available resources
15	30	Nurse-led care	Conditions where nurses can take a leading role in assessment, diagnosis and treatment, for example cardiac care, HIV (human immunodeficiency virus), hypertension and sexual health
16	30	Professional regulation	Different nursing roles and how regulation and legislation can support public protection through education, standards and guidance
17	30	Nursing concepts and processes	A wide range of nursing concepts and processes relating to the practice of nursing, including assessment, diagnosis, classification, intervention and evaluation
18	28	Patient-centred long-term care	The provision of person-centred care to older people and those with long-term conditions
19	28	Mental health care	The use of therapeutic interventions – both psychotherapeutic and medicines – including their management and potential iatrogenic effects
20	27	Heart failure	Risk factors and consequences of chronic heart disease and congestive cardiac failure
21	24	Primary and community assessment	Various aspects of risk screening for alcohol and tobacco use as well as detailing primary and community service provision
22	23	Service development	The importance of teamwork, change management and other service development approaches to addressing various common clinical challenges
23	17	Triage	Triage and evidence-based clinical decision-making to prioritise access to services in urgent care settings (emergency departments, general practice, day surgery and out-of-hours provision)
24	10	Quality improvement	A range of methods used to improve quality, efficiency and effectiveness of services including application of research and quality improvement methodologies

well-established level 5-12; excellent level 13-25; and exceptional level 26-57). This could be because Thomson and Watson (2010) examined the published work of UK scholars and some of the RCN fellows were included; therefore, the published work of these fellows has continued to accrue additional citations over the previous 10 years and their *h*-indices have increased.

Furthermore, Bornmann and Daniel (2007) acknowledged that the *h*-index profile differs by discipline, country and career level. Therefore, the results of this study should not be viewed as potentially comparable to other groups, but rather as a benchmark for future study of the scholarship profile of RCN fellows and how their scores relate to similar groups such as fellows of the American Academy of Nursing.

Figures 1 and 2 demonstrate that the fellows not only collaborate with each other in the production of scholarship, but also collaborate extensively with other colleagues in nursing and other disciplines. Furthermore, as Figure 3 indicates, fellows do not restrict their collaborative work to colleagues in the UK, but rather have an extensive range of co-authors from multiple countries and territories around the world. Therefore, RCN fellows are part of a global scholarship community, sharing their expertise worldwide, and could be thought of as informal global ambassadors for the RCN.

The extent of these global connections is perhaps surprising based on previous findings by Benton and Ferguson (2017) and Benton et al (2019) who, when examining links between nurse leaders across countries or common interests, identified that such connections were infrequent and weak. However, in their study of how nurse leaders connect, Benton and Ferguson (2014) noted that one factor that supported the development of national and international collaboration was participation in professional associations.

The data presented in this study on RCN fellowship supports Benton and Ferguson's (2014) observation that professional association membership positively affects the establishment and sustainability of collaboration across professional networks, nationally and internationally.

In this study, the co-occurrence analysis of keywords used to describe the content of the published work demonstrated the diversity of fellows' expertise. This expertise is closely aligned with major healthcare priorities, covers

the entire life course, and relates to a wide range of conditions essential to the delivery of universal healthcare, as well as other topics essential to the attainment of United Nations' sustainable development goals (sdgs.un.org/goals). RCN fellows provide a rich source of knowledge and have extensive connections that contribute to policy development across a variety of highly relevant and contemporary issues.

While Table 3 details various high-disease-burden topics such as long-term and non-communicable disease, it also includes care settings and themes that are essential to the advancement of the profession and the quality of services. These topics include professional education, fundamentals of nursing, nurse-sensitive outcomes, evidence-based practice, care left undone, nurse-led care, professional regulation, service development and quality improvement. These topics also demonstrate the future-orientated work of the fellows and that they are committed to advancing the art and science of nursing and the improvement of healthcare.

Limitations

There are four limitations that need to be considered in relation to this study.

First, while Scopus has the most comprehensive coverage of material and offers integrated citation data on indexed articles, it is incomplete because not all peer-reviewed journals are included and on occasion there is a delay in the publication of an article and its subsequent inclusion in the index. As a result, the findings of this study underestimate the contributions made by fellows to the scholarship literature. This has implications for underestimating the extent of the co-authorship networks established and maintained by fellows. It is likely that the fellows have a wider and more extensive national and international network of collaborators than the analysis presented in this article demonstrates.

Second, on occasion Scopus misattributes the work of one individual to another, resulting in either an overestimation or underestimation of a fellow's contribution. By carefully cleansing the data, the authors were able to ensure that articles not authored by a fellow were removed. As a result, the authors do not believe that errors in attribution have resulted in any overestimations of fellows' profiles. By completing the two-stage search for

authors, the authors of this article believe they have minimised underestimation of fellows' profiles, but they cannot provide a definitive statement on this issue. Given that one of the aims of the Nursing Now (2020) campaign is to ensure that nurses and midwives have an increasingly prominent voice in health policymaking, the RCN may wish to emphasise this issue to the fellows and their membership to ensure that nursing in general, and individual nurses in particular, are fully discoverable through bibliographic searches.

Third, although modern technology can capture data concerning mentions of an individual's work on social media platforms such as Twitter and LinkedIn, this is not a factor that the software used in this study was able to accommodate.

Fourth and finally, this study explored data from indexed sources and as a result has not captured the entirety of contributions

made by the fellows, particularly those who work in clinical or policy areas. Based on these limitations, the authors conclude that the findings of this article do not fully document the scholarly impact of fellows, but nevertheless offer an important insight into their interests and connections.

Conclusion

Since the inception of the RCN fellowship award, no attempt to produce a systematic analysis of the scholarship contribution of fellows has been made up until this point. While there are limitations to this study in terms of its coverage, it has established a useful baseline and it is clear that fellows' indexed contributions reflect the original intent of the award, which is to acknowledge nurses who demonstrate a commitment to advancing the art and science of nursing and the improvement of healthcare.

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Fifty years on: reflections on research on the role of the health visitor

by June Clark (FRCN 1982)



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The 1960s and 1970s were exciting times for me on a personal and professional level. My personal and professional lives became inextricably intertwined. In 1962, I graduated with a degree in classics from University College London. I had already decided, much against my parents' wishes, that I wanted to be a nurse.

As a student nurse I was already regarded as 'a bit of a troublemaker' and I became active in the RCN. In 1966 I got married and our children were born in 1969 and 1972. In 1967, I qualified as a health visitor

and went to work in Berkshire, where my husband held a university post and we lived on the campus in a university flat. These seemingly irrelevant factors determined the next ten years of my career including, in particular, the development of my research into health visiting.

This study of health visiting in Berkshire was my first attempt at research and was also one of the earliest studies undertaken by any nurse in England. This early study is the focus of my contribution to this RCN Fellow's 2020 publication, nearly 50 years later.

The role of the health visitor: a study conducted in Berkshire, England

Abstract

A study of 1057 home visits undertaken by health visitors in Berkshire in 1969 showed that the range of the health visitor's work was much wider than the stereotype which portrays health visiting as an activity limited to maternal and child welfare and concerned mainly with physical care. The sample was the population of health visitors, 82 in all, employed by Berkshire County Council. The health visitors completed a questionnaire, were interviewed, and recorded their home visits for one week. Seventy per cent of the visits were to households containing a young child, 18% were to the elderly, and 12% to other households. The content of the visits was recorded in terms of the topics discussed. Some topics were essentially medical, and some were within the scope of the stereotype, but many were topics not traditionally associated with health visiting and there was a considerable psychosocial content. Differences were found between visits recorded by younger and recently qualified health visitors and visits recorded by other health visitors.

Citation

Clark J (1976) The role of the health visitor: a study conducted in Berkshire, England. *Journal of Advanced Nursing*. 1, 1, 25-36. doi: 10.1111/j.1365-2648.1976.tb00425.x

Link

onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2648.1976.tb00425.x

Introduction and background

The 1970s were turbulent or exciting times, whichever way you looked at them. The National Health Service (NHS) was embroiled in preparations for its major reorganisation in 1974 which involved the transfer of community health services, including health visiting, from local government to the newly

created health authorities. I was appointed as the nurse member of the Berkshire Area Health Authority, which enabled me to become deeply involved in the development of health and social policy, working with many of the leaders in health care of the day. In 1962, the Health Visiting and Social Work (Training) Act had established the Council for the Training

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of Health Visitors (CTHV), later extended to include education (CETHV) as the new regulatory body for health visiting. The council established several working parties that attempted to define the future role of the health visitor, and in 1966 a training programme with a new curriculum had been introduced, designed to produce a 'new breed' of health visitor with a much broader role (Clark 1968).

I was one of the first to qualify under the new regime. The decade also included the Committee on Nursing (Briggs report) (HMSO 1972) and the 1979 Nursing, Midwives and Health Visitors Act, which replaced the General Nursing Council with the UKCC and abolished the CETHV. The NHS, nursing, and nursing education were turned upside down. Other issues of the day were the development of the primary care team and the attachment of health visitors to general practice, both of which were controversial and were seen by some as a challenge to the autonomy of health visitors. There was tension between health visitors and social workers and the role and status of health visiting was continually challenged.

Already active in the RCN, I found myself involved in numerous working parties and a speaker at numerous conferences. At home with two babies I had the flexibility to serve on lots of committees and task groups. I published articles in the professional press with titles such as *That uncertain knock on the door*, *No new type of visitor*, *What do health visitors do?* The dilemma of identity in health visiting. I became the health visiting consultant to a popular newsstand publication called *Mother and Baby*, even acting for several years as the magazine's 'agony aunt'. I often thought that I did more and better health visiting in this role than I ever did by knocking on doors – it certainly shattered my complacency about how wonderful health visitors were. I was becoming well known as a 'champion' of health visiting.

The trigger for action was the publication of the Report of the Committee on Local Authority and Allied Personal Social Services, *The Seebohm Report*, in July 1968 (HMSO 1968). The report specifically excluded health visitors from its membership and considerations and stated: 'In our view the notion that health visitors might further become all-purpose social workers in general practice is misconceived'. It recommended that a new Social Services Department should be set up in each local authority which would undertake the existing work of the children's

department, the welfare department, and parts of the health department. Functions that health visitors had traditionally regarded as theirs were transferred to social workers who would exercise a central role in the new system.

Social workers were delighted but health visitors were furious. They complained that they had been misunderstood, misrepresented, and undervalued. I agreed and stood up on several conference platforms to say so. But I argued that if people did not understand what health visitors did, it was probably because health visitors had not told them. There was a plethora of opinions and recommendations about what the role of the health visitor should be, but a dearth of factual information and evidence about their actual practice. What was needed, I argued, was some proper research.

But who could do the research? At the time, nursing research in the UK was embryonic. There were a few studies using work study methods undertaken by researchers who were not health visitors, which health visitors rejected as contributing to the misunderstandings. Very few nurses or health visitors had a first degree, which was the normal university requirement for undertaking post graduate research.

Almost none had a doctorate, which meant it was very difficult to find nurses who could supervise nursing doctoral students. My husband's job precluded a move to one of the developing epicentres of academic nursing such as Manchester University. I knew nothing about research methods, and I searched in vain for some kind of course that my family commitments would allow. The mantra of the Briggs Committee on Nursing that 'Nursing should become a research-based profession' was still four years in the future (HMSO 1972).

But I did have a first degree, I was living on a university campus, and I was 'unemployed' because I was pregnant or occupied with babies. My RCN involvement brought support and mentorship from some wonderful nurse leaders such as Marjorie Simpson, Jean McFarlane, and Grace Owen, who were planting the 'little acorns' of nursing research which later grew into oaks. I obtained a grant from the King's Fund – the first one ever awarded to an individual nurse. I joined the fledgling RCN Research Discussion Group. Professor Peter Campbell, Professor of Politics, and Dr Viola Klein from the sociology department at Reading University agreed to take on the formalities of my registration for

a MPhil. At the time, most master's degrees were research-based degrees rather than taught programmes.

I was introduced to Professor Margot Jefferys, one of the founders of the developing discipline of medical sociology, who encouraged me and became my external examiner. And there were other benefits. I had tremendous goodwill from the health visitor interviewees, and I discovered that being accompanied by a breast-fed baby established an immediate rapport in interviews! I sent a questionnaire to every health visitor in Berkshire, achieving a response rate of 89%; I interviewed 79 health visitors and persuaded 72 to record all their home visits for a week using a recording form that I devised, amounting to 2,057 visits in all.

The interviews were recorded on a reel to reel tape recorder the size of a suitcase. The data was analysed using the (then) new Reading University computer which filled a whole building. The thesis was typed on an old-style typewriter with carbon copies – it was more than a decade before computers and word processing came into common use. In 1972 I graduated with the degree of MPhil. The thesis, suitably edited, was published in book form in 1973 under the title *A Family Visitor* (Clark 1973) – the first in the series of research monographs published through the 1970s by the RCN in conjunction with the Department of Health and Social Security (DHSS). I participated in a BBC series of television programmes about primary health care (Bloomfield et al 1974), and I spoke at many conferences at which my study was referred to. The study was also published as a series of three occasional papers in the *Nursing Times*, the newest outlet at the time for academic articles about nursing. The 1976 paper revisited for this article was published in the first issue of the *Journal of Advanced Nursing*.

Impact and influence

This study was undertaken nearly 50 years ago. The health visitor of the 1960s would hardly recognise health visiting as it is today. The 'family visitor' with a caseload that includes people of all ages appears to have become nowadays largely a protocol-driven system of developmental checks on young children – an important function, but not the only one. Health visitors no longer visit older people, and family support is seen as the function of the social worker.

In 1999, I was commissioned by the Welsh government to undertake a review of health

visiting in Wales. The review found that the number of health visitors in Wales had declined dramatically during the previous decade, that the introduction of general management following the 1983 Griffiths report had diminished the position of the health visitor in the organisational structure and led to the loss of professional leadership (Clark et al 2000).

The review contained several recommendations, but the report was quietly shelved. The good news, however, was that some of the local directors of nursing supported the report and quietly implemented several of the recommendations within their own management arrangements. Fortunately, during the past decade, perhaps as a result of the renewed importance of public health in government policies, health visiting appears to be experiencing something of a resurgence.

My increasing profile in health visiting and primary health care during the 1970s led directly to my representing the UK in work with the International Council of Nurses and the World Health Organization (WHO) following the WHO Declaration of Alma Ata on Primary Health Care in 1978 and the WHO Global Strategy for Health for All by the Year 2000. My search for others who were researching in the same field led me to Professor Sirkka Lauri in Finland, which I visited on a Council of Europe Fellowship in 1981 and several times subsequently. What I saw in Finland revolutionised my ideas about health visiting and primary health care. I published more articles and spoke at more conferences, but sadly, my proposals – such as visiting by appointment, structured documentation, sharing records with clients, seemed ahead of their time. At that time, they were not popular with UK health visitors. Now, they are recognised as central to good practice. The Department of Health's continuing search to understand health visiting practice (Clark 1982) led to a new research project to develop a model for explaining health visiting practice which eventually became my PhD (Clark 1985), and a project to identify the outcomes of health visiting practice (Clark and Mooney 2001). Citations in other people's work continued well into the 1990s. In 1982, when I was elected Fellow of the Royal College of Nursing, the citation said, 'for her contribution to the art and science of nursing in the field of health visiting'.

But I can hardly claim that the study itself had any influence on the developments in health visiting in the 1970s, which were largely

determined by the introduction of legislation and other external events over which the profession could exercise little control. In particular, the absorption of health visiting into the new framework of the 1979 Nurses, Midwives and Health Visitors Act moved health visitors from having a unique title and professional registration which was mandatory for practice, to recordable with the Nursing and Midwifery Council as 'specialist community public health nurses' alongside a variety of other nurses with no such requirements. Midwives retained their specialist identity; health visitors lost theirs. With hindsight, the legislation of the 1970s could be considered as marking the beginning of the demise of health visiting as I had known it.

Current and future relevance

It is hard to think that my research of some 50 years ago might have relevance to current and future researchers or practitioners, but it continues to be cited from time to time. Perhaps, however, any influence I might have had applies more to individuals than to big changes in policy. The outcome of which I am most proud is the number of individuals whose careers I was able to help, many of whom are now the leaders of the profession, just as the great nursing leaders of the 1960s and 1970s supported me. Health visitors I meet at conferences and other meetings often recognise me, and the older ones, that is, my contemporaries in health visiting, who are now, like me, approaching their eighties, often refer to my work in health visiting and in particular to this study. I did not know whether to be flattered or horrified when I discovered quite recently that A Family Visitor was still included in some students' reading lists!

As my children grew up, I expanded my interests into other fields of nursing – care of older people, nursing education, and standardised nursing terminology for electronic patient records. I am no longer directly involved in health visiting, but with hindsight I can see some relevance of this study to my and others' later work in other fields. I have been fortunate to be able to combine practice, research, and teaching in my long career (Clark 2016). With hindsight I can see that the methodological approach of trying to capture the essence of health visiting practice through identification and recording of the topics discussed in the home visit, as described in this paper, led directly to my work on the development of a standardised terminology to capture the essence of nursing, the International Classification for Nursing Practice (Clark and Lang 1992), and to make nursing and health visiting visible in electronic patient records. Only now in 2020 do I see the beginnings of understanding among nurses why the use of standardised terminology and structured documentation for nursing practice is important.

Fifty years later I still carry and promote the attitudes and ideas that were born in my health visiting days – the focus on prevention and early intervention, the social determinants of health, public health as opposed to individualised 'treatment'. The principles of health visiting which were set out in the 1970s (CETHV 1977) apply equally today and to every field of nursing:

- » The search for health needs
- » Stimulation of awareness of health needs
- » Influence on policies affecting health
- » Facilitate health enhancing activities.

Health visiting still has much to offer in meeting society's health needs.

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Nursing – a research-based profession

by Jennifer M Hunt (FRCN 1982)



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It is now almost 50 years since the title phrase, taken from the Briggs Report (DHSS 1972), became well known. Then, nurse researchers were few and the quantity and scope of research limited.

As a hospital-based nurse researcher from the 1970s to the 1990s, I had become increasingly aware of the mismatch between the focus of much nursing research and what nurses did in practice. I was also acutely aware of how difficult it was to change practice and implement best evidence.

My initial inspiration came from studies in the United States (Ketefian 1975, Horsley et al 1978, Krueger et al 1979, Haller et al 1979). This US work coupled with my own work on the nursing process (Hunt 1978, Hunt and

Marks-Maran 1980) provided the impetus for the paper that I had published in 1981 and have chosen to revisit for this article.

Despite the paper not being research-based it was published in the *Journal of Advanced Nursing (JAN)* and has been regularly cited. The content and propositions included in the paper evolved from presentations I gave on getting research findings into practice and was predominantly based on a lecture delivered in 1980 at the Second International Cancer Nursing Conference.

Subsequent work added to the understanding of barriers to non-acceptance as I became aware of the need to change not just practice but also policy (Hunt 1981, Hunt 1996, Hunt 2001).

Indicators for practice: the use of nursing research findings

Abstract

Until recently, discussion about nursing research centred on the need to get it carried out. Attention is now being focused on how to get nursing research used since so far, such research findings have not, on the whole, been assimilated into practice. Until this occurs, the practice of nursing will not and cannot be research-based in any meaningful way.

It is postulated that nursing research findings provide nurses with indicators for practice. This assumes that such findings are available and that the main barrier to their use is the poor communication of this research (in a form they can understand), to nurse practitioners. However recent research into the use of research findings casts doubt on this assumption and it can be argued that such a view is too simplistic. In this paper therefore, three questions are asked:

1. Are relevant nursing research findings available which provide indicators for practice?
2. What indicators do such findings provide?
3. Are such findings used by nurse practitioners?

Using specific examples from nursing research, ideas and suggestions are put forward which provide a basis for possible answers. Finally, the paper discusses the interdependence of research and practice and the need for them to develop together.

Citation

Hunt J (1981) Indicators for practice: the use of nursing research findings. *Journal of Advanced Nursing* 6, 3, 189-194; doi: 10.1111/j.1365-2648.1981.tb03211.x

Link

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Introduction and background

For over 50 years I have been involved in nursing research. During that time, I have seen

major changes in health and medical care, organisational structures, and the development of nursing research. I have moved from being

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learner to doer to supervisor to director and now, commentator and assessor.

I was fortunate to start my career in the early days of nursing research as one of the first group of nurses selected for the Department of Health and Social Security (DHSS). Study of Nursing Care Project, the brainchild of key nursing leaders Marjorie Simpson and Jean McFarlane (Inman 1975). The intense research education I received provided a solid knowledge base to progress with nursing research and later senior posts in management and government.

It is only in retrospect I realise how expert and eminent our lecturers were in their fields and how unusual their commitment to a nursing group was at that time. I was influenced too by the fact I had always been questioning and this project gave the opportunity to do just that, to look for evidence and to use knowledge to improve practice. It is worth remembering though that looking for evidence was more difficult then. There was no internet, electronic databases, digital journals, email or even photocopying. Everything had to be done by hand.

My focus then, as now, was clinical practice and hands-on nursing, always with the aim of improving care and outcomes. Except for my last research post, I was always based in hospitals engaging directly with nurses, other clinicians, and the senior managers. I felt at times that I was not considered a 'proper' researcher because I was not in a university.

At the time, as a hospital-employed researcher, unlike many of my academic peers who were focusing on the characteristics of the profession, my focus was on what nurses did in practice (Hunt 1981). My chosen article, from early in my career, was my first publication in an academic journal, though I had published others in weekly nursing journals. It was based on a lecture given at a Cancer Nursing conference organised by Bob Tiffany, chief nurse at the Royal Marsden Hospital in 1980 where I was director of nursing research.

Bob was passionate about nurses and nursing, committed to quality, to developing and stretching nursing staff and engaging them in research – a true nursing leader. He had asked me to chair the Nursing Practice Committee, usually seen by members as a necessary chore rather than an exciting opportunity. But my interest in nursing research utilisation gave me the idea of developing evidence-based nursing procedures.

It was a challenge and by allowing each member to develop a procedure of importance to their practice, we succeeded. The originality lay in each procedure having three sections: the evidence, the nursing problems linked to that evidence and a step-by-step procedure.

The first manual was a huge success on the wards. Numerous journals showed interest, papers were presented, and as a result full time clinical staff were employed to accelerate the work. We increased the number of procedures, published it in book form and it became a runaway best seller (The Royal Marsden 1984). It showed me what could be done and how research and nursing could become synergistic in the right environment.

Influence and impact

The lecture and the subsequent article made two assumptions. First, that relevant nursing research findings are available and second, that they would be used by nurses. This is what drove my original interest in determining if these assumptions were true.

My answer then was a qualified 'yes' followed by 'but'. The reasons I outlined then still hold true today. Namely, in some areas of research, findings provide reliable evidence to inform practice but despite research being available, nurses do not always use it. Also, there are still many practices which have not been studied sufficiently to produce reliable findings. But what are the findings needed to inform practice? My answer was three-fold: what nurses should do, what they shouldn't do, and lastly, are 'should do' findings used by nurses? To understand why findings are not used I identified six reasons for nurses not using relevant findings. These are that nurses:

- » Have problems the research does not address.
- » Do not know about the research findings.
- » Do not understand the findings.
- » Do not know how to use the findings.
- » Do not believe the findings.
- » Are not allowed to use the findings.

Fifteen years later, reflecting on my experience in senior managerial posts and membership of research and other advisory committees, I added another four (Hunt 1996). These are that nurses:

- » Lack the necessary skills to identify and evaluate relevant research findings.
- » Lack time to undertake this kind of activity.
- » Lack access to the right resources.
- » Work in a managerial ethos and culture where they are expected to come up with instant answers.

In 2018, in a guest lecture at Anglia Ruskin University, I added two more:

- » Political pressure and decisions.
- » Alternative and fake facts.

Research has confirmed my original opinions about research findings were justified. But even when valid and reliable research is available, it is not always integrated into practice because getting research into practice involves not just lowering the barriers, but nearly always involves change. So how the initial decision that change is needed is taken is as important for its success – the ‘problem-driven, bottom-up approach’ being more effective than a knowledge-driven or ‘top down’ one.

That still seems very straightforward. In the past I would have said ‘that’s it!’ Increasingly, however, I have concluded that it is not that simple and there are many more questions:

- » **What** if sound evidence is available but is ignored or overridden?
- » **What** about when evidence of harm is ignored, and tradition drives practice?
- » **What** about unpublished evidence?
- » **What** about falsified or biased evidence?
- » **What** if policy makers and senior colleagues tell us ‘to do or not to do’ something not based on, or at variance, with the evidence?
- » **What** is our personal and ethical responsibility?
- » **What** does our regulatory code say?

Health policy decisions, including those about nursing and nurses, have a tremendous impact on what we do. Goldacre (2009) noted that few politicians have research experience and expertise and inevitably are influenced by ideology, economic constraints, party and public opinion and the ever-present next election. So, major changes, rather than being subject to the rigours required by clinical research, are driven by compromise, expedience, and the political climate.

I have thought about these issues more because of recent involvement in the safe nurse staffing campaign, where refusal to implement robust research evidence is only too evident, and more recently when observing nursing and medical care as a cancer patient’s wife. Those experiences made me acutely aware of the major barriers emanating from ingrained attitudes, beliefs, high level policy and politics as well as the risks of ignoring, concealing or even fabricating evidence.

Today, nursing is more complex and more demanding than ever. More nurses can understand, undertake and use relevant research. However, barriers still hinder such

activities now as they did then. I despair when senior managers, policy makers, politicians, other health care professionals, including nurses, say that degree-educated nurses are unnecessary and say they are not ‘caring’ as if education and empathy cannot exist together. If that were true, no healthcare professionals would be educated in universities. I wish too that more research was undertaken into hands-on practice and far more NICE guidelines included specifics on what nurses should do. I wish too that these are then universally adopted and implemented.

Current and future relevance

I have learned that even the most routine activity, like chairing a Nursing Procedure Committee, can result in something as important as the world-renowned Royal Marsden Manual – probably the thing of which I am proudest.

I have learned that like throwing a pebble into a pond, the ripples, a word, an action can reach out to places I never thought they would reach, and touch people I never knew and changed what they did or how they felt.

I have learned that help and support from mentors, friends and colleagues is essential and to be treasured. Some I know about and some I can only guess at, but I am grateful to them all. I have tried to follow their example in enabling and helping others and giving them credit whenever it is due.

I began my training with, and still hold, a passionate belief in the value of nursing and nurses to patients. I have been fortunate to help, through research, to justify those beliefs. Today nurses and nursing are more necessary than ever. What we do, even the most routine nursing action, is important to our patients. We are the web holding everything together. Too often, that web is invisible or thought to be unimportant and only noticed when it is no longer there. We must make that web visible to show others how important it is. Nursing research is a means to that end and not an end in itself.

Florence Nightingale is often remembered as the Lady with the Lamp: an iconic image indeed. But we should also remember Florence Nightingale was ‘the passionate statistician’ who challenged politicians, policy makers and doctors, questioned accepted practices, established nurse training schools, totally changed hospital design, sent her nurses the length and breadth of the country to spread her ideas and improve the care of patients

and so influenced policy at the highest level. Nursing research provides the foundation and the International Year of the Nurse and the Midwife the opportunity to take forward Florence Nightingale's legacy to implement evidence in our practice and use the resulting positive patient outcomes to shape future policy direction.

Yes, 50 years ago I was naïve in believing that, presented with good evidence, nurses would immediately change their practice to align it with the evidence base. The good news is there has been a huge expansion

in nursing and medical research and there is now general acceptance of the need for evidence-based practice by all clinicians (Sackett et al 1996, Evans et al 2011).

Certainly, barriers persist to the wish expressed so clearly in the Briggs Report (DHSS 1972). But, with the opportunities that the World Health Organization, State of the World Nursing Report (WHO 2020) provides, the potential to turn aspiration into reality, I hope and believe, can be delivered by those following in the footsteps of us early pioneers.

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The support of patients with heart disease and their partners

by David Thompson (FRCN 1992)



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This article describes a programme of research focused on supporting people with heart disease. The development of this programme, which continues to evolve, arose from my clinical experience in the early 1980s when I was a senior nurse in a coronary care unit.

The frequent emotional distress that I observed in patients and their loved ones following a myocardial infarction (MI)

sparked my interest in measuring such problems, and later I decided to try to do something to ameliorate them. I therefore designed and conducted the first study to evaluate a nurse-delivered, in-hospital counselling programme for patients and their partners after a first MI, which was reported in 1990 in the *Journal of Psychosomatic Research*. The link to that paper and its abstract are provided below.

A prospective evaluation of in-hospital counselling for first time myocardial infarction men

Abstract

Self-ratings of anxiety and depression were studied over six months in 60 male patients, under 66 years of age, who were admitted to a coronary care unit with a first time acute myocardial infarction. Patients were randomly assigned to either a treatment group, where they received a simple programme of in-hospital counselling in addition to routine care, or to a control group, where they received routine care only.

All patients completed the Hospital Anxiety and Depression scale and a battery of visual analogue scales measuring anxiety on a range of topics related to recovery from a myocardial infarction. Patients who received in-hospital counselling reported statistically significantly less anxiety and depression than those who received routine care alone. This effect was sustained for six months after leaving hospital. It is concluded that a simple programme of in-hospital counselling, provided by a coronary care nurse, is efficacious and should be routinely offered to first myocardial infarction patients in hospital.

Citation

Thompson DR, Meddis R (1990) A prospective evaluation of in-hospital counselling for first time myocardial infarction men. *Journal of Psychosomatic Research*. 34, 3, 237-248. doi: [org/10.1016/0022-3999\(90\)90080-N](https://doi.org/10.1016/0022-3999(90)90080-N)

Link

www.sciencedirect.com/science/article/abs/pii/002239999090080N

Introduction and background

This article, coupled with another (Thompson and Meddis 1990), reports the first randomised controlled trial of an in-hospital package (four 30-minute sessions) of counselling delivered by cardiac nurses to patients with a myocardial infarction (MI) and their wives. This simple, brief intervention was associated with significant reductions in anxiety and depression

and improvements in knowledge (Thompson 1991) and satisfaction (Thompson et al 1990) among patients and wives, which were sustained for six months.

The study was informed by my experience as a senior clinical nurse working in coronary care in the 1980s. I had long been struck by the apparent distress displayed by many patients and their partners after a MI and

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decided to explore the literature pertaining to this topic. I was surprised at the dearth of published research on the emotional aspects of this population, even though the literature exhorted clinicians to provide information and offer emotional support to coronary patients: there was hardly any mention of partners. I therefore started to investigate the experiences of patients and partners coping with such a stressful event and measure their reactions, particularly anxiety, to it (Thompson et al 1982, 1987; Thompson and Cordle 1988). At that time, the emotional needs of patients, and especially partners, often went unrecognised or were given scant attention by nurses, largely I suspect because many nurses deemed them to be comparatively unimportant or felt ill-equipped to deal with them. I found such a gap in clinical care surprising and unacceptable and was determined to try to address it.

In 1986, I was awarded a Department of Health research fellowship to fund me to undertake a PhD in psychology while remaining in clinical practice. Informed by my earlier exploratory research findings, I embarked on designing and conducting a study that aimed to evaluate the efficacy of a simple nurse-delivered package of education and emotional support. I consulted with a clinical psychologist and enlisted the support of a like-minded graduate nurse.

I was surprised that the most challenging aspect of the study was gaining ethical approval. The chair of the ethics committee rang to tell me that members would have had no problem approving the study if it was a drug trial but were flummoxed having to consider an application proposing to 'simply talk to people'! Fortunately, my medical consultant colleague, unstintingly supportive, wrote a letter to the ethics committee guaranteeing to vouch for me and accept responsibility for any adverse consequences should they eventuate.

After pilot work and refinement, the intervention comprised four 30-minute sessions of in-hospital educative-supportive counselling delivered to male patients admitted to coronary care with a first MI, and their wives. Two nurses were trained by the psychologist and me to deliver the intervention, in addition to usual care, over the four sessions: within 24 hours of admission to the coronary care unit; at 48 hours (just prior to transfer to the medical ward); at 72 hours (24 hours after transfer); and at five days (24 hours prior to discharge home).

Patients at that time were predominantly male with wives as partners, hence the choice of sample. Patients and wives as dyads were randomly allocated to either the intervention (counselling) or control (usual care) group. The nurses delivering the intervention were video recorded to ensure fidelity and minimise bias. Outcomes were assessed using standardised instruments and scored by an independent researcher blind to the intervention.

At completion of the trial, analysis of the data revealed statistically significant differences in most, but not all, of the primary outcomes in favour of the intervention. Though pleased, I was also concerned that this may be an atypical finding. Fortunately, when I presented my findings at various nursing research conferences (for example, the International Intensive Care and the Royal College of Nursing (RCN) Research Society) and published them, I learnt that another researcher, a psychologist, had independently developed a broadly similar intervention, but for patients only, and found similar results.

Influence and impact

When the study findings were published there was widespread popular, nursing, psychological and medical press interest and coverage, not only in the UK but overseas, especially in Australia, Canada and the United States. The publishing arm of the RCN, Scutari Press, published the whole study (Thompson 1990), which undoubtedly helped increase its influence, impact and reach.

In 1991, I was invited to participate in a prestigious conference 'Outcomes of nursing: Setting priorities for research' hosted by the Department of Health, and present my work at a select 'by invitation' symposium 'Psychosocial aspects of cardiac rehabilitation' hosted by the British Heart Foundation. These afforded me the opportunity to share my study, network with key opinion leaders and influencers, raise my profile and shape the next steps of my research.

This involved me building and leading a research programme on recovery and rehabilitation after a cardiac event (Thompson 1998) with a continued focus on exploring the emotional reactions and needs of patients and partners (Mayou et al 2000). Drawing on earlier work (Thompson et al 1995), this focus was extended to include patients and partners from different cultural and ethnic backgrounds (Webster et al 2002).

An important strand of this work was to ensure psychosocial aspects (McGee and Thompson 1995) were addressed as a matter of routine in cardiac rehabilitation (Coats et al 1995). Thus, I secured funding from the Department of Health and, together with the RCN, Royal College of Physicians and British Heart Foundation, surveyed the national provision and cost of cardiac rehabilitation and hosted a series of presentations with input from patients, carers, clinicians, researchers, health service managers and policy makers. This culminated in a consensus conference and subsequent formulation of national clinical guidelines and audit standards (Thompson et al 1996). These guidelines emphasised an evidence-based, individualised, needs-led, menu-driven approach rather than the typical conventional 'one size fits all' approach.

However, when we conducted a national survey of adherence to these guidelines, we found it was suboptimal, with psychosocial factors being particularly poorly addressed (Lewin et al 1998). Subsequently, we developed a core set of standardised instruments, including ones for assessing psychosocial status, endorsed by the British Association for Cardiac Rehabilitation and the British Heart Foundation, to be used routinely in cardiac rehabilitation (Lewin et al 2004).

We also conducted further trials of an individualised educational behavioural treatment delivered by cardiac nurses in hospital which indicated substantial benefits for patients (Mayou et al 2002). Building on this work, we also conducted systematic reviews and meta-analyses of these types of interventions for patients and partners (Reid et al 2013, Ski et al 2016), the findings of which lent support to my initial study.

Taken as a whole, this work has been influential nationally and internationally. It has informed and been cited in national and international clinical guidelines (Thompson et al 1997), consensus statements (for example, Colquhoun et al 2013, Glozier et al 2013), Cochrane reviews (for example, Richards et al 2018) and health policy documents (for example, Department of Health 2000). I have been invited to contribute to a variety of influential policy bodies such as the NHS Centre for Reviews and Dissemination, Department of Health working group on health outcome indicators, Scottish Intercollegiate Guidelines Network (SIGN) and Healthcare Commission, and to

advise international cardiac rehabilitation organisations in Australia, Canada, Hong Kong, New Zealand and the United States.

As an indicator of influence and impact, the original publication has been cited well over 100 times (Google Scholar) and serves as the basis of a vibrant, growing, long-term research programme.

Current and future relevance

It is worth remembering that cardiovascular disease is the most common non-communicable disease and leading cause of death and disability globally. The human and economic burden is immense, and efforts are focused on disease prevention, management and rehabilitation to reduce this burden and to enhance the quality of life and well-being of people with the disease. My modest contribution to such efforts is on trying to prevent or alleviate the, often considerable, emotional distress many people (patients and family members, especially partners) experience. In contemporary cardiac care, where this issue is increasingly recognised, and in-hospital patient stay and nurse-patient contact time is reduced markedly, this work is likely even more relevant (Thompson et al 2018). It is likely to help patients and partners (many of whom are informal carers) achieve better health outcomes and experiences, and enhance nurses' knowledge, skills, satisfaction and self-esteem.

The challenge now is to adapt this type of intervention to a variety of patients and partners (regardless of sex, age, race, class, marital status) with different cardiac diagnoses (angina, heart failure, atrial fibrillation, cardiac surgery) and settings (hospital, home, community), taking account of the patient's (and partner's, caregiver's) values, needs, preferences, expectations and outcomes, and evaluate it, not simply in terms of 'does it work?' but 'what works for whom, when and why?' (Thompson and Clark, 2020). Thus, a 'one size fits all' approach is no longer tenable. For example, issues such as choice of delivery and preferred outcomes are important considerations (Thompson et al 2019).

Related to this is my research pertaining to the appropriateness of commonly used outcome measures, particularly of emotional distress, for other cardiac (Conway et al 2016) or ethnic (Le Grande et al 2017) populations. Patient outcomes are rarely shaped by a single factor such as age, gender, race and class but rather a combination of these,

such as a middle-class female older adult of Asian origin who is an immigrant to the UK (Allana et al 2020). It is through adopting such nuanced approaches to designing, describing and understanding the nature and effects of the intervention that we can help identify factors such as its crucial characteristics and determinants of issues such as self-care as well as context, settings and possible mechanisms. I believe the focused, concerted, systematic and on-going programme of research I have described contributes to the body of science in nursing and improvement of healthcare for the people, families and communities who nurses and nursing profess to serve.

I am particularly keen to exploit the rapidly developing field of eHealth technology as an aid to enabling nurses to deliver this type of intervention more effectively and efficiently to help the profession support the attainment of the United Nations' strategic development goals of good health and well-being, gender equality, quality education and reduced inequalities. This poses not inconsiderable challenges already alluded to and will involve new ways of learning, thinking and doing, but I have spent my research career to date trying to be creative, taking risks and being prepared for disappointment. Not always very well. But remember, if at first you don't succeed...

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Shifting the paradigm

by Alison J Tierney (FRCN 1995)



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In a stirring editorial in 2018 to launch the global Nursing Now campaign, its executive director Barbara Stilwell and colleague Jane Salvage incited us to seize the opportunity to tell ‘a new story of nursing’ (Salvage and Stilwell 2018). ‘This is the moment’, they said, ‘to shift the paradigm’.

Paradigm is not a word in nursing’s everyday vocabulary, but it is a relevant concept for any discipline. Kuhn (1962) defines a paradigm as referring to the practices that define a scientific discipline and encapsulate the patterns, theories, standards and methods distinctive of that discipline at any particular time. This distinct identity unifies its members and binds the body of knowledge that underpins their professional practice. Through research and scholarship, that body of knowledge is continuously clarified and refined. As a result, from time to time, one paradigm loses influence and another ascends.

Various paradigm shifts have redirected the focus and ethos of health policy and health services over time: for example, the ‘managerialism’ that drove the health service reforms of the 1980s (Griffiths 1983); the ‘evidence-based healthcare movement’ of the 1990s that demanded clinical decision-making be underpinned by research (Muir Gray 1997); and, more recently, the shift from the overly narrow millennium development goals to more inclusive sustainable development goals (SDGs) for global health in the 21st century (Benton and Shaffer 2016).

Now, for nursing worldwide, the SDGs are driving the agenda mapped out in the recently published State of the World’s Nursing report (World Health Organization) 2020).

All paradigm shifts in health care impinge on nursing and they also can be shaped from within nursing itself. Arguably the work of America’s early nurse theorists from the 1950s onwards took nursing into a new paradigm. Henderson, Johnson, Rogers, Orem, King, Neuman, Roy and Watson are among the best known. Although with varying emphases, their conceptual frameworks, otherwise called nursing models, all promoted the detachment of nursing from the traditional medical model towards a person-centred focus of care. The first nursing model in the UK was produced by Roper, Logan and Tierney, first published in 1980 in *The Elements of Nursing*.

Despite interest in this model, the British nursing profession at large did not warm to the notion of models and theories and as the 1980s gave way to the 1990s the criticisms became more vociferous and more polarised. A paper by Reed in 1995 helped me to understand better the arguments and forced me to think hard about whether nursing models had any continuing role. In turn, I published a paper in 1998 in the *Journal of Advanced Nursing* under the title ‘Nursing models: extant or extinct?’. It is this paper that I chose to revisit for my contribution to this collection of articles by RCN Fellows.

Nursing models: extant or extinct?

Abstract

Although nursing models have always had their sceptics, they are now subjected to more sustained criticism. Critiques have tended to focus mostly on the value of models for nursing practice but, increasingly, their place in nursing science is also being questioned. Reed believes that the growing disparagement of nursing models is symptomatic of the tensions between modernist and postmodernist perspectives on nursing.

Drawing its title from Reed’s discussion, this paper – from the opposite side of the Atlantic – reflects on the original purpose of nursing models and critically examines their relevance now, using the first and best-known British nursing model (the Roper-Logan-Tierney model for nursing) as the particular example for scrutiny.

Although the popularity of this model is acknowledged, concern has been expressed that it has not been tested. Can, and should, models be tested? This question is addressed in view of its apparent importance to the debate about whether or not nursing models have any continuing, legitimate role in theory or in practice.

Citation

Tierney AJ (1998) Nursing models: extant or extinct? *Journal of Advanced Nursing*. 28, 77-85. doi: 10.1046/j.1365-2648.1998.00766.x

Link

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With thanks to the late Nancy Roper (1918 -2004) and Win Logan for such a special partnership and friendship over so many years

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Introduction and background

In my 1998 JAN paper, I rehearsed the arguments in defence of nursing models and addressed some of the dogged questions.

On the question of 'testing', I still fall back on the assertion that a conceptual model is not a theory and, therefore, cannot be empirically tested, at least not in its entirety, but instead that the 'goodness' of a model hinges on the notion of credibility (Fawcett and Downs 1986).

And I still find helpful Reilly's (1975) explanation of the original purpose behind nursing models: 'We all have a private image (concept) of nursing practice which influences our interpretation of data, our decisions, and our actions. But can a discipline continue to develop when its members hold so many private images? The proponents of conceptual models of practice are seeking to make us aware of these private images, so that we can begin to identify commonalities in our perceptions of the nature of practice'.

Fawcett (1984) identified these 'commonalities' as 'person', 'health', 'environment' and 'nursing' and, together, these four concepts provide an overarching paradigm – a metaparadigm – for nursing.

Indeed, those very concepts were at the heart of the first-ever articulation of 'the nature of nursing' by Florence Nightingale in her *Notes on Nursing: What it is, and what it is not* (Nightingale 1860).

Nightingale did not see her 'Notes' as a definitive account: indeed, she described its content as 'hints'. In the Introduction she wrote: 'It has been said and written scores of times, that every woman makes a good nurse. I believe, on the contrary, that the very elements of nursing are all but unknown'.

A century was to pass before Nightingale's portrayal of nursing was further developed by Virginia Henderson (Harmer and Henderson 1955, Henderson 1960) and her definition of nursing was promoted widely by the

International Council of Nurses in a little booklet titled *Basic Principles of Nursing Care*. I still have my copy. It sits side by side with my *Notes on Nursing*. Both were compulsory reading when I was an early undergraduate student (1966-71) in the Department of Nursing Studies at The University of Edinburgh.

That was how I met Winifred Logan – she was one of my lecturers. I met Nancy Roper when I later returned to Nursing Studies to do a PhD under a Nursing Research Training Fellowship and she was there doing an MPhil. Her study (Roper 1976) exposed the fragmentation of clinical experience in registration-level nursing education at the time, and Nancy postulated that a nursing model might help to unify that disparate learning. She invited Win Logan to work with her to develop that idea and, to include a youngster in the team, they invited me. The outcome of our work together was the 'Model for Nursing based on a Model of Living' that provided the framework for our textbook, *The Elements of Nursing* (1980).

Influence and impact

Did the Roper-Logan-Tierney (RLT) model for nursing have an influence? Did it make an impact? I think it is fair to say that it did.

Our model was never intended primarily as a contribution to nursing theory or as a tool for practice. Its purpose was to provide an overarching conceptual framework for introducing nursing students to nursing in a way that shifted the focus from the persisting medical model of health care – centred on disease and treatment – towards a focus on the individualisation of nursing on the basis of a partnership relationship with patients.

Our model placed nurses in an interdependent relationship with doctors rather than in a dependent and subservient role. Those ambitions were somewhat at odds with the primacy of medicine at the time, but

they were in keeping with – and a necessary response to – the societal changes and scientific advances that throughout the 1970s had been gathering pace.

One of the criticisms of our model was that it was little more than a re-jig of Henderson's (1960) definition of nursing. Yes, there was overlap. Just as Henderson built on Nightingale, we built on both. We all stand on the shoulders of giants. The 'RLT model' was not reinventing nursing, but it did contain new concepts and new emphases. Henderson's construct had centred on 'helping (the) patient' with 14 'components of basic nursing care'.

Our 12 Activities of Living (ALs) was not a list of nursing activities. It was a prompt for systematic assessment of how the individual's activities (of living) – each with a range of possible complexities, often inter-related – were or could be affected by their change in health status. This was a radical shift, even if that's hard to believe now, from the routinised and standardised role of nurses that was dictated by the patient's medically diagnosed disease condition and its medical treatment. The pity was that our model was often reduced to a list of the 12 ALs and the all-important more complex conceptualisation of the model as a whole could only be appreciated by studying the book.

The book – *The Elements of Nursing* – became a core text in many first-level nursing programmes in the UK. With more than a dozen translations it also was used in schools of nursing around the world. So, our model did become very widely known. It was the model most often used in hospital wards, if a model was used at all, and especially by nurses trying to 'implement' the then-new Nursing Process because we had integrated its steps – assessment, planning, implementing, evaluating – into the RLT model. This systematic approach is taken for granted in today's evidence-based approach to practice but, back then, 'the process' was resisted by nurses and ridiculed by doctors (Mitchell 1984, Tierney 1984).

Does the fact that the RLT model became well known mean that it influenced the development of nursing? That it made an impact on the mindset of a generation of nurses? That it changed day-to-day practice? Impossible to say. All I would claim is that our model was timely, even prescient, and arguably that it (along with other models) did play a part in the sea change – the paradigm shift – that radically changed British nursing through the eighties and nineties.

Current and future relevance

So, do nursing models – an invention of last century – have any continuing relevance for 21st century nursing? That was essentially the question behind my 1998 JAN paper 'Nursing models: extinct or extant?'. I think now that I rather fudged the answer or, at least, hid behind the conclusion drawn by Reed (1995) that our 'systems of knowledge' in nursing must always be seen as 'open and alterable, and always evolving'.

We could have continued to evolve the RLT model but Nancy, Win and I already had decided not to produce a further edition of *The Elements of Nursing* (Roper, Logan and Tierney 1980, 1985, 1990, 1996). Not because we believed the model was entirely redundant, indeed its core concepts were rooted in values and ideals that still had real relevance, but because updating a large generic textbook was becoming an impossible task with research now burgeoning. Instead, we published a millennial monograph (Roper, Logan, Tierney 2000) to document our development of the model and its refinement over time, and to bring to a close our work together, leaving others to build on it if they so wished.

As the new millennium has progressed, there definitely has been a continued decline of interest in nursing models and Shi-FanHan et al's (2017) bibliometric analysis shows that related publications have been steadily decreasing. However, they also point out that a diminishing literature does not necessarily signal redundancy of a subject but, instead, could reflect a process of maturation and assimilation. It is the case, in all disciplines, that ideas which were novel, sometimes disruptive, do become accepted and assimilated to consolidate the paradigm shift. That, I suggest, is what has happened with at least some of the conceptualisation that was central – and novel – to models of nursing.

Models certainly get no mention in the State of the World's Nursing report (WHO 2020). However, I can discern in its summarisation of what nursing encompasses (para. 20) and in its description of nursing roles in 21st-century health systems (paras. 23-28) that many of the concepts which nursing models promoted are embedded in current thinking about nursing and its future directions.

We may no longer want models, but we still need to be articulating and documenting our evolving thinking about nursing. My sense is that the nursing profession still recoils from theoretical writing and debate. However, there

are important reasons for continuing to reflect on our disciplinary development.

We need to be clear about the core and the boundaries of nursing in order to focus and prioritise our research endeavours, and to understand and negotiate our inter- and multi-disciplinary interactions. That was much simpler in the past when health systems were still hospital-dominated and staffed primarily by doctors and nurses. In contrast, there is nowadays a huge range and diversity of health services and healthcare teams, in and across hospital and community settings,

and at the interface of health and social care. The world of health care in the 21st century is a very complex web indeed. And the challenges are huge.

If our profession really is to play a pivotal role in tackling these challenges, the 'new story for nursing' requires a bigger paradigm shift than ever before. One in which nursing looks outwards rather than inwards, working together with other health professions and the public to co-construct the broader story that could take us closer to achieving that compelling global aspiration of 'health for all'.

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A turning point for community psychiatric nurses

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There have been so many who have supported, encouraged and inspired me over the past 50+ years of my career. One person stands out. Professor Isaac Marks, a psychiatrist by background, changed the course of my life when I spent 18 months training as a nurse therapist on a programme that qualified me to be an autonomous nurse practitioner.

In 1972, Isaac, in launching the first nurse therapy programme, identified mental health nurses as a much-undervalued workforce and realised that their background experience and training made them ideal candidates to deliver clinically effective interventions.

Isaac experienced great resistance to his efforts, a great deal of which came from

within the nursing profession. In a sense, many believed at the time that nurses should 'know their place'. Thus, a significant contribution was made to the creation of the first generation of clinical nurse specialists in mental health; many graduates of the programme became leaders in various fields of healthcare. Most continued in clinical practice for many years. My own clinical practice has continued, alongside my other work, until the present day; now employing interventions in the COVID-19 era. For those interested in how our profession developed, Professor Peter Nolan provides what is arguably the most authoritative history of mental health nursing in his book (Nolan 1993).

Community psychiatric nurses in primary health care

Abstract

Background Community Psychiatric Nurses (CPNs) are increasingly working in primary health care with non-psychotic patients. This study was designed to test the efficacy of this work.

Method The study was carried out in six health centres in north London with a total of 36 participating general practitioners (GPs) and 11 CPNs. Using a randomised controlled trial, 177 patients were referred by their GP and randomly allocated to continuing GP care, immediate community psychiatric nursing intervention or placed on a 12-week waiting list, after which time the patient was offered CPN intervention. A range of measures of symptoms and social function were used, and ratings were carried out at assessment and at 24 weeks.

Results Patients improved on all measures over time ($P < 0.001$ for all measures). However, there was no difference between the group of patients receiving GP care and those who received immediate CPN care. Improvements seem to be independent of the amount of contact. Dropout rates from CPN intervention were high (50%). CPN dropouts had greater levels of psychiatric symptoms. Patients were more likely to drop out from the care of CPNs who had completed a one-year, post-qualifying CPN course than from the care of those without that training. Following referral, patients continued to attend the GP at the same rate.

Conclusions The results add weight to the argument that CPNs should refocus their activity on people with serious mental health problems and indicate that CPN education should focus on skill acquisition and interventions of proven effectiveness.

Citation

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The author's collaborator on this research, Professor Julia Brooking, sadly died in 2014. Her contribution to nursing cannot be described with any adequacy in this footnote. See her Obituary in *The Guardian* (2014). The study that is the subject of this article was funded by a research grant from the UK Department of Health (1988-1991).

Notes

¹Throughout this article, the term community psychiatric nursing (CPN) is used, rather than the term community mental health nursing. The term community psychiatric nursing has continued in common currency, used by most mental health professionals and the general public alike.

²The Institute of Psychiatry has been renamed as The Institute of Psychiatry, Psychology and Neuroscience (Kings College, London).

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Introduction and background

In the 1960s, I began a course of integrated training that would lead me to become dually qualified, as both a mental health and learning disabilities nurse. I started my apprenticeship in two large hospitals that were typical of those dotted around the UK at that time. These hospitals contained many patients who should not have been admitted to hospital at all and who could have been safely cared for within community settings.

By the 1960s, the process of deinstitutionalisation had begun, and the number of mental health inpatient beds had fallen from 140,000 in 1960, to under 20,000 today. Over the course of the next decade, I obtained further experience in general nursing, and then as a charge nurse in a psychiatric hospital.

In 1976, I was fortunate to be selected for an innovative 18-month full time training as a nurse therapist at the Maudsley Hospital and Institute of Psychiatry², London. The programme, directed by a psychiatrist, Professor Isaac Marks, focused on skills acquisition in evidence-based approaches, cognitive behaviour therapy (CBT) for phobic, obsessional states and other common mental health problems. Over 25 years, this programme delivered hundreds of graduates and is regarded as one of the best examples of skills acquisition in mental health care (Gournay et al 2000). At the Maudsley/Institute of Psychiatry I was exposed to a world-leading research environment that began to form my belief that mental health care should be evidence based and that it is essential to test hypotheses using a rigorous scientific methodology.

On graduating as a nurse therapist in 1978, I began my career in a district general hospital psychiatric department. By then, I had decided to pursue my own research. With generous help from the NHS, in the form of a small research grant and study leave, I was able to undertake a randomised controlled trial (RCT) of treatments for agoraphobia. This was to become the basis of my PhD in psychology and, eventually, the basis of a textbook on outcomes and treatment process (Gournay 1989).

In the course of my clinical work, I had observed the work of CPNs in my own outpatient service. This workforce was growing rapidly, as deinstitutionalisation continued. The development of community psychiatric nursing has been well described

by Brooker and White (1995) who conducted national surveys of the work of CPNs over the late 1980s and early 1990s.

A survey of CPNs in England in 1989 showed that a quarter of all CPNs did not have a single client with a severe and enduring mental illness, such as schizophrenia, on their caseload (White 1993). CPNs were increasingly based in general practice (23%) with 37% of all referrals coming from general practitioners. It had become clear that CPNs were, in the majority, working with people with non-psychotic disorders, such as general anxiety, 'stress' and relationship difficulties.

Being intrigued by these developments and finding that, at that time, there was no evidence of CPN effectiveness, I approached the UK Department of Health, arguing quite simply, that this topic should be investigated, because of the relevance to national mental health policy. As I was a full-time NHS employee, I was advised to seek a collaborator from an academic background. I then asked Julia Brooking, who was first, a senior lecturer at the Institute of Psychiatry and then, Professor of Nursing at the University of Birmingham, to join me in this research. The Department of Health grant of nearly £200,000 funded the RCT that is the subject of this paper (Gournay and Brooking 1994).

The RCT also allowed an economic analysis (Gournay and Brooking 1995); this involved a consideration of costs to patients and their families, the health care system and quality of life gains. Our analysis showed that the quality of life gain, per unit of cost for the primary care population, was considerably less than the quality of life gain in populations where CPNs were working with people with schizophrenia. In addition to the RCT and economic analysis, we also conducted a study of CPN skills in assessment methods, by collecting many hours of videotape. This process study (Deville and Gournay 1995) demonstrated the need to develop CPN skills.

Influence and impact

The 1994 paper had both personal and more general influence and impact. With regard to general impact, at the same time as our study was being conducted (1988-1991), a classmate of mine from the Nurse Therapy Programme, Professor Charlie Brooker, reported the results of a study using a quasi-experimental design to evaluate the effect of training CPNs to undertake psychosocial interventions, with families caring for a relative with schizophrenia

(Brooker et al 1994). The study showed that CPN training led to an improvement in both positive and negative symptoms in patients, benefits to relatives and tentative evidence that their interventions reduced inpatient episodes. The results of our studies were made known, prior to publication, to the governmental review of mental health nursing led by another Fellow of the Royal College of Nursing (FRCN), Professor Tony Butterworth (Butterworth 1994). The review had come to learn that 80% of people with schizophrenia were not receiving the services of a CPN and therefore made the following recommendation: 'That the essential focus for the work of mental health nurses lies in working with people with serious or enduring mental illness in secondary and tertiary care, regardless of setting.'

This recommendation was wholeheartedly implemented across the entire UK in the years that followed. An additional measure of the influence and impact of our study and that of Brooker et al (1994) was the fact that both papers were published in the same edition of a world leading psychiatric journal, the *British Journal of Psychiatry*, rather than a nursing journal. For the first time, the wider mental health community was made aware of the importance of CPNs in the task of delivering appropriate care to a population in great need; that is, those with serious and enduring illnesses such as schizophrenia.

At a personal level, the study stimulated me to pursue, in addition to my clinical work, as much postdoctoral education as possible. I thus acquired knowledge and skills in epidemiology, statistics and more generally, neuroscience. As our study completed in 1991 and by a happy coincidence, Professor Dame June Clark FRCN – then President of the Royal College of Nursing (RCN), was appointed to develop a school of nursing at Middlesex University. June asked me to head the mental health division. I will be forever grateful to her for opening the door to areas of nursing and healthcare that were, at the time, foreign to me. Over a short period of time, I obtained incredibly valuable experience, serving on several governmental bodies as well as being active in the RCN Mental Health Society.

I must here acknowledge the inspiration and support I derived from society colleagues, notably Malcolm Rae, FRCN, and Tom Sandford – at that time, the RCN's mental health adviser. I was also introduced to government at the highest level by the then Chief Nursing Officer, Dame Yvonne

Moore, who became yet another source of encouragement. In the mid-1990s I began visiting innovative mental health services across the world, notably in Europe, the United States, Australia and New Zealand. I developed an interest in international development; over the years and until recently, working in several countries, including the Czech Republic, Russia and Palestine. My involvement in research also continued in my clinical setting, with an epidemiological study and an RCT of treatment for body image disorders: (Boocock et al 1996, Veale et al 1996).

In 1995, I was appointed the first Professor of Psychiatric Nursing at the Institute of Psychiatry. This provided the opportunity to continue my research interests in the development and testing of training programmes for nurses and other mental health professionals. I also set up several research collaborations across Europe, Australia and the United States (US). I was honoured to be elected Psychiatric Nurse of the Year in the US in 2004. During my appointment at the Institute of Psychiatry, my psychiatrist colleagues proved to be supportive of both nurses and nursing. I served for two years as chair of the institute's academic board: an experience that taught me a great deal about higher education. Over the 11 years at the Institute of Psychiatry, I became involved with training programmes for CPNs in evidence-based approaches, notably the Thorn Nurse training programme (Gamble 1995).

Today's multidisciplinary training programmes for community mental health professionals owe much to the original Thorn Nurse concept. I also took a particular interest in nurses' skills in medication management and, with my PhD student and then postdoctoral fellow, Richard Gray, developed training programmes that were evaluated in RCTs; these studies being funded by the Medical Research Council, the European Commission and the National Government of Thailand (for example, Gray et al 2004, Gray et al 2006, Maneesakorn et al 2007). The interest in medication management led to my involvement in early work on mental health nurse prescribing and the publication of a discussion paper on the topic (Gournay and Gray 2001).

My interest in the development and evaluation of training generalised to other areas, for example, nurses working with people with multiple sclerosis (Askey-Jones et al 2012), training in the management of violence for nurses in secure units (Rogers et al 2006)

and in practice nurses in primary care settings (Plummer et al 2000). In addition to research in primary care settings, I became involved in the development of national primary care policies, starting with a discussion paper with the Professor of Psychiatry at the Institute of Psychiatry, Sir David Goldberg (Goldberg and Gournay 1997). Notably, Sir David has been a source of enormous support and encouragement to me and many other nursing colleagues, including the aforementioned Charlie Brooker and Tony Butterworth.

Thus, it might be argued that our 1994 paper had enormous personal and professional impact and influence and provided me with a springboard to pursue interests in other areas of mental health care. For example, I chaired the guideline development group for the National Institute for Health and Care Excellence (NICE) on the management of disturbed/violent behaviour in mental health care, served as a special adviser to the UK Joint Parliamentary Committee on Human Rights in their work on deaths in custody and contributed to research and practice in high secure psychiatric services at Broadmoor and Ashworth hospitals. I also secured funding for a study on nurse stress in all four UK high secure hospitals (Reininhaus et al 2007). Realising that building a research nurse infrastructure was a priority for the future, I began developing training programmes for nurse researchers. In addition to supervising PhDs, I also obtained funding for postdoctoral fellowships and took part in multidisciplinary research training initiatives. The primary lesson learned at this time was that one should regard the PhD as the starting point for training to become a competent researcher, rather than an end point.

Current and future relevance

As noted above, our study began a complex 'domino effect'. The training programmes I have mentioned had a variety of outcomes. For example, we found that specific training in medication adherence worked well in a UK community mental health team setting (Gray et al 2004) but failed to show effectiveness in a five country European study (Gray et al 2006). Similarly, the study we conducted on training professionals in the management of dual diagnosis (the combination of drug and alcohol and mental health problems) (Craig et al 2008) showed that training made little difference to mental health, social functioning and cost outcomes. The importance of evaluating training programmes

has been expressed in the general psychiatric literature (Gournay and Thornicroft 2000) and in the outcome of the workforce action team that was set up to support the 1999 National Service Framework for Mental Health (Brooker et al 2002). Thus, we now face this situation. As a country, we spend many millions of pounds on the education and training of mental health professionals, in interventions from CBT for anxiety disorders to psychosocial interventions for those with serious and enduring mental illnesses.

However, there is a conundrum. Research has told us that training in evidence-based methods may, or may not, improve clinical skills and patient outcomes. Furthermore, even if training is shown to be effective in a research trial, can one then assume that the generalisation of training to the wider workforce will lead to the same results? In one sense, our 1994 paper is still relevant because of the ongoing need to ensure that the workforce has the requisite skills and knowledge. Sadly, it appears that any comprehensive evaluation of education and training for the workforce is no longer a national or global priority.

Ensuring the mental health workforce is provided with evidence-based skills should be a priority around the world. Over the past 25 years, I have been involved in research in Australia and have worked with colleagues there to develop national treatment guidelines (Gournay 2017). The challenges of workforce development are the same in that country and, as I have observed first-hand, exactly the same in the Czech Republic, the West Bank and Siberia. My experiences have led me to the view that mental health nurses, wherever they are, remain greatly undervalued and that scant attention is often given to nurturing them or providing them with high quality continuing education and training.

Finally, another lesson from 1994. The paper remains relevant insofar as it demonstrated that one can mix research methods. Under the umbrella of an RCT it is possible to undertake qualitative studies that will tell us much more than the comparison of pre and post test results on standardised measures of change.

The study also has relevance insofar as the lesson learned about the need to consider the cost and economic value of what we do. While one might argue about costing methods and whether or not one can quantify quality of life, we exist in a world reality of an expanding and infinite demand for healthcare and only a finite workforce to meet that demand.

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Frameworks for emergency nursing assessment and management: the Components of Life Model and the Jones Dependency Tool

by Gary Jones (FRCN 2002)



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During the 1980s, nursing in the UK was moving from the traditional ‘completing tasks in a certain way because Sister says so’ (Laurent 2019) to more evidence-based practice. Part of this move included the need for structure that came with the introduction of the nursing process which, in the UK, including in my own hospital in Orsett in Essex, became prominent in the latter part of the 1970s and early 1980s. From this, further developments included the use of nursing models.

Although the nursing process and nursing models were important tools in structuring nursing care, my concern was that emergency

department (ED) nursing was very different from that on the wards. Any move towards using both the nursing process and a model of nursing had to link to other developments in emergency care, particularly since the introduction of triage as part of the initial patient assessment.

It was also essential that any framework was linked with the anatomical/physiological aspects of the medical model and was simple and quick to use. The development of the Components of Life Model achieved these requirements and gave us an added bonus in that the components were able to be used in the development of a dependency tool.

Care of the emergency patient: frameworks for nursing assessment and management

Abstract

This article provides the reader with an insight into various models and frameworks used in emergency care and focuses specifically on the Components of Life framework. Throughout the article, the use of the Components of Life framework is linked with clinical conditions that commonly present in the emergency care setting, showing how a structured approach to nursing care can be achieved.

Citation

Jones G (2003) Care of the emergency patient: frameworks for nursing assessment and management. In Jones G, Endacott R, Crouch R (Eds) *Emergency Nursing Care: Principles and Practice*. Cambridge University Press, Cambridge, pp9-21.

Introduction and background

The development of the Components of Life Model/framework and the Jones Dependency Tool (JDT) took place during the latter part of the 1980s at Orsett and Basildon Hospitals, Essex in the UK. Earlier in the 1980s, the school of nursing had introduced the nursing process and models of nursing. Although focused primarily on the ward patient, it was clear that

the ED had to become involved. After returning from a Florence Nightingale Travel Scholarship to Canada and the United States in 1980, I had introduced nursing documentation and was keen to take this further. The work being undertaken by the school of nursing and the director of nursing was, with some adaptation, the opportunity to develop a structured approach to nursing care in our EDs.

The model was part of a wider development of nursing models for the whole hospital group and it would eventually link to a computerised nursing care system. The development group for the ED model comprised of the lead nurse for the hospital project and staff from the ED. Although we looked at the traditional theorist models, I found the terminology, fundamental needs or activities of daily living and many other aspects of the models difficult to link to the ED environment. I was also concerned that the documentation in many of these models was lengthy and could become overwhelming.

Because of the nature of ED nursing, the important links between nursing and medical care and the fast turnover of patients (in 1980s we had no 'trolley waits' or four-hour targets), I was keen to develop a model/framework from practice. Practice-based development of nursing models had been given credibility by Wright (1986). The group chose this approach to develop the Components of Life Model.

From the components that make up the model/framework, a dependency tool was designed. The purpose of the tool was to enable each patient to receive a dependency rating that would determine the required level of competency of the nurse allocated to the patient, and an overall dependency rating across the department. Over the years, the model/framework and the dependency tool have been refined.

Influence and impact

The model was constructed by observing nursing practice in the EDs of the two hospitals. Several component headings emerged and an agreed philosophy comprising beliefs, values and goals was established.

The model is based on the belief that all humans are individuals with individual human needs. It is also based on the belief that during their life, the individual is engaged in various self-care activities to retain independence. Seven components of life comprising physical, human behavioural and social aspects were identified and, when in balance, maintain health and quality of life. An event (physical illness, mental illness, or injury) in the course of the individual's life can upset the balance and disrupt the ability to maintain health and quality of life. The individual identifies emergency care staff as the resource to assist them to re-balance the components, re-establish independence and therefore continue physical, emotional and social comfort.

The model includes four universal goals:

1. To establish a partnership with the patient/relatives.
2. To achieve a level of independence in the patient appropriate to the illness or injury.
3. To enable the individual to avoid ill-health or injury through self-care, health education and environmental safety.
4. To ensure optimum effectiveness of nursing and medically prescribed treatment.

The dependency tool was based on the seven components and rating scores were identified for each component. A total rating score determined the patient dependency for nursing care. Once the model and dependency tool had been signed off, nursing documentation was designed, and staff training introduced.

When the model and dependency tool were introduced in the two EDs in South Essex, they provided an improved structure to the initial assessment and subsequent nursing management of the patient. The component headings in the nursing documentation provided for much improved nursing records. When I published the model and dependency tool (Jones 1990), I had no idea at the time how the model would influence emergency nursing care throughout the next two decades.

As chair of the Royal College of Nursing (RCN) Accident and Emergency (A&E) Association and, in 1992, taking on consultancy work in the ED, I was able to introduce the model and dependency tool to a number of EDs throughout the UK. I also had the opportunity to publish articles in emergency care journals and chapters in emergency care books. After a number of departments began using the model, and after I began working with a number of EDs developing nursing records and dependency tools, the model was revised from seven to six components:

1. Communication – consciousness/human behaviour/human senses.
2. Airway/breathing/circulation.
3. Mobility.
4. Environmental safety, health and social well-being (previously two components covering environmental health and health promotion).
5. Personal care.
6. Eating/drinking/elimination.

The model was one of several documents that aided the RCN A&E Association working party to establish the mission statement, philosophy, role and scope of practice of the ED nurse. Accident & Emergency –

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Challenging the Boundaries (RCN 1994) states, probably for the first time, what the service and emergency nurses are all about.

As part of the ongoing development, I was always keen to have the dependency tool validated and this was undertaken by Crouch et al (2001). Through a three-round Delphi study, the six components linked with the model were drawn down to five (personal care was linked with eating/drinking/elimination) so that triage scoring could be linked to the dependency tool thus making six components:

1. Communication.
2. Airway/breathing/circulation.
3. Mobility.
4. Eating/drinking/elimination and personal care.
5. Environmental safety, health and social needs.
6. Triage.

Each component heading has three ratings. On arrival, and subsequently throughout the stay in the ED, this tool provides the overall ratings that determine which of four dependency levels the patient falls into. Dependency levels are: low, dependency=0, medium, dependency=1, high, dependency=2, total, dependency=3. The main study in six EDs in England provided evidence that the refined tool (now named by Crouch, the Jones Dependency Tool (JDT), is a reliable and valid instrument for measuring adult patient dependency in the ED (Crouch et al 2006).

The main purpose of the JDT is:

1. To ensure that the patient is allocated to a nurse with the relevant competencies to provide the care required.
2. To provide a dependency rating across the department that can be calculated, and actions taken if the threshold level is reached.
3. To determine nursing numbers and, with dependency/competency factors, determine skill mix.

New versions of the refined model/framework and the JDT were published in 2003 (Jones et al 2003) and in 2008 (Accident & Emergency: Theory into Practice (Dolan and Holt 2008)). Since then, many more departments have taken to using the components from the model, mainly as a structure to their nursing documentation, and many individuals have used the model as part of their emergency nursing studies.

The JDT has been widely adopted in departments in the UK and internationally.

Papers have been published in the UK, Australia, Brazil and Portugal. I was interviewed for the January 2002 Emergency Nurse journal that published a news item indicating that government advisers were considering the merits of the JDT to assess patient dependency in emergency settings (Lipley 2002). I said: 'We are still measured on how many patients come through the door. If you can measure dependency and link that with the number of patients in the department and link this with competencies of the nurse, you have got for the first time three parts of being able to say "this is the establishment and skill mix we need".'

Research undertaken in the ED of Bristol Royal Infirmary (O'Brien and Bengier 2007) showed the JDT to be an effective tool that can be used with minimum difficulty and inconvenience. The conclusion to the publication indicated that patient dependency is one of the essential determinants of nursing grade mix and with further work and adaptation, the JDT can be used to predict workload, resource use and the optimal staffing levels that will provide safe and effective patient care. Dependency can be readily and repeatedly assessed, and we recommend this approach to other EDs.

A further study in the Prince of Wales Hospital, Sydney, Australia in 2010 (Varndell et al 2013) demonstrated the reliability, validity and sensitivity of the JDT for the first time in an Australian adult ED. It showed patient dependency can be measured in a hectic environment and enabled appropriate patient placement in the department and capacity planning.

Much work has also been undertaken in Portugal and the JDT is used as an integral part of patient assessment in several departments. In 2014, I was invited to meet with senior nurses from emergency care in Portugal and to see their work on the JDT. In 2015, I presented a joint paper with the Portuguese ED nurses at the International Council of Nurses conference in South Korea. The National Institute for Health and Care Excellence (NICE) safe staffing guideline (NICE 2015) recommended that, when determining ED nurse staffing, patient dependency should be considered using for example, the JDT.

Current and future relevance

I am aware from contacts, that the model and JDT continue to be used in departments in the UK and internationally. The JDT is a major

component of the RCN Baseline Emergency Staffing Tool (BEST) (RCN 2015). Using BEST requires every patient attending the ED to be scored using the JDT. The total number of patients are then entered into the RCN BEST website.

The result is the nursing numbers needed per hour to provide for the workload 80% of the time. The whole-time equivalent workforce is then calculated to provide those numbers. The skill mix is then assigned to the whole workforce using the Faculty of Emergency Nursing competency levels. The tool provides a baseline on which to build workforce planning strategies.

The Components of Life Model is recommended for use within the Framework to Support the Delivery and Recording of Nursing Care in Emergency Care Networks in Ireland (Eire) (National Emergency Medicine Programme 2017). The model's philosophy and goals permeate throughout the framework document and the components are used for the recording of nursing care.

Before the Components of Life model and the JDT, little was available to provide a structure to nursing care in the ED. Today, both the model and the JDT enable EDs across the globe to maintain a framework for emergency nursing assessment and management.

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Nurse staffing impacts on patient and nurse outcomes

by Anne Marie Rafferty (FRCN 2002)



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Although it's always been obvious that there has to be a link between nurse staffing levels and quality of patient care, it wasn't until the 1990s that research led by Linda Aiken in the United States (Aiken et al 1994) began to produce evidence of the nature of this relationship. I led the first study in England to establish whether or not similar links would be apparent in NHS hospitals, and its findings were reported in 2007 in the paper that underpins this article.

The idea for that study, however, took root some years before. It began in 1995 at a meeting in Bellagio, Italy at the Rockefeller Conference Center, nestled in the hills around Lake Como. It brought together some of the key international protagonists in nursing and outcomes research across Europe to start fleshing out a study design and ironing out methodological challenges in advance of

writing a grant application. I was invited in my dual capacity as a new arrival at the London School of Hygiene and Tropical Medicine – as director of a think-tank for nursing and allied health research, the Centre for Policy in Nursing Research – and Harkness Fellow collaborator with Linda Aiken.

What a sublime start to a research study, one I haven't managed to repeat since, and in marked contrast to the usual wave of frantic, pent-up nervous energy that goes into grant writing. Instead, this was a more leisurely mix of workshops and scholarly seminars where we also mixed socially over dinner with colleagues from other disciplines who were resident at the centre, this being the practice there to foster cross-pollination of thinking. It was a perfect environment to enable ideas to ferment in a congenial and convivial setting.

Outcomes of variation in hospital nurse staffing in English hospitals: cross-sectional analysis of survey data and discharge records

Abstract

Context Despite growing evidence in the United States, little evidence has been available to evaluate whether internationally, hospitals in which nurses care for fewer patients have better outcomes in terms of patient survival and nurse retention.

Objectives To examine the effects of hospital-wide nurse staffing levels (patient-to-nurse ratios) on patient mortality, failure to rescue (mortality risk for patients with complicated stays) and nurse job dissatisfaction, burnout and nurse-rated quality of care.

Design and setting Cross-sectional analysis combining nurse survey data with discharge abstracts.

Participants Nurses ($n=3984$) and general, orthopaedic, and vascular surgery patients ($n=118752$) in 30 English acute trusts.

Results Patients and nurses in the quartile of hospitals with the most favourable staffing levels (the lowest patient-to-nurse ratios) had consistently better outcomes than those in hospitals with less favourable staffing. Patients in the hospitals with the highest patient to nurse ratios had 26% higher mortality (95% CI: 12-49%); the nurses in those hospitals were approximately twice as likely to be dissatisfied with their jobs, to show high burnout levels, and to report low or deteriorating quality of care on their wards and hospitals.

Conclusions Nurse staffing levels in NHS hospitals appear to have the same effect on patient outcomes and factors influencing nurse retention as have been found in the United States.

Citation

Rafferty AM, Clarke SP, Coles J et al (2007) Outcomes of variation in hospital nurse staffing in English hospitals: Cross-sectional analysis of survey data and discharge records. *International Journal of Nursing Studies*. 44, 175-182. doi: 10.1016/j.ijnurstu.2006.08.003

Link

www.sciencedirect.com/science/article/abs/pii/S0020748906002446?via%3Dihub

Introduction and background

In many ways the study started before Bellagio and had been incubating during the year I spent in 1994-5 on a Harkness Health Policy Fellowship at the University of Pennsylvania where I was mentored by Linda Aiken, the world-renowned policy researcher in nursing. I undertook a post-doctoral analysis of the American nursing political positioning and lobbying tactics used during the Clinton health reform effort in the early 1990s, and what we could learn in the UK from those tactics.

Part of my fellowship experience involved joining meetings that Linda was leading with her research group on different studies that were being proposed at this time. I was just a lowly lecturer and humble historian at the University of Nottingham and while my MPhil (Surgery) at Nottingham University in a previous life had given me some understanding of clinical research, I was blissfully unaware of the world of health services research. So, my initial baptism into that world occurred during my Harkness Fellowship, which has had a profound impact on my career and interests ever since. The policy analysis I undertook gave me some understanding of how evidence and policy could work together to bring about advocacy for change.

A notable meeting to which Linda invited me was at the American Academy of Nursing in Phoenix, where she was laying out the findings from what became the landmark paper published in *Medical Care* (Aiken et al 1994) and the first to demonstrate the impact of nurse staffing levels on patient mortality in acute care in the United States (US). What really impressed me at the time, and still does, is Linda's infallible and uncanny ability to articulate policy through evidence. As with the best researchers, she is also a brilliant communicator.

'Penn' was to be a milestone in my career. It was while I was there that I was headhunted to take up the role of director of the new Centre for Policy in Nursing Research. This was a joint venture with the Royal College of

Nursing (RCN) to produce an evidence base and policy justification to change funding structures for nurses and midwives and the allied health professions. It was a very exciting time in a dynamic multidisciplinary environment and I really relished that experience, including collaborating with Professor Michael Traynor, another RCN Fellow who has contributed an article to this collection.

The grant application we wrote following the Bellagio meeting was successful in getting funded by the National Institutes of Health in the US. The study laid down the foundations for a major platform for policy influence. We published a number of papers, mainly from the survey data, including reports of the state of the nursing workforce in the different countries where studies had been conducted – Scotland, England, US, Germany and Canada – so that, in many ways, it was the prototype for subsequent studies which some of us would collaborate on and an antecedent for the RN4CAST study across different European countries (Sermeus et al 2011).

My co-authors on the 2007 *International Journal of Nursing Studies* (IJNS) report of the English study were Sean Clarke, James Coles, Jane Ball, Philip James and Martin McKee, along with Linda Aiken. We all learned a lot from this study about how different countries' health systems collected and curated their staffing type and numbers, and their outcomes data such as patient mortality and complications. I recall in meetings that data systems were a major focus. Across the Atlantic our meetings were scheduled to coincide with the American Academy of Health Services Research, their blue-chip meeting. It was exciting presenting our findings there to a health services and policy research audience.

Influence and impact

The 2007 IJNS paper has had over 650 citations in publications on subjects ranging from nurse satisfaction to burnout and education, with most relating to quality of

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The author would like to give her profound thanks to Linda Aiken for her support and inspiration over the past 25 years; to all other co-authors of the 2007 *International Journal of Nursing Studies* paper and the teams from the hospital outcomes study and RN4Cast for exemplary collaborations; to Dr Ivanka Ezhova; and to Alison Tierney, long time mentor since my student days at Edinburgh University, for stellar editorial input to this article

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RESOURCES

New European study overhauling hospitals for nurse wellbeing
www.nursingtimes.net/news/hospital/exclusive-new-european-study-overhauling-hospitals-for-nurse-wellbeing-24-02-2020

care and later research on staffing levels and patient mortality, patient safety and the work environment. Examples of publications that have cited this paper include Aiken et al (2012, 2014), Duffield et al (2011), Twigg and Duffield (2009), Sermeus et al (2011), Schubert et al (2008, 2012), Shekelle (2013), Ball et al (2014), Ausserhofer et al (2014), West et al (2014), Dall'Ora et al (2015).

Of course, one study and the publication of one paper rarely can change the status quo, but a new or counter narrative can be set in motion. And the paper remains important as a drawbridge between the initial large hospital outcomes international study and the replicability of that design, and as the bridgehead it provides into a successor study known as RN4CAST (Sermeus et al 2014) [Q1: Should this be Sermeus et al 2011 – Sermeus et al 2014 is not in the reference list?]. This has become one of the most successful studies in terms of its type, and one of the largest and most impactful studies in terms of nursing policy across Europe.

The RN4CAST study was designed to forecast nurse staffing requirements on the basis of known links between staffing and quality of care. The most significant paper published from that study quantified the impact of nurse staffing on patient mortality and confirmed that it was not only numbers but capabilities that mattered in terms of how nurses were educated, specifically whether or not to graduate level (Aiken et al 2014).

Current and future relevance

The RN4CAST study and all of the research that has been done over the past 20 years or so on the subject of nurse staffing and its impact on patient care link to the international debates that we are having in 2020, designated by the World Health Organization (WHO) as the International Year of the Nurse and the Midwife. Much of the content of the State of the World's Nursing (SOWN) report published in April (WHO 2020), focuses on or impinges on staffing. Gaping shortages in the workforce supply across the globe are revealed, with serious maldistributions as upward of 80% of these shortages are in lower to middle income countries. The world is short of six million of the 29 million nurses it is estimated to need, so there is a huge deficit in healthcare capacity worldwide.

We are at a critical juncture in our history. Staffing standards matter for patient safety, not just in countries with well-developed

and aspirational healthcare systems but arguably even more so in low to middle income countries as an essential underpinning for implementing the sustainable development goals (SDGs) of the United Nations (UN) and for ensuring universal access to healthcare.

It is imperative that we now seek to lobby governments around the world to implement the recommendations of the SOWN report which advocates mass investment in education for nurses and midwives, decent jobs with good working conditions and leadership at all levels. These investments will in turn facilitate the UN's SDGs in health, education and gender development (RCN 2020).

In the UK, legislative reform has been leveraged in Wales in 2016 and Scotland in 2019 using evidence generated from the accumulated research over the past 20 years and now we hope that England and Northern Ireland will follow. The 2007 IJNS breakthrough paper provided part of the platform to support further cross-national studies in Europe (RN4CAST), but now it is time to move forward to building on the evidence base to focus on intervention. In a recently funded Horizon 2020 multi-country study (Magnet4Europe) of an organisational intervention designed to protect the mental health of nurses and doctors we are taking the evidence base in staffing and quality improvement to the next level.

I am delighted to be involved in this exciting new study which is under the overall leadership of Linda Aitken and Walter Sermeus, with the UK arm led by Jane Ball, another RCN Fellow and one of the team who worked with me on the 2007 study. Burnout was a significant finding in that study and it remains a pressing issue, only likely to increase in the future. Given we are in the grip of a pandemic, this move towards intervention is highly relevant to the present situation and how we might respond and future-proof the workforce.

Evidence alone can rarely change the policy weather but it can raise the temperature by feeding into dialogue and the heat of a campaign. The RCN (2020) is building a level of sophistication in campaigning methods and garnering public support with a cast-iron evidence-based case for legislation. Northern Ireland led the way by taking a stand on staffing and pay, even being prepared to take strike action. COVID-19 has raised the profile of nursing as never before. This is our moment and we, as nurses, need to seize the day.

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Nurses at the top table: the Munich Declaration and its sequelae

by Ainna Fawcett-Henesy (FRCN 2004) and David Benton (FRCN 2003)



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The two of us originally had intended to write our own separate articles for this RCN Fellows' publication but, with shared interests in policy development, we decided to team up. We are both passionate about the need for nurses to be involved in – and sometimes to lead – policy formation, and we both have experience of being at 'the top table'. We vehemently believe in advocating for the contribution of nurses in envisioning, formulating, and implementing nursing, health, and social policy.

At the heart of this article is the question as to why nurses should be involved in policy formation. We believe nurses bring a unique perspective to healthcare policy development because of their education, professional values and ethics, advocacy skills, and experience (Benton et al 2017). Social justice is a core value, and nurses have an opportunity to serve as advocates for patients, families, communities, vulnerable populations, other nurses, and healthcare organisations.

Nurses know the specific needs of the communities they serve. They can protect quality of care and mitigate risk by ensuring a safe environment and access to required resources and opportunities. They are a

crucial caregiver, spending more time with patients than most other professions. It is nearly impossible to imagine a care system without them. Nurses have always been at the forefront of change in healthcare and public health (Benton et al 2019). Nurses innovate. So, decision-makers need to hear from nurses.

Accordingly, we have chosen to focus principally on a significant regional declaration endorsed by the World Health Organization (WHO). The development of the Munich Declaration was driven by the first author (Ainna) and served as a touchpoint for assessing the profession's progress for the second author (David) when working for the International Council of Nurses.

The declaration made at the WHO European Ministerial Conference on Nursing and Midwifery in Munich (2000), spoke directly to the role and contribution of the profession. We look at what went well with its implementation as well as examining the barriers to progress. In many regards the content of the declaration was well ahead of its time and contained material that is fully aligned with several of the United Nations' General Assembly (2015) sustainable development goals (SDGs).

Munich declaration: nurses and midwives: a force for health

Abstract

At the WHO European Ministerial Conference on Nursing and Midwifery in Munich in 2000, ministers identified their policy objective – 'to tackle the public health challenges of our time' – and acknowledged nurses and midwives as best placed to deliver them. The 'Munich Declaration' called on relevant authorities in the WHO European Region to strengthen both nursing and midwifery by:

- » Ensuring a nursing and midwifery contribution to decision-making at all levels of policy development and implementation.
- » Addressing the obstacles, in particular recruitment policies, gender and status issues, and medical dominance.
- » Providing financial incentives and opportunities for career advancement.
- » Improving initial and continuing education and access to higher nursing and midwifery education.

- » Creating opportunities for nurses, midwives and physicians to learn together at undergraduate and postgraduate levels, to ensure more cooperative and interdisciplinary working in the interests of better patient care.
- » Supporting research and dissemination of information to develop the knowledge and evidence base for practice in nursing and midwifery.
- » Seeking opportunities to establish and support family-focused community nursing and midwifery programmes and services, including, where appropriate, the family health nurse.
- » Enhancing the roles of nurses and midwives in public health, health promotion and community development.

Citation

World Health Organization Regional Office for Europe (2000) Munich Declaration: Nurses and midwives: a Force for Health. World Health Organization Regional Office for Europe, Copenhagen

Link

www.euro.who.int/__data/assets/pdf_file/0007/53854/E93016.pdf

Introduction and background

The genesis of the 2000 Munich Declaration is important to understand. The first World Health Organization (WHO) nursing conference was held in Vienna, Austria, in June 1988. The Vienna Declaration on Nursing published by the World Health Organization Regional Office for Europe (1988) had three principal objectives that embraced the concept of health for all, set a range of targets and offered a way forward (Salvage and Heijnen 1997).

However, by 2000 Europe had changed. The region had expanded to 51 countries, which included the more disadvantaged countries of the Newly Independent States (NIS) and Central and Eastern Europe (CEE). The population was ageing. There was a vast increase in non-communicable diseases, including cancers, and several countries were grappling with the return of malaria and polio. Tuberculosis (TB) was also on the rise. HIV, AIDS and the increasing problem of antimicrobial resistance, were adding to the disease burden.

On a positive note, many countries were enjoying extended life expectancy, but there were inequalities in all, and these inequalities were increasing. If this was not enough, some countries faced internal conflict and war causing additional burdens for some parts of the region (WHO Regional Office for Europe 1999).

It was against this formidable public health agenda that the Munich Ministerial Conference, the follow-up from Vienna, was organised. Ainna, in her capacity as Regional Adviser Nursing and Midwifery at the World Health Organization Regional

Office for Europe, arranged for ministers from across the region to join together with nurses, doctors, patient representatives, and non-governmental organisations (NGOs) to jointly consider the future direction for the professions. The aim of the three-day event was to identify the reasons for the limited success of the implementation of the Vienna Declaration, lessons learned, and set a new direction.

It was agreed that changes in education, legislation, and practice would be required to ensure that nurses and midwives could assist with the public health challenges. Nurse shortages and fewer entrants to the profession were issues. How should we prepare the professions so that they were capable of working in interprofessional and intersectoral ways? How far should educational programmes be health- rather than illness-focused, and what legislation and regulation were in place across the region? Furthermore, to what extent could nurses and midwives undertake research, measure patient outcomes, and convert the data into information that could influence health policy? All these questions shaped the narrative and search for a declarative statement on the way forward.

Ministers agreed to the Munich Declaration, which supported the right of nursing and midwifery to be involved in relevant decision making (WHO Regional Office for Europe 2000). The appointment of a government chief nurse in every country of the region was vital if progress was to be made, particularly to address long-standing and challenging issues of achieving gender equality, raising the status of nurses and, at times, medical dominance of the profession.

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To this end, financial incentives and effective workforce strategies were needed and as a result, Moving on from Munich (WHO Regional Office for Europe 2001) provided a modus operandi to pursue the agenda.

Three years later, Büscher and Wagner (2004) provided an analysis of progress. However, two decades on, success has been limited.

Influence and impact

Although not every country had a government chief nurse, the group that met in Madrid in 2003 endorsed the Munich Declaration. Still, in 2004, it was considered that while innovative thinking had been encouraged, there was little evidence of any impact on the quality of nursing and midwifery practice or services (Büscher and Wagner 2004). Additionally, a survey in 2009 showed patchy progress (Büscher et al 2009). Positive developments in education were found but there was limited, if any, interprofessional learning. Role expansion was increasing, yet little support and funding were available for research. Gender issues persisted. Even by 2009, not all governments had appointed a chief nurse, with the knock-on effect of an absence of nurse input in policy arenas.

So why, 20 years on, do many of the messages need to be repeated? While many broad-brush statements of what we want, such as those featured in the SDGs, support our case, what can they themselves achieve? Certainly, the second author, (Benton and Ferguson 2016, Benton and Shaffer 2016), has repeatedly highlighted the possibilities. But we must go further. In short, we must ask what action is needed? On reflection, the 2000 Munich Declaration was ahead of its time in identifying an agenda for action since it targeted, what would become, six of SDGs (SDG 3, 4, 5, 8, 10 and 17 – health, education, gender equality, decent work, reduced inequalities, partnership).

Oliver et al (2014) and Shariff (2014), identified in their studies on participation in policy development, that facilitators and barriers exist. The former included: being involved in health policy development, having knowledge and skills, enhancing the image of nursing, and enabling structures and processes. The latter included lack of involvement, a negative image of nursing, and structures and processes which exclude them.

A significant issue in Europe is the diversity of traditions, for health systems carry with them the cultural features of the societies

in which they have developed (Gobi 2014). This has been apparent in the problems of harmonising nurse education, which underpins the freedom of movement European citizens have come to expect.

Few members of our profession would regard our current modest influence on policy as satisfactory. The coronavirus pandemic has thrown much into focus. Policies have sprouted up rapidly, but often at national and international levels, where patient representatives and nurses have been conspicuous by their absence. This, despite repeated verbal platitudes from government that the contribution of nurses to patient care has been fully recognised. Why? There are reasons intrinsic to the profession, and external to the environment in which we operate. However, evidence from other disciplines, such as the medical profession, can provide insights into how we might be more effective (Benton et al 2020a). Namely, the need to focus on real world policy problems that help politicians address the concerns of the day rather than focus on issues exclusively of interest to the nursing profession. This may result in many more requests for input to policy formation, not simply its enactment.

Current and future relevance

In our profession, as throughout politics, administration and business run on the concept of 'value-added'. People are esteemed in policymaking, not for the symbolic utility of their professional group, but for what they bring to the table (Benton et al 2020b). If we wish to develop a vaccine, we do not employ a social scientist.

Anyone who has worked his or her way up an organisation will know that worth must be proven. As it is said, we should judge on performance and not on promise. Florence Nightingale earned her position of leadership by hard work, endurance, speaking out, and statistics. She proved her value. Not every one of us is a Florence Nightingale, but we are not short of quantity and quality of candidates. The number of nurses, for example, who have become successful chief executives of health and social care organisations demonstrates this, sad though their loss has been to nursing. It is the responsibility of every senior nurse to mentor, encourage, and develop those around them. We need politically astute nursing leaders able to influence public policy and operate strategically. We must avoid an interned nursing silo and aim for partnership working

with doctors, economists, politicians, and the media. We must learn to make our case succinctly and effectively (Benton et al 2020c).

Externally, however, we do need help. It has long been the case that while many doctors – more in some countries than others – will treat nurses as subordinates, there are others who will become helpful allies. In government, things can be grim. It has been said that a week is a long time in politics. If the three critical functions of government are defence, the preservation of the currency, and the maintenance of public order, health itself is not at the top of the list (Encyclopaedia Britannica 2020).

The nurturing of an individual professional group is even lower down. Changing parties bring new priorities. Even with a new government, there is a limit on the number of changes they can achieve before the spectre of re-election looms. A new chief executive is often equally selective. There is little point in the profession arguing against this. We must work with it, turning each crisis to our advantage and maintaining pressure on our professional organisations and governments to keep their word.

The new WHO Director General, Dr Tedros Adhanom Ghebreyesus, the driver behind WHO's decision to mark 2020 – the bicentennial anniversary of Florence Nightingale's birth – as the International Year of the Nurse and the Midwife, called on all governments to recognise the crucial role of these professions in contributing to the achievement of the SDGs. To date, there is little to convince us that the response of governments to this WHO calling will be more than transitory. Long-term success will largely be dependent on the action of our profession itself.

So, whether you are at the start of your career or have been in the profession for some time, there are multiple opportunities to bring the nursing voice to the many policy tables that exist at local, organisational, regional, national and international levels. Build alliances, open doors, and make your voice heard. The SDGs provide opportunities, not just in the health space, but across many other policy domains. We are the largest health profession in the world. We can – if we are smart, connected, and focused – be the most influential.

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Animating children's pain research: using arts-based approaches to disseminate knowledge and mobilise emotions

by Bernie Carter (FRCN 2009)



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Across more than 20 years I have undertaken research and scholarly work focusing on children's pain (Carter 1994, 2020), with a particular focus on the assessment of pain in children with profound cognitive impairment (PCI) (Carter et al, 2002, 2016, 2017). However, research is not just about writing bids and doing the research; increasingly, it is about translating findings into action.

This article focuses on how I have tried to make change happen based on the evidence of my own and other people's research. The specific trigger is a longitudinal qualitative study in which eight mothers of children with

PCI shared stories of their experiences of learning, enduring, knowing and advocating for their child's pain. The research itself is modest – small scale and regional – yet it is one of very few studies to address the issue.

In a separate article, the perspectives of clinicians, collected during the same study, are reported (Carter et al 2016). Long after the study was finished, I knew it was not finished with me. This article reflects on how I have continued to walk with the stories from this study. This article has its roots in my earliest work but is most recently connected to an article published in 2017. The link to that article and its abstract are provided below.

Developing a sense of knowing and acquiring the skills to manage pain in children with profound cognitive impairments: mothers' perspectives

Abstract

Children with profound cognitive impairment (PCI) are a heterogenous group who often experience frequent and persistent pain. Those people closest to the child are key to assessing their pain. This mixed methods study aimed to explore how parents acquire knowledge and skills in assessing and managing their child's pain. Eight mothers completed a weekly pain diary and were interviewed at weeks one and eight. Qualitative data were analysed using thematic analysis and the quantitative data using descriptive statistics. Mothers talked of learning through a system of trial and error ('learning to get on with it'); this was accomplished through 'learning to know without a rule book or guide'; 'learning to be a convincing advocate'; and 'learning to endure and to get things right.'

Experiential and reflective learning were evident in the way the mothers developed a 'sense of knowing' their child's pain. They drew on embodied knowledge of how their child usually expressed and responded to pain to help make pain-related decisions. Health professionals need to support mothers/parents to develop their knowledge and skills and to gain confidence in pain assessment, and they should recognise and act on the mothers' concerns.

Citation

Carter B, Arnott J, Simons J et al (2017) Developing a sense of knowing and acquiring the skills to manage pain in children with profound cognitive impairments: mothers' perspectives. *Pain Research and Management*. 2017, 25:14920. doi: 10.1155/2017/2514920

Link

www.hindawi.com/journals/prm/2017/2514920

Introduction and background

Children with profound cognitive impairment (PCI) (or profound and multiple learning disability) are children whose severe learning disability and other disabilities significantly impact on their ability to communicate (National Health Institute 2018). Many children with PCI are fully reliant on their parents and caregivers to care for their complex health and social care needs. Children with PCI are a diverse group, both in terms of their underlying condition (for example, cerebral palsy, neurodegenerative and metabolic disorders) and the range of comorbidities they experience (for example, perceptual disorders, physical impairments, and respiratory and feeding problems) (Bottos and Chambers 2006).

Typically, children with PCI have a high burden of pain that increases across their lifetime. They can experience pain from a wide range of sources, some specifically related to their underlying condition (for example, gastro-oesophageal reflux, muscle spasms) or their treatment (for example, suctioning, venepuncture) as well as the more commonplace pains of childhood (for example, earache). Considering the frequency, range and burden of pain that many children with PCI carry, it is of particular concern that their pain is often both poorly managed and under-assessed and undertreated (Valkenburg et al 2012, Cascella et al 2019).

Children with PCI display a heterogeneity of response to and expression of pain; this partly reflects the child's particular comorbidities and motor development disabilities (Pivalizza and Pivalizza 2008) and the effect these may have on their behavioural and physiological responses (Breau and Camfield 2011). This can result in a 'perfect storm', with some children with PCI receiving inadequate assessment and treatment (Genik et al 2017) while experiencing frequent, persistent, and significant pain (Breau et al 2003, Jayanath et al 2016). The situation of this group of children troubled me a lot 20 years ago. It continues to trouble me today. Their situation remains an invidious one.

Influence and impact

Although children with PCI are a diverse group, they share the characteristic of being unable to self-report their pain. With the 'gold standard' of self-report no longer available, the landscape of pain assessment

is shifted to one which relies on other, less certain, strategies. Part of the problem is that when clinical uncertainty is high (Carter et al 2016), and clinician knowledge is low (Genik et al 2017), which it often is when caring for children with PCI, clinicians do not always recognise parents' expertise and experience. Consequently, parents face challenges advocating for, and convincing clinicians of their child's pain.

Day in, day out, year in and year out, parents attend to their children's pain, developing a 'sense of knowing' of their child's pain. They develop a deep and intrinsic knowledge of how their child usually expresses and responds to pain; their knowledge arises from a genuine, authentic form of experiential and reflective learning. Clinicians, despite a developing evidence base and validated pain tools, report navigating uncertainty in relation to assessing and managing the pain of children with PCI (Carter et al 2016).

Despite my own efforts and those of a relatively small band of other researchers and practitioners in the field, only limited pockets of pain-related change have occurred for this group of children over the past 20 years. There have been important advances in the development of validated pain assessment tools (Breau et al 2002, Hunt et al 2004, Malviya et al 2006), but they are not consistently embedded in practice (Yamada et al 2017). Even in 2020, there is still only a 'small, slow moving body of pain research' (Genik and McMurtry 2020) for this population of children.

It was against this context of slow change and progress that I assessed my best efforts. I had undertaken research and managed to attract small pockets of funding to support the research. I had worked with parents, practitioners, educators, and charities. I had published, been cited, written books and been invited to present the findings at conferences, workshops and study days in hospitals, hospices, community settings and universities in the UK and internationally.

I had written lay publications, reports, and contributed to pain guidelines. I had lobbied, presented evidence at parliament, been chair of the RCN Pain in Children Group, and been awarded my Fellowship of the Royal College of Nursing (FRCN) based on my work on pain. Despite all this, the message was not getting through as strongly as I had hoped. I was not making change happen in the way I wanted it to.

Acknowledgement

The research work that underpins the 'Developing a Sense of Knowing' paper was undertaken with Dr Janine Arnott (now Reverend Arnott), Dr Joan Simons from the Open University and Professor Lucy Bray from Edge Hill University. All things are possible when you work with great people, and these are three of the best

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RESOURCES

Communicating Lily's Pain
www.tinyurl.com/Lily-Pain

30Bird
www.30bird.org

Mister Munro
www.mistermunro.co.uk

WellChild
www.wellchild.org.uk

Like other researchers, I turned to arts-based methods as a synergistic knowledge-translation strategy (Rieger and Schultz 2014). I determined to work differently, and in the past three years I have worked with children and young people, parents, people with chronic pain, dancers, performers, illustrators, graphic designers, writers, creative directors, sound installation experts, trainee vicars, a contortionist, teachers, the general public, and many more.

Current and future relevance

I homed in on using creative methods and the arts as a means of communicating research knowledge, conveying evidence-based information, symbolising experience, generating discussion, provoking meaning-making and different ways of knowing. Other researchers, aspiring to similar outcomes, have created beautiful and evocative work, such as exhibitions on menopause (Carpenter et al 2019), dementia (Bartlett 2015), and open heart surgery (Lapum et al 2012). Like these other researchers, I have discovered the rewards and the perils of using the arts; the arts can disrupt in unpredictable ways over which the researcher has little control (Bartlett 2015).

Landmarks on my journey include the creation of an immersive soundscape installation, exploration of somatic practice, poetry, creative explorations at festivals of science and a resource called 'Communicating Lily's Pain'. Each of these elements has been powerful in further shaping my understanding of children's pain and in creating opportunities to stimulate new dialogue and engagement. Each has given new opportunities to engage with people and to share findings from my research and to try and shape thinking and practice. Like Carpenter et al (2019), I believe and have evidence that these approaches have helped to stimulate learning, dispel myths, spur dialogue, and increase empathy.

Serendipity played a role at the outset of this journey; a chance meeting resulted in an introduction to Rob Young, a writer and artist and generally inspirational individual. I shared the (anonymised) stories of the parents and clinicians and both my passion for and frustration about changing people's hearts and minds about children's pain. Rob instinctively grasped the essence of what needed to be conveyed and we started to work together in earnest.

Our initial project was as artists in residence at 30Bird, a company that works with artists,

practitioners and scientists to create new interdisciplinary art forms and performances. In this project, I was the scientist/academic and Rob was the artist. During a one-week residency we were given space, time and a vanishingly small amount of funding to create a performance. We had few rules, some amazing guidance from the director Mehrdad Seyf, and we were both pushed out of our comfort zones. We created an immersive sound and light installation called *The Mother Of All Pain*. This installation consisted of an authentic soundscape composed of the voices of parents, members of the public and from YouTube videos of parents supported by WellChild (a national children's charity).

The soundscape was projected through speakers on the arms of a giant 4.5 metre mobile (an upscaled version of a mobile that might hang over a child's cot). The installation was performed in a blacked-out studio with the only lighting being tiny LED lights attached to the speakers on the mobile's arms; as the mobile spun, an evocative and otherworldly mix of light, dark and overlapping words was created.

At its first performance, its impact was visceral. Every performance since has provoked a similar response; people have cried, felt the need to talk to us, shared stories about their own pain and expressed concern for the children and their families. This response has occurred regardless of whether the audience has been the general public, practitioners, pain specialists, people with pain, or parents of children with PCI. However, the aspects of the installation that meant it was powerful (for example, blackout, ceiling rigs, technical audio support) mitigated against it being easily presented at conferences or in hospitals. Although it can be adapted, the experience is not the same. These limitations meant I needed a way to try and make the essence of the experience available to more people.

The Mother Of All Pain is the inspiration for *Communicating Lily's Pain*; its DNA is evident in pretty much every aspect. However, *Lily's Pain* is a much more practical distillation of the research findings than is evident in some of the other arts-based adventures. *Communicating Lily's Pain* is a resource that aims to help parents and health professionals assess pain in children with PCI. Every step of the way has been collaborative and informed and shaped by parents, professionals and artists with relevant expertise and experience, including the brilliant team at MisterMunro.

The animation takes the story of one child, Lily, and her mother. The script is drawn directly from quotations from the research and the voice-over is performed by a parent. Condensing research findings accurately, authentically and precisely into a tiny script and generating images, the tone, style and pacing of the animation was both incredibly challenging and rewarding.

Evaluation and feedback from clinicians and parents and the wider public has revealed that its impact potentially outweighs all of my other books, articles, presentations and so on. It is immediate, accessible and has 'mobilise[d] emotion' (Bartlett 2015). The information sheets are important aspects of the resource, but the most powerful element is the animation itself.

My sense is that arts-based approaches to knowledge translation and dissemination

are a key component for researchers to consider. Determining the effectiveness of art in communicating research is not without challenge, although there are methods for thoughtful evaluation (Rieger and Schultz 2014). Arts-based approaches are not appropriate for all research; they are not easy, and they require commitment to working and thinking in a different way to the ones we are traditionally trained to work in.

Lapum et al (2012) observe that researchers who engage with arts-based approaches are 'not merely marked, but re-shaped'. I would agree with this. I know that my thinking, understanding and ways of working about children's pain assessment have been re-shaped; I am hoping that engagement with the work I have been involved in producing has re-shaped the people it has touched.

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Twenty-five years of the EdFED scale: a useful scale for measuring mealtime difficulty in older people with dementia

by Roger Watson (FRCN 2009)



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The 'EdFED' is the Edinburgh Feeding Evaluation in Dementia (EdFED) scale. 'Ed' points to where the scale was developed – Edinburgh University – and 'FED' is shorthand for 'feeding'. Finding a meaningful acronym is always challenging, but this one seems to have worked: once understood, it is easy to recall.

The development of the EdFED scale arose from my experience in clinical practice in the 1980s. I was a charge nurse in a long-term care setting for older people and the problems

that older people with dementia had at mealtimes and our inability to manage these sparked my interest. Early in this journey, it was apparent that we needed some way of measuring these problems and I discovered from doing a literature search that no method existed.

I first reported the EdFED scale in a paper published in 1994 in the *Journal of Advanced Nursing*, the journal of which I am now the Editor in Chief. The link to that paper and its abstract are provided below.

Measuring feeding difficulty in patients with dementia: developing a scale

Abstract

Feeding difficulty in elderly people with dementia is well documented and the need for research in this area of nursing care has been raised by several authors. One hundred and twelve elderly people with dementia were entered into a study of feeding difficulty. Data were gathered by means of a questionnaire administered to the nurses caring for the patients.

The aspects of feeding difficulty which were investigated were based on reports of relevant behaviour in the literature and included refusal to eat, turning the head away, refusing to open the mouth, spitting, allowing food to drop out of the mouth and not swallowing. It was possible to arrange these different aspects of feeding difficulty under three headings: (a) refusal to eat, (b) spitting and (c) inability to swallow, and to analyse the pattern of accumulation of these feeding difficulties by means of Guttman scale analysis. According to this analysis, the feeding difficulties investigated form a cumulative and unidimensional pattern. The implications of this pattern and the possibilities for further research are discussed.

Citation

Watson R (1994) Measuring feeding difficulty in patients with dementia developing a scale. *Journal of Advanced Nursing*, 19, 257-263. doi: 10.1111/j.1365-2648.1994.tb01079.x

Link

onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2648.1994.tb01079.x

Introduction and background

When I first started thinking about what eventually developed into the Edinburgh Feeding Evaluation in Dementia (EdFED) scale, we were beginning to see in clinical practice an increase in the number of older

people as a result of the ageing population of the UK. Also, the health policy context was changing in the wake of the Griffiths report (1988) on care in the community that formed a key part of the NHS reforms under the Thatcher government. This policy had a

disproportionate effect on the care of older people. Many long-term care facilities for older people closed and an exponential rise in the nursing home industry took place. Few long-term care hospitals remained (and I worked in one), and most commercial nursing homes were reluctant to take older people with dementia, which led to a sudden increase in the number of older people with dementia being admitted to long-term care hospitals.

Older people with dementia had some common problems and among these was difficulty at mealtimes, which included difficulty with eating. These problems were matched by our apparent lack of knowledge about how to help older people with dementia to eat, as I identified in a literature review (Watson 1993). I became interested in trying to investigate and develop strategies for alleviating the difficulties.

I was unusual in nursing as I already had a PhD in biochemistry before entering nursing, which equipped me with some knowledge of research. However, I had no experience of clinical research. Naively, I set about designing a clinical trial where we would test our ability to help older people with dementia to eat and I applied for a research grant to the Scottish Office. Quite rightly, the funding was not awarded, and I received scathing feedback on the proposal. The feedback indicated I did not have a way of measuring the mealtime difficulty of the older people with dementia and, therefore, no rigorous way of measuring whether the proposed interventions would make any difference. This glaring omission led me to search the literature for a suitable measure. I found none and that set me on a course of research which has lasted for 30 years.

Measurement, scale development and psychometrics in UK nursing, with a few exceptions, were rare at the time I embarked on this work. Fundamentals such as reliability and validity were poorly understood. My own understanding of these concepts and some of the more sophisticated aspects of scale development and testing developed after I moved to the University of Edinburgh through collaboration with a psychologist – Ian Deary – in the Department of Psychology. This was a truly interdisciplinary collaboration as the problem we were investigating lay firmly in the nursing domain and the methods required to investigate it lay within psychology.

Before the involvement of Ian Deary, I was indebted to Ian Atkinson, then working in

the Nursing Research Unit, who looked at some of my initial data and suggested I consider a method called Guttman scaling. This, essentially, set the pattern for my research over the next 30 years. Guttman scaling, which had been useful in the early stage of developing the EdFED (Watson 1994a, 1994b) was superseded by Mokken scaling, which was subsequently applied to the further development of the EdFED scale (Watson 1996).

Influence and impact

The idea of a scale did come from practice, but the EdFED was primarily designed as a research instrument. However, I have observed it being used for clinical assessment in the Tokyo Institute of Geriatrics and Gerontology, where it was translated into Japanese. It was adopted in the United States by the Hartford Foundation as a clinical assessment instrument for the care of older people in hospital and is still available online (Stockdell and Amella 2008). It has also been translated into and published in Chinese in Taiwan (Lin et al 2008) and in mainland China (Liu et al 2014), Italian (Watson et al 2017) and translations exist in French, German, Lithuanian, Turkish, Korean and Persian.

Alzheimer's Disease International (2014), in its report *Nutrition and Dementia*, referred to the EdFED as the most validated instrument for measuring mealtime difficulty in older people with dementia and cited specific aspects of the validation (Watson 1997, Watson et al 2001, Watson et al 2002). The report described the EdFED as: 'brief and simple enough to be used in routine care. It establishes the level and type of feeding disability and can be used to plan effective interventions.'

The EdFED scale also has had its critics. Some of the terminology in the scale has been criticised as being patronising and inappropriate – both the name of the scale and the way the items are expressed within the scale (for example: Does the patient refuse to open his/her mouth?). With the benefit of hindsight, I completely agree. Therefore, I have been encouraging colleagues and research students with whom I work to adopt the more general term 'mealtime', rather than focus narrowly on 'feeding'. I also believe that this is a more accurate description of the problem.

Mealtimes are a complex activity which older people with dementia must negotiate (Gallant 2019) of which eating (which implies some choice in the food eaten and in the

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social aspects of mealtimes), and feeding (moving food from a plate to the mouth), are components. However, the EdFED has international currency and has already been translated into many languages, so the name and the items have been retained.

Other useful criticism has been raised; for example, if an older person with dementia is able to eat independently, there is no provision for this on the scale; nor does it provide for someone who is unable to respond and is beyond the stage where assistance with eating is no longer a valid option. I was remiss in not being consistent in labelling the various versions of the EdFED scale that are being used.

The original version contained 11 items, soon reduced to 10 items (the most commonly used version), but I have mainly used a six-item version that focuses on the behavioural aspects of mealtime. All these versions are referred to as the EdFED scale. Science is rarely as neat as we might like.

In assessing the influence and impact of the EdFED scale, it is as a research instrument that it has proved to be most useful. The EdFED was used as the main outcome measure in the first randomised controlled trial of mealtime interventions for older people with dementia in Taiwan (Lin et al 2010, 2011). In Canada, it is the main outcome measure in a national Canadian Institutes of Health Research-funded project into the nutritional status of older people with dementia in nursing homes (Keller et al 2017, Slaughter et al 2020). I am pleased that the EdFED has been picked up internationally and incorporated into such high-profile and prestigious work.

Current and future relevance

The EdFED continues to be used. Some examples of its use in research already have been provided. In my own work, the EdFED has been a key outcome measure in two recently completed PhD projects that I have supervised. One of these projects investigated environmental influences on mealtime difficulty of older people in nursing homes in Italy (Palese et al 2018a, 2018b, 2018c, Palese et al 2019a, 2019b, Palese et al 2020a, 2020b, 2020c). The other project investigated the use of spaced retrieval, a method of retraining people by using procedural memory, which is relatively unaffected in dementia and allowing time to learn over progressively longer intervals, in alleviating mealtime difficulties

of older people in nursing homes in the UK (Rehman et al 2019).

Interest continues to be shown by clinicians and academics in many countries in the use of the EdFED, and I still receive requests to use it or to translate it. I have never claimed copyright of the EdFED scale and have always permitted its use and translation free of charge. In addition to some criticisms already mentioned, the EdFED scale may not contain all the possible difficulties that an older person may experience at mealtimes, including some problems that may not be directly related to eating. I encourage others to use the EdFED and to develop other more comprehensive scales. However, I always urge others who may take it forward to bear in mind that the EdFED is attractive to researchers and clinicians because it is very short and easy to use and, importantly, its psychometric properties are well established.

What the EdFED does not do is tell the practitioner how to respond to the measurements made using the scale in terms of improving help for a person who is having difficulty at mealtimes. This is a valid criticism, but the EdFED was only designed to measure and we are still largely in the dark about how, from an evidence based perspective – as comprehensive systematic reviews have consistently shown – to alleviate mealtime difficulty for older people with dementia (Abdelhamid et al 2016a, 2016b, Herke et al 2018, Watson and Green 2006). However, from my own research programme, we know that the nursing home environment has a major influence positive and negative on maintaining independent eating among nursing home residents (Palese et al 2019a). And in single-case experimental work that is still under way we have shown – using the EdFED scale as an outcome measure alongside measures of nutritional status – that spaced retrieval can be effective in alleviating mealtime difficulty.

So, 25 years on, the EdFED continues to have relevance. It certainly has a place in the history of research into dementia generally and, specifically, into mealtime difficulties of older people with dementia. My work with the scale is nearly over but I will look with interest in future at work in this area. Unless a cure is found for all the common forms of dementia, I expect the EdFED, in some form or other, will still be in use for many years.

For nurses entering clinical practice or research, I think it is important to note that

this programme of work arose directly from my observations and frustrations in clinical practice. I followed my instincts here and

I hope you can do the same. It may take many years but, eventually, you may make a difference.

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Transforming advanced dementia: the Palliare Best Practice Statement, an interprofessional learning framework and tool for improvement

by Debbie Tolson (FRCN 2011)



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Dementia is an umbrella term, used to describe progressive, terminal illnesses such as Alzheimer's disease that disrupt brain health. As the condition progresses from the mild through to the advanced, then terminal stage, the needs of the individual change, increasing in both intensity and complexity. Textbooks often refer to mild, moderate and severe dementia jumping quickly from the middle stages of illness to end of life. However, for many people, there is a stage inbetween when they are living with advanced dementia. This period may involve months or years of life with advanced illness.

Although the term 'advanced dementia' is used in practice and by family carers, there is no definitive definition. I coined the term 'Palliare', derived from Latin, meaning to cloak in support, to begin a new positive practice narrative for dementia specific palliation. I wanted to find a new single term, meaningful in different languages, to describe and distinguish dementia specific palliation from palliative care related to other conditions. Palliare and the Palliare projects are about advanced dementia care.

The Palliare Best Practice Statement offers a framework for practitioners to improve advanced dementia care in practice.

Improving advanced dementia care an interprofessional learning framework

Abstract

The original Palliare Project was completed by a collaboration of seven European countries. The featured publication (Tolson et al 2017) – an editorial – compresses the findings of 11 work streams into a highlight article and overviews the Palliare Best Practice Statement (BPS), which sets out the components of best practice. The BPS recognises the complexity of advanced dementia care, values interdisciplinary contribution and embraces the centrality of family caring and rights-based approaches. It offers a refreshing and positive perspective focused on living the best life possible with advanced dementia, acknowledging that there is for many, a lot of living with advanced dementia to be done before end of life care is required.

The six elements of best practice are accessibly presented in the BPS in terms of 'what' is required, the underpinning evidence and the 'how' to demonstrate delivery of practice at its best. Offering the BPS as an interdisciplinary learning framework, as done in Tolson et al (2017), provides a structured way for educators to optimise care through Palliare education, and for managers and service providers to understand what practitioners need to know to provide good quality advanced dementia care. The editorial challenges the status quo, introduces a new positive Palliare narrative and a tool whereby evidence informed, advanced dementia care can be described and delivered. Rather than passive acceptance of what is, this editorial calls for improvement actions to achieve in practice what should be.

Citation

Tolson D, Holmerova I, Macrae R et al (2017) Improving advanced dementia care an interprofessional learning framework. *Journal of the American Medical Directors Association*. 18, 7, 561-563. doi: 10.1016/j.jamda.2017.03.014

Link

[www.jamda.com/article/S1525-8610\(17\)30185-8/fulltext](http://www.jamda.com/article/S1525-8610(17)30185-8/fulltext)

Introduction and background

In 2013, I moved to a new role as the inaugural Director of the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland (UWS). Having come from a previously purely academic role, I was excited by the opportunity to set up the new centre in partnership with Scotland's leading dementia charity. This I felt, was bringing me closer to my nursing practice roots. At that time, I was frustrated that so much of our service response and policy rhetoric about dementia reflected a social model. I felt this was wrong. After all, neuroprogressive illnesses such as Alzheimer's disease, cause dementia. For me, there has never been any doubt that living with dementia is an illness experience and I find the lack of awareness about the complexity of advance dementia care perplexing (Brown and Tolson 2020, Brown et al 2020).

Setting up the new centre gave me a blank canvas to start new programmes of work and challenge the status quo. With the support of UWS nursing colleagues and policy colleagues from Alzheimer Scotland, the ideas for the Palliare Project began to take shape. A funding opportunity presented itself, namely the Erasmus+ K2 Strategic Partnership Fund and, although not focused on nursing or healthcare, we crafted a project to fit the agenda for modernising the approach to practice-based learning within universities in response to a societal problem. And at that time, what bigger societal problem was there than dementia and the development needs of the European workforce?

With the 'bravado of the new in post' and the backing of my 'you can do it colleagues' I contacted and managed to assemble a team of inspiring leading nurses, doctors and other health and social care professionals from across seven countries. Ideas flowed and together we shaped what was to become the Palliare Project and some now refer to as the Palliare movement. The first Palliare Project objective focused on understanding and describing best practice for advanced dementia care during the extended palliative care phase. This we investigated by a combination of an interrogative literature review, policy analysis, in-depth case studies, educational gap analysis and a pedagogical review.

The second project objective was to use the findings from our first set of activities to develop an innovative approach to interprofessional learning, designed to equip the qualified European dementia workforce to transform

practice and achieve good quality dementia Palliare. To do this, we combined the findings from the research activities listed above, and presented them in the form of a best practice statement (BPS). It would have been naïve to do this in isolation from stakeholders and we used consensus methods to refine the BPS with a range of professional and lay stakeholders helped by Alzheimer organisations from the collaborating countries (Holmerova et al 2016). Activities included a consensus conference held in Prague, online feedback and dialogue events. Once finalised, the BPS was originally written in English and translated into Czech, Spanish, Swedish, Portuguese.

As a team, we published a number of journal articles during the lifetime of the project and following completion of the project, were invited to write an editorial in the Journal of the American Directors Association. This editorial provided an opportunity to present the BPS as an interprofessional learning framework. What we hoped for was this editorial to be seen as a call to action to dementia educators; what we were unsure about was how this would be received, and how, if at all, the BPS would be used directly in practice or its potential for policy influence (Tolson et al 2017).

Influence and impact

Palliare Project funding supported various dissemination activities including two conferences, one in Prague, Czech Republic, and an end of project conference in Porto, Portugal. In addition, local events were organised to share findings with practitioners and the public in the participating countries. Testimony to wider interest in the work was an invitation to me to give keynote presentations at the Alzheimer Global Summit in Lisbon, in 2017, and at Europe's largest long-term care conference hosted by the Together We Change the World Foundation in Poland in 2019. The project plan also included a commitment to preparing manuscripts for peer review publications. Our publications included an article sharing the literature review (Hanson et al 2016), policy analysis (Tolson et al 2016), educational gap analysis (Hvali -Touzery et al 2018), and user experience case studies (Lilo-Crespo et al 2018). The best practice statement was made available online with English language, Czech, Portuguese, and Spanish versions (Holmerova et al 2016).

An invited editorial in the Journal of the American Medical Directors Association,

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RESOURCES

Scottish Parliament debate on the Fair Dementia Care Commission Report
www.parliament.scot/parliamentarybusiness/report.aspx?r=12155&i=109835

Erasmus+ K2 Strategic Partnership Fund
www.erasmusplus.org.uk

Alzheimer Global Summit, Lisbon, 2017
sede.imserso.gob.es/InterPresent2/groups/imserso/documents/binario/folletocumbre.pdf

Together We Change the World Foundation conference, Poland, 2019
mkod2019.syskonf.pl/?lang=en

gave us an opportunity to write about the BPS in a peer review journal (Tolson et al 2017).

These dissemination activities were important in sharing our work with different audiences, and in promoting the Palliare BPS as a tool for improving advanced dementia care.

There have been three main ways in which the BPS has demonstrably influenced advanced dementia care through:

- » Impact on the quality of care.
- » Impact on practitioner education.
- » Policy influence.

Some of these impacts and influences were predicted, others unexpected.

Impact on the quality of care. We were delighted to learn from the Czech Alzheimer Society that they had used the BPS to develop quality indicators creating new Vážka criteria, a set of quality indicators developed by the Alzheimer Society in the Czech Republic to demonstrate long-term care facilities are delivering best-practice care for people with dementia and advanced dementia, and a quality certification system. To date, some 70 social care facilities in the Czech Republic have achieved certification as compliant with the Vážka criteria, demonstrating improvements aligned with best practice as set out in the Palliare BPS (Mátlová 2019).

In Portugal, the BPS has been used as a benchmarking tool to raise standards of advanced dementia care in a number of services including hospices (de Abreu 2019). Improvements have focused on understanding and managing advanced dementia symptomatology including stress and distress, pain, and promoting comfort through introduction of sensory interventions. In the UK, realisation of practice impact has been slower; the Scottish Alzheimer Scotland Dementia Nurse Consultant Group is reviewing how best to draw on the BPS. Before the recent pandemic lock down, one of the nurse consultants was preparing an improvement programme in acute care and I will watch with interest to see how helpful this is both during, and post-COVID-19.

Impact on practitioner education. The BPS and principles for advanced dementia care have been used to create several master's degree level modules that we offer online and by blended learning as part of the University of West of Scotland MSc in Gerontology (with dementia care). Internationally, the BPS has influenced and changed dementia education in Spain, Portugal, Russia and Brazil (de Abreu 2019),

which now has specific content on advanced dementia. In the Czech Republic, the Institute of Post Graduate Medical Education has changed some of its courses for long-term care practitioners to promote 'Palliare Practice'.

Policy influence. When Scotland's third dementia strategy (2017-2020) (Scottish Government 2017) was being prepared, the Palliare Project was in progress. We were delighted that our literature review (Hanson et al 2016) was cited in the new strategy and our call for a positive new practice narrative for advanced dementia embraced.

More recently, the Scottish Fair Dementia Care Commission drew on evidence from the Palliare Project to inform the Fair Dementia Care Commission Report (Alzheimer Scotland 2019). The report called on the Scottish Government to recognise the needs arising from advanced dementia as healthcare needs, promote access to expert nursing and end inequalities that mean that people with advanced dementia pay for care which is free to people with other progressive terminal conditions. The definition of advanced dementia used by the commission draws on the Palliare definition. The Scottish Parliament has debated the Fair Dementia Care Commission Report and the proposed definition of advanced dementia was acknowledged as a strength: '...the Parliament ... believes this to be an important contribution to the understanding of advanced dementia and the care needed by people across Scotland'.

Over 14,000 members of the public have pledged support for the campaign, urging reform to address the inequalities in Scotland that people living with advanced dementia face. Public interest and the interest of Scottish parliamentarians in the call for dementia care that is fair are encouraging. As a nurse, it is affirming that the work I have led has contributed to one of the most significant campaigns and calls for action progressed by Alzheimer Scotland. It is heartening that Palliare findings have contributed evidence and strengthened the call to action. Although we tend to think about the World Health Organization's (WHO) sustainable development goals (SDGs) in relation to countries with less developed health and care systems, it is important as nurses that we raise awareness of inequalities and tackle those that exist in our own countries. I am in no doubt that the Palliare BPS has the potential to support dementia leaders to propel change in policy and practice.

Current and future relevance

The Palliare BPS is a unique resource in that it does not attempt to be a clinical guideline, nor is it presented as a care standard.

It is a reference resource that seeks to expose the complexity of advanced dementia care, and promote a cohesive approach to best practice and practitioner education through consideration of six domains of practice:

- » Protecting rights, promoting dignity and inclusion.
- » Future planning for advanced dementia.
- » Managing symptoms and keeping well.
- » Living the best life possible.
- » Support for family and friends.
- » Advancing dementia Palliare practice.

It is a starting point for those interested in promoting positive approaches to evidence-informed, advanced dementia care and the quest for best practice. The SDGs are predicated on ideas about best practice and resonate with the WHO (2017) global action plan for dementia. The Palliare BPS, with its explicit focus on living the best life possible with advanced dementia, aligns with the global development agenda. This is relevant in terms of achieving fair dementia care in Scotland and elsewhere in the UK (Social Market Foundation 2019), and internationally.

One of our recent projects undertaken collaboratively with nurses in southern India highlights the lack of dementia care infrastructure and the vulnerabilities and hardships of people with advanced dementia and their families (Ritchie et al 2020). This preliminary project brings into sharp focus the urgent need for community and practitioner education about advanced dementia and the

BPS is providing a road map for collaborating nurse educators to refresh and strengthen pre-registration nurse curricula. It has also shone a light on desperate acts of care, which include the use of potentially harmful physical restraints by families who feel they have no other way to stop a person with dementia from leaving the safety of the family home. These acts need to be contextualised to be understood in relation to related hardships and poverty linked to shortfalls in the care infrastructure.

The BPS has provided a useful starting point for the team in India to envision what is needed. It is affirming to know that a project undertaken by our nurse-led team in the Alzheimer Scotland Centre for Policy and Practice at UWS has utility here in Scotland, in Europe and beyond. I know that this is a relatively small contribution towards making a better world for people living with dementia; but I am proud of what has been achieved in a relatively short period of time. I am also realistic about the scale of the challenge ahead, particularly given the disruptive impact of the COVID-19 pandemic.

When I began my career as a nurse, I wanted to change the world and soon realised that, if I could use my skills to support an individual to have a better day, I had done a good job. In my role as a professor, I have an appreciation of the different ways that nurses can use their knowledge, skills and leadership resolve to improve practice and influence policy. I am often asked by people I meet what professors of nursing do. For me the answer is simple: we make a difference through practice-based scholarship and projects like Palliare.

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Factors related to the disproportionate representation of BME nurses in NHS disciplinary proceedings

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It is important that NHS organisations can apply disciplinary procedures to ensure that staff behave in an appropriate and professional manner. Anecdotal evidence and a growing body of empirical studies indicate that black minority ethnic (BME) doctors are more likely to be referred to the General Medical Council (GMC). Comparatively less is known about the experiences of minority ethnic staff from other occupational groups in the NHS.

This article discusses the findings abstracted from a larger study to assess the extent of involvement of BME staff in disciplinary procedures in the NHS over ten years. The original study in 2008 comprised several

distinct phases, including a web audit of NHS trusts, and an examination of disciplinary policies and practices through workshops with human resources managers and representatives of health profession regulatory bodies, alongside workshops with service managers to validate study recommendations to ensure relevance to the end users.

Sufficient attention was not always given to transmit the ethos and values of the NHS, nor the organisational culture in which staff would be expected to work. There was repeated mention of a custom and practice culture existing in the NHS that was considered to perpetuate unwritten workplace norms and was instrumental in reproducing inequalities.

Disproportionality in NHS disciplinary proceedings.

Abstract

Background/aims This article investigates the representation of black and minority ethnic (BME) staff in NHS disciplinary proceedings.

Methods The study involved an in-depth knowledge review and analysis of literature on the representation of BME staff in NHS disciplinary proceedings from 2008 to 2017, as well as semi-structured interviews with 15 key stakeholders. Participants were stakeholders from both primary and secondary care and included equality and diversity leads, human resource professionals, NHS service managers, representatives of trade unions and health professional regulatory council representatives.

Findings The knowledge review indicates that to date, BME staff are disproportionately represented in NHS disciplinary proceedings. Evidence gathered demonstrates the continuation of inappropriate individual disciplinary action and failure to address organisational shortcomings against BME members of staff.

Conclusions Overall, six factors were identified as underpinning the disproportionate representation of black minority ethnic staff in disciplinarys: closed culture and climate; subjective attitudes and behaviour; inconclusive disciplinary data; unfair decision making; poor disciplinary support; and disciplinary policy misapplication.

Citation

Archibong U, Kline R, Eshareturi C et al (2019) Disproportionality in NHS disciplinary proceedings. *British Journal of Health Care Management*. 25, 4. doi: 10.12968/bjhc.2018.0062

Link

www.magonlinelibrary.com/doi/full/10.12968/bjhc.2018.0062

Introduction and background

I was first contacted by members of NHS Employers Equality and Diversity (E&D) Core Reference Group (CRG) in 2007 led by Professor Carol Baxter, who was the head of NHS Employers E&D team. The CRG was concerned about the involvement of black and minority ethnic (BME) staff in disciplinary proceedings brought to their attention by human resources managers. In response, I led the Centre for Inclusion and Diversity (CfID) of the University of Bradford in 2008 in a study to assess the extent of involvement of BME staff in disciplinary procedures in the NHS, and to identify good management practice in this area (Archibong and Darr 2010).

Our study took place during a period of widespread recognition of financial challenges in NHS organisations (Farrar 2009) and the need for the NHS to deliver greater efficiencies against a vision for trusts to provide the highest quality of care for patients and good value for the taxpayer (Department of Health 2008). In addition, the NHS Constitution (Department of Health 2009) mandated NHS staff to be more aware of their roles and responsibilities in elevating standards of professional practice. Employers were reminded to provide greater support in the workplace to improve the health of, and reduce levels of stress, among staff, irrespective of who they were, the role they performed or the level at which they worked in the organisation (Boorman 2009). At the same time, NHS organisations should be able to apply disciplinary procedures to ensure staff behave in an appropriate and professional manner to safeguard patient safety. It follows from this that the disciplinary procedures applied should be transparent, fair and 'fit for purpose' (Archibong et al 2013).

However, there was a growing body of evidence which suggested that staff from BME backgrounds were overrepresented in disciplinary procedures and that disciplinary processes were not being applied consistently in the NHS (Esmail and Everington 1994, Lyfar-Cissé 2008). This was of serious concern, given that individuals of BME background made up 14% of the NHS workforce with the NHS being the largest employer of BME staff in England. We were always being reminded by the work of Akinsanya (1988) and Obrey and Vydelingum (2004) of the immense contribution made to the delivery of health services in the UK by BME staff who were

deemed the 'backbone' of the service at a time when labour was in short supply.

I was curious to establish why the people who had given so much to the NHS would experience such structural racial inequalities and I wanted to give voices to BME staff to present their lived experience. More specifically, the objectives of the study were to analyse trusts' disciplinary data to assess whether BME staff were overrepresented in disciplinary procedures, examine reasons for the involvement of BME staff in informal and formal disciplinary proceedings, and engage with professional regulatory bodies to examine monitoring systems in relation to disciplinary proceedings. The study also compared literature on the experience of disciplinary proceedings among BME staff working in other public sector organisations and identified examples of good practice in relation to fair and transparent disciplinary proceedings.

The key findings of the study were:

- » BME NHS staff were almost twice as likely to be disciplined. BME staff were significantly overrepresented in disciplinary proceedings in acute, primary care, mental health and learning disability and care trusts.
- » Five key causes of the disproportionate number of BME staff involved in NHS disciplinary proceedings were: organisational culture; poor management practice, including lack of experience and confidence; poor leadership, including a lack of diversity among leaders; poor awareness of equality and diversity; and attitudes and behaviours of staff members.

Influence and impact

Following publication of our work (Archibong and Darr 2010), many health care unions, including the Royal College of Nursing (RCN) (Sprinks 2014) and the Royal College of Midwives (RCM) (2012, 2016), sent freedom of information (FOI) requests to trusts to gather information about staff subject to disciplinary proceedings, broken down by ethnic group.

Findings from the RCN request suggest that BME nursing staff were highly overrepresented during formal investigation and disciplinary processes in the NHS. The RCM report showed that over a five-year period, a higher proportion of BME midwives than white midwives had been dismissed during disciplinary proceedings. During the five-year period, 38 midwives were dismissed and 37 of these were from a BME background.

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Out of the 37 BME midwives dismissed, 32 were black or black British. Overall, from July 2010 to June 2015, 13.2% of the BME midwives who faced disciplinary proceedings were dismissed, compared with 0.7% of the white midwives who faced disciplinary proceedings. I believe that such a level of disproportionality could never be a mere coincidence, but a subject of structural inequality faced by BME staff in the NHS. The high levels of discrimination against BME staff in the NHS have been widely evidenced (Berwick 2013, Likupe and Archibong 2013, Kline 2013, 2014, Likupe et al 2014).

Staff from BME backgrounds have been reported to face discrimination during NHS recruitment processes (Kline 2013), promotion (Esmail et al 2007), access to training, representation during disciplinary procedures and bullying in the workplace (Kline and Prabhu 2015, Sehmi 2015).

The Francis (2013) report highlighted that BME staff who have reported wrongdoings in their organisation frequently feel like they have been treated less favourably than non-BME staff who reported similar issues in the same organisations. These negative experiences have been shown to have a direct impact on the productivity of NHS BME staff (Kline and Prabhu 2015).

Following a number of research activities that identified disproportionate representation of BME staff in disciplinary proceedings, the NHS England Workforce Race and Equality Standard (WRES) was developed to enable standardised collection of data across service providers to help identify the scale of the problem. In 2016/2017, I was commissioned with CfID colleagues by the WRES team, to inform ongoing actions and to examine the extent to which NHS employees from BME backgrounds received fair treatment in the workplace.

We examined progress made in the ten years following a study conducted in 2008 (Archibong and Darr 2010) on the involvement of BME staff in NHS disciplinary proceedings (Archibong et al 2019a). The study specifically sought to analyse published academic and government literature on the representation of BME staff in NHS disciplinary proceedings from 2008 to 2017; examine trusts' disciplinary data; identify contributing factors for any disproportionality; and highlight interventions and examples of good practice in relation to fair and transparent disciplinary proceedings.

I was concerned to see that while BME staff were 1.2-2 times more likely to enter the formal disciplinary process in 162 (70%) NHS trusts, the relative likelihood of BME staff entering the formal disciplinary process was higher than 2.1-3.0 in 39 trusts (16.9%); and higher than 3.0 in 20 trusts (8.7%). Six key factors at both individual and organisational levels, not dissimilar to the factors in the 2018 study, were uncovered as contributing to over-representation of BME staff in NHS disciplinary proceedings. These factors were: close culture, subjective attitudes and behaviour, inconclusive disciplinary data, unfair decision making, and poor disciplinary support and discipline policy misapplication.

In addition to providing some examples of changes made by NHS trusts, we have suggested ways of preventing, managing and remedying the disproportionate representation of the BME workforce in NHS disciplinary proceedings (Archibong et al 2019b), which emerged from the study. These are presented in three stages: interventions to decrease the likelihood of BME staff entering the formal disciplinary process, actions during the disciplinary hearing, and remedial actions after disciplinary hearing has taken place.

Our study has concluded that while progress is being made in raising the awareness of the over-representation of BME staff in NHS disciplinary proceedings, progress is slow and the problem persists. Evidence gathered points to the continuation of inappropriate individual disciplinary action and failure to address organisational shortcomings. Collectively, the studies undertaken since our earlier study (Archibong and Darr 2010) show that BME staff are still disproportionately represented in NHS disciplinary proceedings.

Recent publications of the analysis of the data collected from WRES (NHS England 2017, 2018, 2019) show there is still disproportionate representation of BME staff in disciplinary proceedings. It is reasonable to suggest that the slow progress in dealing with this problem may be due to a combined force of structural inequalities, discrimination and bias.

Our contributions have influenced work at regional (Bradford District NHS Care Trust 2020), institutional (West Hertfordshire NHS trust 2016), professional (GMC 2019, West and Nayar 2016, West et al 2017), national and international (Priest et al 2015) levels.

I have been involved in leading debates at different professional platforms such as the General Pharmaceutical Council (2016).

Our work has served to address the gap in empirical data that did not provide the reasons for the disproportionate discipline of BME NHS staff or the misrepresentation of disciplinary policy as an individual deficit (Traynor et al 2013), often resulting in BME employees being held to a different standard (Luksyte et al 2013).

Current and future relevance

More recently, there has been ample evidence that individuals of BME background work at the forefront of their clinical areas with considerable experience, expertise and skills from which the NHS has benefitted (see, for example, the work of BME healthcare professionals during the COVID-19 pandemic). However, the COVID-19 pandemic has magnified the racial inequality that exists in the NHS. For example, we have witnessed BME healthcare staff being 'whitewashed' out of media coverage of the coronavirus crisis, with the focus being mainly on white colleagues.

I cringed at the sight of the UK Prime Minister interviewing three retired white nurses in commemoration of the 72nd anniversary of the NHS. Where were the BME nurses who had sacrificed so much since the inception of the NHS and were, sadly, over-represented in COVID-19 deaths? And why was there such an omission at a time that coincided with the 72nd anniversary of the merchant vessel *Empire Windrush* arriving at Tilbury docks carrying 492 workers from the Caribbean? These workers came to the UK to assist with post-war reconstruction and many of the *Windrush* generation went on to work in, and thus support the establishment of, the newly created NHS (Naqvi 2020). The arrival of the *Windrush* helped to mark a new chapter in the birth of our NHS and the growth of multicultural Britain (Naqvi 2020).

Discrimination against BME staff in the NHS reflects wider discrimination, racism, and health inequalities in the UK and globally. BME NHS staff are less likely to be treated favourably, they have poorer experience of recruitment and promotion processes (Kline

2013, Esmail et al 2007), and progression opportunities, with evidence of substantial under-representation of BME staff in senior leadership positions (West 2014), a situation that has changed little in over 30 years. There is a clear link between discrimination and aggression against staff to patient satisfaction (Dawson 2009).

Recently, the world's population reached a watershed moment in relation to issues of race and inequality. The combination of the feeling of being unheard over the years, a growing number of cases of injustice, and the death of George Floyd in the United States, have collided to culminate in people demanding accountability and real actions in tackling racism in all its forms.

The elevated profile of the Black Lives Matter campaign has posed a real challenge for senior leaders of increasingly diverse organisations to dismantle structural inequalities. Even the acronym 'BME' is being contested and provoking offence for some (Fakim and Maccaulay 2020).

The NHS cannot be silent to the widespread and systemic racial inequity and prejudice plaguing the health sector (Kline 2014) and nursing and midwifery (Brathwaite 2018, Likupe et al 2014, Wren Serbin and Donnelly 2016). Staying silent is being complicit and is not compatible with the founding principles of the NHS, the NHS Constitution (2009) and our nursing values (Moorley et al 2020, NMC 2020).

Our fight to dismantle institutional racism must go beyond rhetoric to the acceptance and application of an anti-racist approach. It is time to do much more to tackle systemic racism by adopting a holistic approach. This will mean taking decisive actions against racial injustice at organisational level, including the NHS. This may involve providing psychologically safe spaces for critical reflection, equipping leaders and managers to lead the change, and leaders co-creating actions with BME colleagues, both within and beyond the health sector.

It is time to improve the culture and leadership of the NHS to ensure all staff members are valued, treated fairly and with respect, and equipped to provide exceptional levels of patient care (NHS Resolution 2020).

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Enhancing and advancing spiritual care in nursing and midwifery practice

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The World Health Organization (WHO 2020) designated 2020 as the International Year of the Nurse and the Midwife. This celebration also recognises the 200th anniversary of Florence Nightingale's birth. Nightingale is one of the pioneers and founders of the modern nursing profession. In considering her legacy, there is no doubt that she recognised the importance of caring for the whole person, body, mind, and spirit.

The past three decades have seen a proliferation in international research

detailing and debating the role that spirituality and spiritual care plays in nursing. Early studies investigating spirituality in nursing originated in North America and the UK.

Early findings, therefore, reflected a Western understanding of spirituality and spiritual care, rooted in the Judaeo-Christian tradition. However, anyone conducting a literature review of these concepts today will see that this body of research has extended across many continents and cultures.

Preparing undergraduate nurses and midwives for spiritual care: some developments in European education over the last decade

Abstract

In recent years, preparing nurses and midwives to be competent and feel confident in providing spiritual care has become the subject of international research. There is an emerging body of evidence affirming the importance of spirituality in promoting the health and wellbeing of individuals. Despite this growing recognition, there are still inconsistencies in the way that undergraduate nursing and midwifery students are taught and prepared to assess and address this dimension of person-centred care, and fundamentally how these concepts are integrated in programmes of education.

This article charts the evolution of a European programme of research, spanning a decade, exploring undergraduate nurses' and midwives' perception of spirituality and perceived competence in providing spiritual care. The research culminated in an educational research study that led to the co-production and development of best practice standards for spiritual care education for Europe, and the launch of a network to sustain and advance this neglected area of nursing and midwifery practice.

Citation

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Introduction and background

Within healthcare, the term 'spirituality' is generally considered to be broader than religion, additionally encompassing peoples' personal and existential beliefs, values and

practices. However, there remains a tendency to associate spirituality with religion. The prevalence of this view means that spirituality and spiritual care may be considered only relevant to people who are religious, rather

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than to all, meaning that non-religious spiritual needs may not be addressed. Therefore, nurses are confused about what spirituality and spiritual care mean for their practice. In addition, media coverage of instances where nurses have been investigated for overstepping the mark by allowing their personal beliefs to encroach on patient care, means that nurses are reticent to engage with this aspect of their practice and have asked for more guidance. For example, an on-line survey by the Royal College of Nursing (RCN) (2011) of its members ($n=3,181$) found that 79.3% considered they did not receive sufficient education and training concerning spirituality and spiritual care and ($n=3,207$) 79.8% wanted to see the topic formally integrated in programmes of education. Other international studies have since replicated the RCN survey, reporting similar findings, suggesting that there is a gap in spiritual care education internationally (Austin et al 2017, Egan et al 2017).

The EPICC Project was a landmark initiative: Enhancing Nurses' and Midwives' Competence in Providing Spiritual Care through Innovative Education and Compassionate Care. This project was funded under the Erasmus+ K2 Strategic Partnerships funding stream. The grant awarded was €242,093. The project involved six partners from four countries in Europe. Collectively, the group was known as the EPICC Strategic Partners. The partnership involved Professor Wilfred McSherry of Staffordshire University; Prof Linda Ross of the University of South Wales; Dr Josephine Attard, University of Malta, Msida, Malta; Professor, René van Leeuwen, Vias Christian University of Applied Sciences, Zwolle, Netherlands; Professor Tove Giske, VID University, Bergen, Norway; Professor Tormod Kleiven, VID University, Oslo, Norway; and EPICC project manager Dr Adam Boughey of Staffordshire University.

The EPICC Project sought to clarify what spirituality and spiritual care mean for nursing and midwifery practice, and to provide the evidence-based guidance that nurses have been seeking for over three decades. This article reports on that landmark initiative, which brought together 31 nursing and midwifery educators from 21 European countries and international stakeholders (including the RCN and governments) to achieve those aims using action learning cycles and on-line questionnaires between November 2016 and July 2019.

To clarify these definitions, we started with a consensus definition of spirituality adopted by the European Association of Palliative Care (EAPC) (2011), and the National Health Service Education Scotland (NES) (2009) definition of spiritual care widely used in healthcare practice. The EAPC (2011) defined spirituality as: 'The dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.'

The spiritual field is multidimensional:

- » Existential challenges (for example, questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy).
- » Value-based considerations and attitudes (for example, what is most important for each person, such as relations to oneself, family, friends, work, aspects of nature, art and culture, ethics and morals, and life itself).
- » Religious considerations and foundations (for example, faith, beliefs and practices, the relationship with God or the ultimate).

The NES (2009) defines spiritual care as: 'Care which recognises and responds to the human spirit when faced with *life-changing events* (such as *birth*, trauma, ill health, *loss*) or sadness, and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship and moves in whatever direction need requires' (NES 2009).

These definitions were accepted as being relevant for nursing/midwifery, with the addition of the italicised words, which were added to reflect wellbeing as well as illness. It is evident that spirituality and spiritual care acknowledge and respond to peoples' personal, religious, and spiritual beliefs but also go beyond that to encompass what gives their lives meaning, purpose and fulfilment and what facilitates connection with self, others, nature and the transcendent (Puchalski et al 2014, Weathers et al 2016, Murgia et al 2020).

EPICC's co-produced novel outputs offer an evidence-based suite of interventions to enable nursing and midwifery educators and practitioners to integrate spiritual care in new and existing programmes of undergraduate

education. The EPICC (2019a) Spiritual Care Education Standard describes the spiritual care competencies expected of undergraduate nursing and midwifery students. It sets out the knowledge, skills, and attitudes expected for each of the four competencies:

1. **Intrapersonal spirituality.** is aware of the importance of spirituality on health and wellbeing.
2. **Interpersonal spirituality.** Engages with persons' spirituality, acknowledging their unique spiritual and cultural worldviews, beliefs and practices.
3. **Spiritual care: assessment and planning.** Assesses spiritual needs and resources using appropriate formal or informal approaches, and plans spiritual care, maintaining confidentiality and obtaining informed consent.
4. **Spiritual care: intervention and evaluation.** Responds to spiritual needs and resources within a caring, compassionate relationship.

The preamble provides the definitions of spirituality and spiritual care.

- » EPICC (2019b) Gold Standard Matrix for Spiritual Care Education is an evidence-based diagram that represents the cultural, social and political environment in which spiritual care competency develops. It should be read in conjunction with the accompanying EPICC (2019c) Gold Standard Matrix Narrative.
- » EPICC (2019) Adoption Toolkit contains teaching and learning activities designed to help students achieve the four competencies, grouped accordingly.
- » The EPICC Website and 5. Network exist to sustain, develop, and advance the EPICC project that ended in August 2019.

Influence and impact

The impact of EPICC has been rapid and substantial with key improvements taking place across Europe and beyond in just 12 months. EPICC has raised awareness of the importance of spirituality and spiritual care in the nursing/midwifery professions and offers a standardised approach to curriculum development. EPICC responds to the United Nations (UN) (2015) sustainable development goal 3 (good health and wellbeing) through the development of quality education (goal 4).

Testimonials provided by EPICC participants/organisational leaders demonstrate the reach and impact of the EPICC project since the launch of its outputs at the University of South Wales, Cardiff, on 1-2 July 2019 by the Minister

for Health and Social Services Wales. The following are examples from the Netherlands, England, Austria, and Poland. These accounts are in addition to the change in pre-registration nursing and midwifery programmes in Wales in September 2020 and Norway already published (Health Education and Improvement Wales 2020, McSherry et al 2020).

A head of school in the Netherlands described how: 'The EPICC outputs are used within curriculum design in our bachelors of nursing programme. The competencies described in the EPICC Spiritual Care Education Standard are also used to train nurses in practice and on a specialist programme we deliver for practitioners to become special caregivers in spiritual care. We also offer training to people from other healthcare institutes throughout the Netherlands. This e-learning programme is based on the outputs from the EPICC projects, as they are very practical e-learning tools. We are leading the way in spiritual care in the Netherlands, students specifically attending our university to develop competencies within this field'.

One participant from England stated: 'I believe strongly that the work of EPICC has raised the awareness of spirituality in nursing and midwifery and created a cohesive language which can be used across Europe. ... In order to continue to ensure spirituality is embedded in the undergraduate nursing and midwifery curriculum in the UK there have been high level discussions with policy makers, the Nursing and Midwifery Council, higher education institutions and clinicians regarding the work of EPICC, findings and resources. This work is not without its challenges when there is still confusion about the concept of spirituality. The work carried out by EPICC has reduced the confusion about the meaning of spirituality and how this can be integrated into nursing.'

A participant from Austria concluded their testimonial by offering a future vision and expansion of the EPICC project: 'I believe that the EPICC Network – under the excellent leadership of Prof Ross and Prof McSherry – has wider relevance for all kinds of nursing, through improving training, communication issues and reflective practice. It could be used in public health, illness prevention, and by nurses based in schools, so that people understand how important these questions of meaning, or spiritual moments in nature are, when taking care of ourselves daily, not just in crisis.'

A participant from Poland recounted: 'I translated the first draft of the standard into

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Polish and informed the Polish Association for Medicine Care of its salience and utility. This translation of the EPICC standard plus a presentation about the EPICC project and spiritual care has been on the Polish Association for Medicine Care website since late 2016. Its inclusion on the website sparked a lot of interest and led to the beginning of discussion with nurses and other healthcare professionals about the importance of embedding spiritual care into research, education, and practice. The translation of the standard and the competencies made this more concrete – it increased awareness with healthcare professionals of their role in the provision of spiritual care’.

These examples selected from four countries across Europe illustrate the current and potential impact of the EPICC project.

Current and future relevance

In the short-term the EPICC project is shaping pre- and post-registration curriculum

development in multiple institutions and countries across Europe and beyond. In the mid-term, these innovations will lead to advancement and improvements in nurses’/midwives’ educational preparedness to support their patients’ spiritual needs better.

EPICC’s longer term legacy will be to offer a more cohesive language for spirituality and spiritual care, dispelling some of the myths and misconceptions that still exist in the nursing and midwifery professions and wider society.

The EPICC outputs are starting to influence the education of other healthcare professions beyond nursing/midwifery and in continents beyond Europe through the project’s website and expanding network.

The EPICC Network has 69 members from 25 countries across six continents. The project responds to the call from nurses and patients for better preparation of nurses for spiritual care, acknowledging Florence Nightingale’s vision for true holistic care.

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Right people, right roles, right time

by Jane Salvage (FRCN 2012) and Barbara Stilwell (FRCN 1994)



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This story starts with two old friends in a blizzard in North Carolina, January 2018. Barbara Stilwell is based there, working for the United States (US) non-governmental organisation IntraHealth, and Jane Salvage has just landed from the UK via a week's work in Belize, narrowly missing a tsunami.

We have a packed schedule to help launch the Nursing Now campaign in the US. Jane had been instrumental in producing *Triple Impact* – the influential report on which the campaign was founded (All Party-Parliamentary Group on Global Health 2016). Though not known to us, Barbara is soon to

return to the UK to become Nursing Now's global executive director.

A snowstorm marooned us in Barbara's lovely home, scuppering many of our seminars, lectures and media appearances. Instead, inspired by our talks about the politics of global nursing and the Me Too! movement, and invigorated by our long walks in winter wonderland, we wrote an article, *Breaking the silence*, which was published as an editorial in the *Journal of Clinical Nursing* (Salvage and Stilwell 2018). The feminist clarion calls and impending campaign launch seemed to herald the possibility of real change.

Breaking the silence: a new story of nursing

Abstract

This joint editorial highlighted the urgent need for a paradigm shift in the ways that nurses think about and present themselves, and the way others think about and treat nurses. We called for nursing and nurses to be taken seriously, at a time when old certainties and ways were being shaken to the core by economic crisis, climate change, insecurity, a deep desire for stronger social solidarity, and the rising clamour of women's voices.

The urgency of this call has heightened in the COVID-19 pandemic, in this International Year of the Nurse and the Midwife. The editorial, which struck a chord worldwide, was a distillation of a shared philosophy developed over many years of work and friendship.

Citation

Salvage J, Stilwell B (2018) *Breaking the silence: a new story of nursing*. *Journal of Clinical Nursing*. 27, 7-8, 1301-1313. doi: 10.1111/jocn.14306

Link

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Introduction and background

Writing from a global health perspective, our 2018 editorial drew on shared values, goals and work driven by professional, political and policy activism throughout our long nursing careers. We called for a paradigm shift in the ways that nurses think about and present themselves, and the way others think about and treat nurses. It was time, we said, to move on from the old story of nursing and build new nursing narratives. Time that nursing and nurses were taken seriously.

The COVID-19 pandemic has heightened the urgency of our call: old certainties and ways are being shaken to the core by its

amplification of existing challenges on top of new ones. Climate change is triggering natural disasters and different health issues; the disease burden is rising while health systems buckle under the strain; and black and minority ethnic groups, women, and many others are demanding fundamental social change. Corporate capitalism and its political allies provide no answers, while economic crisis and financial, social and physical insecurities deepen the desire for social solidarity.

Our editorial was grounded in work we have developed over decades as colleagues and friends in our unusual careers. From the start we were both considered radical. Jane

was known for her activism, starting as a nursing student with a controversial column in *Nursing Mirror*, co-founding the Radical Nurses Group, publishing (and talking about) *The Politics of Nursing* (Salvage 1985) and writing award-winning columns as editor of *Nursing Times*. Barbara introduced the nurse practitioner role to the UK, researched and championed advanced nursing practice, and undertook pioneering work on health workforce issues, especially in Africa. King's Fund seminars on nurse practitioners in primary health care brought us together with other present and future Royal College of Nursing (RCN) Fellows – Tony Butterworth, Trevor Clay, Ainna Fawcett-Henesy, Jane Robinson and Muriel Skeet (Salvage 1991).

Since then we have been fellow travellers on many other programmes for governments and influential organisations, including IntraHealth, *Nursing Now* and of course the RCN – publications, projects and committees – in addition to writing, research and teaching. We worked together for the World Health Organization (WHO) in Europe and at headquarters, where we called out sexual harassment by our department director and fought a long battle for justice.

We look back on wonderful shared experiences as well as the tough ones, but we do not hanker for the 'good old days'. In our vision, the nursing profession of the future will be respected for its science as well as its art. It will reflect the diversity of the communities it serves, and enjoy safe working conditions, good pay, positive practice environments, strong leadership, and many funded opportunities for continuing professional development.

Influence and impact

We ask each other why so many of the changes long called for by nurses worldwide have been so slow to materialise. Although we are proud that we have helped to introduce positive changes in nursing in the UK and worldwide, with support and stimulation from countless nursing colleagues over the decades, our shelves groan with unheeded reports, unheard calls to action and unimplemented recommendations. The changes have not been far enough or fast enough, and we face old and new challenges when choosing priorities in these difficult and uncertain times. Helping nursing worldwide to move forward in this International Year of the Nurse and the Midwife, will the future be different? Are we,

authors and RCN Fellows, stuck in the Nurses' House, speaking only to those who already agree with us, rather than influencing those who do not (Robinson 1991)?

Back in the 1960s, nursing was thought of as a female 'soft skill'. Sociologists considered it a 'semi-profession' rather than a profession because nurses relied on medical doctors to dictate the scope of their practice, supervise it and teach aspects of it (Etzioni 1969, Abbott and Meerabeau 1998). While medics needed five to seven years to qualify with an academic degree and a licence to practise, most nurses qualified and registered with just a two- or three-year diploma. Nurses were considered practical rather than intellectual – ministering angels bathing, feeding, and comforting people. Nursing was not, and was not seen as, based on a body of research-based knowledge that demanded scientific rigour. This British picture also rang true worldwide, particularly where Anglo-Saxon colonial and religious influences remained strong.

Importantly for us, it was the dominant view when we were nursing students in the 1970s. We all have our tales: Barbara had to hide in a cupboard in one hospital as the consultant did not know there were students on the wards, while Jane was verbally abused by a consultant who arrived late for his round and everyone else was at lunch. Those daily battles to be respected and heard turned us into radical nurses.

We stood on the shoulders of giants, and shoulder to shoulder with many others who were trying to transform the nursing profession into an evidence-based science and art, with a strong moral compass that defined its own scope of practice and saw nursing as a force for health co-creation. Looking back, we see how far we have travelled, and how the power of many raised voices, including our own, got us to this point – but it is not our final destination.

Current and future relevance

The International Year of the Nurse and the Midwife was marked by the publication of the first ever State of the World's Nursing report (WHO 2020). It only took WHO 72 years to get round to it! While the report is in many ways a missed opportunity, telling us what we already know and sidestepping many important issues, we can use it to make our case yet again for investment in nursing. We can also use it as a mirror of how our profession is seen by others.

Stating that nine out of ten nurses globally are female, it reminds us how nursing is viewed by professionals, policy-makers and public, though it fails to explore why nursing is a gendered occupation and what impact this has. Jane discussed this familiar story in *The Politics of Nursing*, while sociologist Celia Davies' brilliant analysis remains highly relevant (Davies 1995).

Nursing Now recently contributed to a global survey of 2,500 nurses to explore the effects of being a woman on attaining leadership roles in nursing and health care (Newman et al 2019). As most respondents indicated, the belief that men and women have specific roles in society and health care is an important barrier to women obtaining leadership positions or functioning effectively in them. The perception of nursing as a 'nurturing' and 'feminine' profession (often seen as synonymous) was a consistent finding among both male and female nurses, and across the world. Regardless of gender or region, 77% of respondents said that stereotyped images of doctors as dominant, and nurses as subservient, helped to explain why female nurses struggle to advance to leadership positions. Female nurses are more likely to be expected to be subservient to doctors than male nurses, and disproportionately face discrimination and sexual harassment at work, which increases poor health, stress and attrition rates.

Changes in perceptions of nursing have clearly not gone far enough. People have great trust in nurses, and in this pandemic year call us 'heroes', but also hold a rather paradoxical view that nursing remains more suited to women than men. Even now the media perpetuate this view: just watch the American television series *Grey's Anatomy* where, in its 16th series since 2005, nurses literally have no voices – they are not heard at all. One fascinating analysis of nurses and the media through the ages shows that little has changed (Hallam 2000).

Globally there are 144 distinct titles for a licensed nurse, says WHO (2020) – findings that should ring alarm bells. Is this true of any other profession? It is difficult to find a profession that reinvents itself quite as much as nursing, with the result that people do not really know what they are getting when they get a 'nurse'. Nursing has proved to be flexible and adaptive as other professions change, as population needs change and as technology makes different models of practice

possible and necessary. And yet changes tend to happen in an ad hoc way – and while all change is usually unstructured, for nursing it can mean that practice development has little long-term impact on health systems or workforce design, and lacks formal recognition in scope of practice legislation linked to specific titles.

This matters, and it is not just a nursing issue. We need to bring the attention of stakeholders outside nursing to what we do and what we need to know to do it – a Triple Impact recommendation and a key aim of Nursing Now. It is the person-centred art of nursing that enables the successful application of science, a proposition that has underpinned more research into the practice of nursing than of any other health profession. Little has changed despite the wealth of good research underlining the safety and efficacy of nursing in many settings. At this COVID19-induced watershed for nursing, we need to tell our story to the wider world in a way that moves society beyond the superhero image to that of a respected, smart professional who should be seen, heard and heeded.

This is what impels us to tell a new story of health and healthcare through the Nursing Now campaign. Nurses, as leading actors in this new story, will be at the heart of sustainable health systems that meet individual and population needs, are fit for the present, and innovative and adaptable for the future. As Triple Impact noted, the sustainable development goals (SDGs) will not be achieved without nurses. Nursing is threaded through all the interconnected SDGs because nurses influence and accompany every step of every care pathway in and outside healthcare settings, from before conception to after death. At their best, they focus on where the needs are greatest and where there is most potential to gain health and reduce inequalities. They take their understanding and experience as hands-on practitioners into all subsequent roles as clinicians, managers, teachers, researchers, scholars, policy-makers and leaders.

In a future-focused vision, nurse leaders are experienced, educated, confident and effective champions of quality with a powerful voice at all levels of health and policy systems, recognised and valued by the public, service users, colleagues and policy-makers. They are in post in the right places and right roles and receive the support and resources they need to help nurses deliver their potential.

They ensure the distinctive nursing perspective is included in policy-making and decision-making.

Achieving this vision requires champions to provide support and funding on a scale commensurate with these huge challenges. Long-term and widespread capacity-building

programmes are needed to maintain impact beyond the Year of the Nurse and the Midwife 2020. Investing in nursing in this way will provide great returns. Now is the moment to find our individual and collective voices: not just #MeToo but also #NursesToo, and Nursing Now.

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Through their eyes: building resilience and well-being by listening to children and young people with complex needs about their health preferences

by Jane Coad (FRCN 2013)



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This article seeks to draw out exploratory approaches that I have used but, at the same time, it will add to the debate about how children and young people have been involved in co-creation approaches to support adults (families and health professionals) in shaping healthcare services.

Children's and young people's participation in research work and developing services has had a high profile in health, social

and political arenas for at least 15 years (Gibson et al 2010, Clark and Moss 2011, Coad and Hambly 2011, Lundy et al 2011, Carter et al 2012, Christensen and James 2017, Blaisdell et al 2019, Coad et al 2020, McKay et al 2020).

At the same time, children and young people have taken advantage of this societal change and want a voice and to be part of the decision-making processes that govern their lives.

Building resilience through listening to children and young people about their health preferences using arts-based methods

Abstract

Many writers over the past 20 years have reported that in order to listen and act on children and young people's views, we need to use age and development-appropriate approaches. In research and in developing clinical services, papers have focused on arts-based methods, participation and more recently co-creation to name only a few (Christensen and James 2017, Blaisdell et al 2019). In this article, they will be termed exploratory approaches. While there have been advancements made in using different approaches, there is less critical evidence about children and young people with complex health needs and how that translates and has transformed healthcare services.

This article captures all that has gone before in terms of my work and draws specifically on how exploratory approaches have been used to effectively elicit the views of children and young people with complex health needs, irrespective of age, development, culture and complex health needs. I am including critical discussion not only of using exploratory approaches in real world settings, but how I believe they can be used to positively impact on children's resilience, development and well-being now and in the future.

This work is important in advancing the practice and science of nursing in this growing group as they develop (or survive) into adulthood. It builds their resilience and directly links to the sustainable development goal of good health and well-being. But more than that – it is about having their voices heard and listened to.

Citation

Coad J (2020) Building resilience through listening to children and young people about their health preferences using arts-based methods. In McKay L, Barton G, Garvis et al (Eds) Arts-Based Research, Resilience and Well-being Across the Lifespan. Palgrave Macmillan, London, 47-62. doi: 10.1007/978-3-030-26053-8_4

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Introduction and background

Firstly, what is meant by exploratory approaches and how have they influenced my own work? When we explore what is meant by exploratory approaches, key words such as participatory, consultation, involvement and co-creation emerge in many papers. I had a background in both art and nursing, which influenced me a great deal.

Background aside, what is important to me is that I know as much as I can about the children, young people and families who will be involved in research and that throughout, I am respectful in capturing their voices.

According to Lansdown (2001), the founder and director of the Children's Rights Alliance for England, the levels of research range from 'consultative processes', where children have no control, and activities are adult initiated, led and managed, to full 'participatory processes', which involve collaboration with adults and inclusive sharing.

In my work, I have used these levels of research across a wide range of projects spanning over 20 years. How do I and others use such approaches? The list is extensive, and each must be considered in the context of the child or young person's age, development and abilities (Coad 2020, McKay et al 2020). Suggestions for arts-based approaches used with children and young people:

- » Arts and design-based: Examples could include drawing, colouring, painting, clay, making masks, pottery, 3D insulations, woodwork, collages, scrapbooking and an extensive list of arts-based materials.
- » Writing-based: Examples could include diaries, journals, poster-making, letter activities, storytelling, graffiti walls, symbols or post-its and use of symbolic language.
- » Film and digital-based: Examples could include the use of technology/mobile applications/on-line, photographic imagery and film making.
- » usual person-centred: Examples could include performance arts including role play, singing, dance or any form of human expression and movement.

However, there is nothing quite like seeing an example working in practice. For this article I am drawing on three case examples to show how exploratory participatory techniques have been used in different healthcare settings to ensure children and young people had a voice in shaping services.

- » **Example 1.** Using photographs in building young people's resilience around their views of community health care services (Coad 2007).

I have used photographs in several settings because they offered an interactive approach and also illuminated in-depth views and feelings, particularly in school-age children and young people (Coad 2012). In particular, photographs were used to evoke a response such as a viewpoint or memory, or to enable participants to talk about more difficult, abstract concepts. These are known as photo-elicitation techniques.

This project was conducted to explore what young people believed about health and what preferences they had for their community healthcare services. We used a two-phased project with young people aged 13 to 17 years in two locations in England ($n=62$). While there were two locations, each area and group of young people had the same aims and a consistent approach. Access and recruitment included three secondary schools, one youth club, one child and adolescent mental health (CAMH) facility, one children's home and one health-based advisory group.

All of the young people had used healthcare services in the community at least once, and many of them multiple times. We ensured full communication was sent to all the families and that we obtained informed consent from each participant and, if they were aged under 16 years, also from the parents/guardians.

We invited the young people to be the photographers and planned two participatory workshops for each group. Workshop one included an introduction to the cameras, and ground rules for taking photographs, including safe behaviours. In workshop two, the young people were invited to display their photos and talk about what they were and why they had taken them. Analysis included the development of themes, which were initiated by the young people in workshop two. The report was sent to each location to check it represented what they had said.

We were able to draw out some important and novel findings using photographs in this way. The young people felt the process was different from normal school or college activities, and their energy was captivating. The process involved building their personal strategies for resilience and gave them choice as they engaged with one another, and perhaps also with the team in a way they might not have done using another method.

The photographs provided an opportunity to have group discussions around a visual prompt and was easier than interviewing them about their health beliefs and what they felt about community health services.

» **Example 2.** Building resilience through exploring young children's views in a developing a new hospital (Lambert et al 2014a, 2014b)

As part of an excellent team (Lambert et al 2014a, 2014b) in Ireland, I was invited to contribute to the development of an ongoing, multi-stakeholder consultation initiative conducted by the development board of a proposed new children's hHospital of Ireland.

The aim of the project was to explore school-aged children's (aged 5-8 years) perspectives of hospital environments so that the physical places and social spaces of the new hospital would be responsive to their needs. Led by Professor Veronica Lambert, we used arts-based exploratory approaches and actively engaged in three existing children's hospitals in Ireland to generate data.

We used verbal and visual participatory methods, such as semi-structured interviews, to which we added arts (pens, colouring, paper) and crafts (such as stick on fabric; shining materials) to stimulate the children to talk and interact. Young child participants (aged 5-8 years) were purposively recruited from inpatient, outpatient and emergency departments and consent was obtained from parents/carers and from all the children. Interviews and exploratory activities took place at the bedside or in small workshops.

Thematic analysis was employed, following which we were able to draw out novel and interesting findings. These included findings about personal space, physical environments and social spaces, which emphasised that young children have very strong views on what their hospitals should look and feel like. They could express this opinion once given the opportunity, using appropriate participatory mediums such as arts-based materials. They were resilient and expressed strong views on what home meant and how the hospital should reflect them as individuals in the context of their family.

» **Example 3.** Building resilience through engaging young people in developing cancer services.

Delivering cancer care for young people is highly specialised because it involves paediatric and adult settings and includes all cancer disease sub-specialties.

Coad, Thomas and the research team used appreciative inquiry (AI) to underpin the exploratory methods to learn what young people wanted from cancer services. AI is an emerging research methodology that has theoretical and philosophical underpinnings in action research, organisational learning, and organisational change (Cooperrider and Whitney 1999).

Novel approaches were used by the team to extract the information, including exploratory interviews, arts-based workshops, surveys and blogs. We obtained informed consent from each participant and collated data from two regional specialist units and 18 NHS general hospital trusts in England. A key aim was to ensure that young people with cancer were given a 'voice' in the design and delivery of their treatment, clinical care and pathways and management.

We used the innovative, arts-based methods in four half-day focus groups to capture their views, and we did this in different settings, including hospitals and social spaces, such as a bowling club and a local ski slope. Participants shared their views on what was working well, what could be better and the future of cancer services from their experience.

Data analysis included framework analysis where we agreed a framework for each set of data. Results were transformative in that young people asked for improved communication within and across services; improved use of information technology; improved psychological support specific to young people and improved facilities in outreach areas.

This was an important exploratory study for this group. We were informed hospitals had re-planned some services specifically around the outcomes of this work. Young people felt empowered to have a voice and at least two were later invited to be in expert stakeholder teams, thus offering knowledge to ensure holistic support and treatment for their individual needs. It was hugely rewarding to be part of building some of those skills.

Influence and impact

Having set out three case exemplars, I will now reflect on using such approaches with children and young people in terms of influence and impact at the time, and over time. There are many writers who reflect on and discuss the influence of using well-designed exploratory approaches in building resilience, from planning to exiting the field or event.

I hope the case exemplars discussed here have highlighted a range of approaches but also provided new insights into children, young people and their family's views and experiences. The work has informed and influenced healthcare services on resilience and optimism, empathetic awareness and altruism in mutual support, and a need to reflect on the child's autonomy.

In terms of building resilience and a sense of well-being, feedback and reward are fundamental to the valuing the child or young person's contribution to the activity. However, any reward needs to be appropriate to the age/cognitive development and needs of the child. At the end of the activities I always give feedback to participants about what will happen to the work and how it will be used.

Further, using exploratory approaches can help children and young people communicate to you in ways they might not otherwise use. Some things might be too difficult to express. This is especially true if you are adult strangers to them. Using exploratory appropriate activities can help support positive psychological well-being, both of which are core components of resilience and well-being. In short, they are the real lived experience of that child or young person through their eyes.

Current and future relevance

I have been using such approaches for over 20 years and they continue to have relevance. However, there are also some challenges that I faced that should be considered. Children and young people, like us all, are individuals and so a 'one size fits all' does not work. In the case exemplars in this paper, some children and young people had learning difficulties and/or mental health problems which could have affected their cognitive ability to develop abstract conversations and concepts when using direct interview techniques (Gibson et al 2010, Coad and Hambly 2011, Manning et al 2018, Coad et al 2020).

Using exploratory approaches meant that the tangible nature of the approach in most cases helped children and young people to articulate their ideas and gave them control. Some children and young people had life-limiting conditions and for some they said that their participation in the workshops was their legacy, their voice after their lives had ended. This was indeed powerful.

In all the teams, and cases here, we needed to be considerate of the type of approaches, the purpose for which we were using them and then be doubly prepared for all eventualities. We did this by clearly communicating across the teams, much preparation and practices beforehand and having a range of arts-based tools to hand which I call my Just-in-Case resources. But this needs to be balanced against available resources, including funding. In my experience, children and young people enjoy the spontaneity, but if the materials are old or do not appear well considered they will tell you, or even worse quickly lose interest. I always 'practice' using them with team members from start to finish, so we are fully prepared, comfortable and it all appears to 'naturally' flow.

This article referenced consent and assent in each of the case exemplars. Children or young people's consent (or assent) should be ascertained on an ongoing basis in all research as part of good ethical practice in research.

In terms of exploratory approaches, children and young people need to fully understand and agree before you start any activity. But once you start, the activity can be all consuming, energetic and a lot of fun. It builds rapport in a relatively short time, and resilience. I have found that the most difficult part is ending the activity because the children and young people and the team are often so engrossed. I always tell them at the start how long any activity will take and give them notice of the end at various time points.

Building resilience through using exploratory approaches with children and young people is innovative, fun, rewarding and an immense privilege. I have used these approaches for the past 20 years and have worked with some very talented nurses and health professionals. Many are cited in the reference list. Many are cited in the reference list. For me, it exploratory approaches can be the child or young person's platform in having a 'voice' so they had relevance 20 years ago and still does today.

Such learning has been so powerful and is important in advancing the practice and science of nursing in this group as they develop (or survive) into adulthood. It builds their resilience and directly links to the sustainable development goal of good health and well-being. But it is more than that; it is about hearing and listening to children and young people's voices directly, rather than through an adult acting as their representative.

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Practical advice based on evidence, when people most need it: producing a guide on dementia

by June Andrews (FRCN 2014)



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After more than three decades as a nurse in hospitals, government, a university and care homes, I was working on improving the public understanding of dementia. People affected by dementia, whether directly, or through a relative or patient, often asked me after we talked, ‘Why did no one ever tell me this before?’ Public information and consultations with professionals did not seem to provide people with what they wanted to know. Profile

Books asked me to write a book with sensible advice for people when they most need it.

I put the commonest answers to the usual questions, describing in plain language what ought to happen, and what in real life does happen, when you have dementia and are in the hands of the health and social care system. The need for this did not abate in the following five years and the book went on to international editions and sold in tens of thousands.

Dementia: the One Stop Guide; Practical Advice for Families, Professionals, and People Living with Dementia and Alzheimer’s Disease

Abstract

Written in response to the prevalence of people living with dementia in 2015 (44.4 million world-wide) and in the absence of hope of a cure, this book fills the gap experienced by people who feel unsupported in their search for practical information and support for living with, or caring for, dementia. With clear and sensible information about recognising symptoms, getting help, managing financially, staying at home, treatment, being a carer and staying positive, it sets out to help those with dementia and their families to stay well and happy as long as possible. Information and options are provided in clear language. It advises on getting financial and legal affairs in order, well in advance, and how to survive the risks associated with an acute hospital admission. Correct information can help people stay better for longer, along with certain lifestyle changes.

Virtually all of the information in the book could be accessed on the internet, but people faced with this problem are tired, troubled, busy and running out of options. They might lack the knowledge and experience to sift through the multitude of open sources of variable quality and reliability, in order to access practical, evidence-based information. They also may have no time. I decided to put in the time to produce the One Stop Guide.

Citation

Andrews J (2015) Dementia the One Stop Guide; Practical Advice for Families, Professionals, and People Living with Dementia and Alzheimer’s Disease. First edition. Profile Books

Link

profilebooks.com/dementia-the-one-stop-guide.html

Introduction and background

Years before writing Dementia: What You Need to Know (Andrews 2016a), I had used the travel time on regular train journeys

between London and Edinburgh for a major dementia writing project. A colleague professor of liaison psychiatry in the medical school at Leeds, Allan House, with his team was

facing the challenge of disseminating findings of research on what matters to people with dementia and their carers (Hulme et al 2009). Memory problems didn't even feature in the top six issues. They needed help with aggression, anxiety, sleeplessness, wandering, repetitive vocalisation ... a wide range of issues which are amenable to non-pharmacological care solutions. I translated the huge volume of their findings into a little yellow covered plain English pamphlet called 10 Helpful Hints for Carers of People with Dementia (Andrews and House 2009).

It had sold over 60,000 copies. Andrew Franklin, director of Profile, an independent publisher in London, approached me and commissioned a larger book, which would be a one-stop guide to the issues. The essential elements were that it would be down to earth, based on what people with dementia or carers say, and evidence-based. It would bring together science and the real experience of people with dementia and those around them.

My clinical experience is as a mental health and general nurse caring mainly for older people. I have worked in the independent sector and charities, helped to shut down a psychiatric hospital as part of the large-scale closures of psychiatric hospitals in the later stages of the deinstitutionalisation of UK mental health services, and been the adviser to the Royal College of Nursing (RCN) on ethics and HIV. I was an NHS director of nursing at hospital and board level and had worked in the senior civil service and, in addition, was working at the Dementia Centre at the University of Stirling.

More recently I'd been advising charities and businesses on care of older people and people with dementia. Through all of this I spent a lot of time with people who were struggling with every aspect of 'acquired cognitive impairment', whether age related or not. At all levels in government, policy settings, acute care, care homes, care at home services, financial support, carer's needs; every part of the system was struggling to find a way forward. At that time, rates of dementia diagnosis were standing at about 20% in many parts of the UK, meaning that eight out of ten people with dementia could die without ever seeing a nurse or doctor who specialised in their condition. From personal experience working on improvement of dementia diagnosis across the UK, some doctors consciously withheld the diagnosis in the misguided belief that there is no benefit

in imparting it. Bradford et al (2009) suggest something similar has happened in the US.

Hospitals in the UK were then unsafe places for patients with dementia (Andrews 2015) and delirium was largely unrecognised and untreated, sometimes because it was mistaken for a sign of dementia itself, and therefore regarded as an inevitable stage of later life, not amenable to any positive intervention. National dementia strategies in each part of the UK existed, but implementation was slow, and the planned future improvements were of little value to those affected. I would regularly hear from people who were told at a clinic that they had dementia and that they should come back in a year's time. There was an emphasis on awareness raising with campaigns such as 'dementia friends', a programme launched by the Alzheimer's Society in the UK in 2014 for people to wear 'Dementia Friend' badges after viewing a short lecture in person or online. The programme was misconstrued as education for health and social care staff in some places though it was at best awareness raising for lay members of the public or service providers who were not directly providing care, such as shop assistants. The practical help and advice for those living with dementia seemed to be in inverse proportion to the publicity effort.

Influence and impact

The publisher printed 7,000 copies of the Guide in advance, but then had to reprint before publication day because of significant advance orders. For the first two weeks after publication it was in the top ten Amazon overall best sellers' list. I was interviewed on BBC radio and television and on daytime TV on commercial channels. As of now, over 40,000 copies of the UK edition have sold. It has been translated into Polish (Andrews and Kotowska 2017) at the request of a Polish publisher and further editions have been produced for the North American market (Andrews 2016b) and other international markets in English speaking countries, such as Australia, New Zealand, Hong Kong and Singapore. I have been teaching and lecturing in each of these settings, giving opinion based on the fundamental ideas in the book.

Not everyone was happy, however. Chapter 12 was about the dangers of a hospital admission for someone with dementia, showing how hospitals were, and may still be, places where older people with cognitive impairment as part of their diagnoses may soon become systematically deconditioned,

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whereby they lose fitness or muscle tone, especially through lack of exercise. Decline is accelerated by: disturbed sleep and poor diet; minimal exercise; overuse of anti-psychotics (Simmons et al 2018); and failure to prevent, diagnose, treat, record and follow up delirium, all of which can be compounded if the people concerned are kept in long after the clinical need has ended. Indeed, delayed discharge is often due to administrative processes and budget constraints.

I took a detailed and forensic view about what you need to do as an individual to keep someone you care about safe when they are in the hospital system. This would often be based on three levels of evidence: published research on what makes a practical difference in dementia, which at the time was rare; extrapolation from research on the needs of any person with sensory and physical impairment, because a person with dementia is less able to compensate for their own needs and usually has multiple problems; and extensive personal experience, including gathering international examples of best practice and consensus about what works.

Falls and infection risks were not the only hospital-acquired problems. This caught the imagination of the press (Puttock 2015), which has the privilege of exaggeration and I suffered criticism at many hands, including the chief executive of the NHS at the time who telephoned me to say that I was undermining public confidence in the NHS, and asking me to retract. I offered to withdraw any part of the book that he could tell me was not based on evidence and consequently heard no more. Some nurses and other clinical staff working in the dementia field ('dementia champions') also felt insulted, as if the book implied that they were not doing their job. I only had to point them back to the 80% of patients who never saw or heard of a 'dementia nurse consultant' or other clinician with 'dementia' in their job description. The book was intended for those patients and their families who were on their own with this devastating diagnosis. The main audience, however, the people who needed this book, described it as easy to read, useful and 'cutting through the current narrative'.

It was put to me by a nurse teacher that the absence of references and footnotes made it unsuitable for nursing students, but I did not agree. Student nurses need plain language as much as anyone if we are to encourage them to make change happen. They also need evidence-

based advice couched in plain language to show them examples of how to help patients and families in language that everyone understands. I was, and still am, happy to respond personally to anyone who doubts the evidence base of the book's messages. For example, one family court judge thought that the section on legal issues was superficial, so I asked him to rewrite it and that section is now available, open access, on my website under his name (Ashton 2020). I was and remain happy to support anyone who wants to improve one of the chapters.

Current and future relevance

Five years after publication, an updated second UK edition is due for publication in January 2021 by Souvenir Press. Very little content needed to be changed. Some things have certainly improved, but people are still very much on their own with dementia to a larger extent than they would be with other life-limiting conditions. Improvements include better access to diagnostic and post diagnostic support.

Awareness of the risk of delirium for people with dementia and its prodromal role in dementia appears to be increasing in hospitals. Nursing staff in acute hospitals have a much better understanding of the needs of agitated people with cognitive impairment. I saw this with my own eyes when volunteering in an acute ward during the COVID-19 pandemic in early 2020. The public attitude to dementia may have improved in that it is now an open topic of conversation more than it was before. Another improvement is (in the absence of any prospect of a cure) a real slowing of the incidence of dementia, as public health measures, management of metabolic conditions and lifestyle changes are delaying acquired cognitive impairment in increasing numbers of the population (Alzheimer's Research UK 2019).

Being on your own with dementia is still largely about the funding of home care and residential or nursing care when needed. Successive governments have failed to propose a fiscal solution to this looming problem. Up to 90% of people in care homes and a significant number of those in delayed discharge hospital beds have dementia as part of their diagnosis. The second edition of the guide was timed to come out along with a new book, *Care Homes: The One Stop Guide* (Andrews In press).

At the time of writing, while the world is rocking from the COVID-19 pandemic,

the care homes book is a source of sorrow, because I was not prescient enough to include a chapter on how to manage a pandemic in a care home. Every day in the media, we heard of the mounting toll of tens of thousands of people in care homes, many of whom have dementia, who are dying from this virus or related issues. With hindsight, one can see that it was the wrong decision to move old people with dementia out of hospitals into care homes over a matter of weeks. It may have helped to save the NHS, but at a terrible cost. It did not require hindsight to know that keeping those older people with dementia in hospital was building up trouble, a situation that should have been addressed well before this point, so we could have prevented the circumstances that gave rise to this tragic error of judgement. It is the very thing that I was criticised for talking about five years earlier.

In a Cassandra-like stroke at the start of the pandemic, I asked politicians at the Scottish Government public audit committee hearing if they were waiting for a pandemic to clear away their delayed discharge problem. In mythology, Cassandra was given the power to see the future, but also the curse of never being believed. I was not believed

when I suggested that the health service and social care service in the UK has not been designed to include the needs of the ageing population, especially those who are frail and cognitively impaired (Andrews 2018, Scottish Parliament TV 2020).

The official response was silence, while on the ground thousands of older people across the UK were suddenly forced out of hospital and into care homes. Deaths of older care home residents from dementia are now well above normal rates, as a direct result of the loneliness, isolation and disruption created by the management of this flow during the pandemic. Even if they have avoided death or if the immediate impact of COVID-19 has passed, the rushed policies that did not take dementia into account caused excess suffering for people with dementia (and their families).

My guide book on dementia, with its emphasis on avoiding hospital where humanly possible, and staying by the side of the person living with dementia when possible, is as relevant now as it was when it was first written. It will continue to be relevant until someone finds a cure, fixes the health and social care system, or writes a better book.

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Reflecting on the characteristics and values of military nurses: war zone qualitative research

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In 2013, I (AF) was appointed as the first UK Ministry of Defence Professor of Nursing, with an implicit responsibility to lead and support military nurses in undertaking high impact research. Early into this assignment, I deployed into Afghanistan to complete a series of qualitative nursing research studies. This included an exploration into the characteristics and values that military nurses defined as being pre-requisite to successfully undertaking their role in a harsh and demanding environment.

In part, I was motivated through a reflection on principles such as compassion, resilience and clinical competency that are attributed to significant military nursing

role models, such as Mary Seacole and Florence Nightingale, and attempting to conduct an empirical study to determine their relevance in a modern setting.

This in situ nursing research was novel, and I was indebted to other civilian authors, including RCN Fellows Hugh McKenna and Kath McCourt, who provided their academic expertise and support to ensure that the research was built on strong methodological foundations.

As such, this article is drawn from the only qualitative nursing studies conducted in a War Zone and published in *Nurse Education Today*. I have been the assistant editor of the journal since 2016.

Characteristics and values of a British military nurse. International implications of war zone qualitative research

Abstract

Background Between 2001 and 2014, British military nurses served in Afghanistan caring for both service personnel and local nationals of all ages. This paper is from the only qualitative nursing research conducted in situ in Afghanistan, in 2013.

Aim To explore the characteristics and values that are intrinsic to military nurses in undertaking their operational role.

Design A constructivist grounded theory was used. UK Ministry of Defence Research Ethical Committee approval was obtained.

Conduct of work Semi-structured interviews with 18 British armed forces nurses.

Results A theoretical model was developed that identified the intrinsic characteristics and values required to be a military nurse. The nursing care delivered was perceived to be outstanding.

Recommendations Originality, and linked to sustainable development goals in good health and wellbeing and informing quality education.

Citation

Finnegan A, Finnegan S, McKenna HP, McCourt K et al (2016) Characteristics and values of a British military nurse. International implications of War Zone qualitative research. *Nurse Education Today*. 36, 86-95. doi: 10.1016/j.nedt.2015.07.030

Link

www.sciencedirect.com/science/article/abs/pii/S0260691715003007

Introduction and background

The foundations of modern medicine and nursing are directly correlated in caring for armed forces personnel in times of conflict and war (Gabriel and Metz 1992, Medicine and The Military 2020). This extends to the formation of the (Royal) College of Nursing (RCN) in 1916 (Finnegan and Nolan 2012).

It was during the Crimean war (1853-1856) that field hospitals were first established. During this war death was common due to yellow fever, dysentery, cholera and tuberculosis (Gill and Gill 2005). It was here, while attending wounded servicemen and delivering care in hostile territories and under dangerous conditions, that Florence Nightingale began to formulate her concepts about nursing (Nightingale 1859). These advancements resonant today with the spotlight on infection control, hospital epidemiology, and hospice care. It was fitting that the network of 'field' hospitals quickly set up during the COVID-19 pandemic were given the name Nightingale.

In World War I, military nurses demonstrated extreme flexibility and resilience at clinical, physical, psychological and environmental levels, including caring for local nationals and enemy troops (Gerolympo 1995). Nurses were at risk (Harper and Brothers 1918, Hay 1953), and their patients were positively influenced by the calm way the nurses went about their duties, while the nurses were inspired by the performance, fortitude and cheerfulness of their patients (Hay 1953). Evidence can be found in the diaries of nursing leaders such as Maud McCarthy who, as matron in chief to the British Expedition Force, had sailed on the first ship to France in 1914 and then maintained her position throughout the entire campaign until 1918. However, few research studies have assessed the effectiveness of the military nurses' operational role, and a comprehensive literature search identified no published empirical study that explored the core characteristics and values required by military nurses in the operational arena.

In this century, an International Security Assistance Force comprised of British, American and other allied troops were deployed to Afghanistan (2001-2014) in support of a NATO mission and to care for all patients, including local nationals of all ages and captured persons (CPers) (Simpson et al 2014). The major hub for medical activity was Camp Bastion Hospital, which contained multi-national British, American and Danish

clinical staff under British command. Coalition patients were quickly repatriated to their home countries. The local population's progress, rehabilitation, community care and future treatments were through a local healthcare facility outside of the military's scope of influence.

By 2013, military medical and mental health research were dominated by positivist theories and quantitative research, and no qualitative nursing research had been undertaken in the Afghan/Iraq war zones. In 2013, I (AF) deployed to Afghanistan to collect data for four studies. In addition to this study (Finnegan et al 2016a), data were collected on educational and clinical preparation (Finnegan et al 2016b), the psychological implications (Finnegan et al 2016c), and the role of the mental health team (Finnegan et al 2014a, 2014b). Approval for the study was granted by the UK Ministry of Defence Research Ethical Committee.

Interviews were conducted with 18 military nurses based at Camp Bastion Hospital, Afghanistan during June and July 2013. The intent was to accurately reflect the respondent's interpretation of a wide range of emotions, behaviour, thoughts and beliefs. This led to an emerging theoretical model categorised as: personal values, military skills, scope of practice and clinical leadership. These groupings were responsive to the common dynamic healthcare factors faced by any nurse in relation to manpower, experience, motivation, satisfaction, and the type of casualty with associated ethical issues. I had the support of civilian academics who had military experience and they helped scrutinise the data to ascertain comparators and differences. It is important to recognise that this model was an emerging prototype, and needed testing and further research on its functionality and to consider wider transferability.

Influence and impact

Respondents were volunteers who had made a lifestyle choice to deploy in support of fighting troops. The participants believed that the nursing care delivered in the conflict area was of a very high standard for all patients. They reported a sense of self-worth and pride aligned to strong team integration as being significant positive factors in underpinning the excellent care. Prior experience of this environment helped and made the nurses less likely to be negatively psychologically affected by either the clinical presentation of casualties, high activity levels or the austere environment

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(Finnegan et al 2016c). Senior staff identified the importance of advocacy, being tenacious and backing their judgement to deliver compassionate care. Role modelling and getting to know their staff were important in building a rapport to understand other peoples' views and aspirations. As with other parts of the nursing workforce, it was important to be conscious of some of the multifactorial stressors, although it was also noted in Afghanistan that many nurses thrived.

Nurses talked of quality care, helping each other, communicating with each other, reminding each other of what is expected, and recognising the qualities that nurses brought to the multi-professional team. An emphasis was placed on patient needs, which were determined through robust communication built on a trusting relationship. These included lessons learned from caring for CPers, where the nurses consciously detached themselves from any legal processes and treated the casualty as a vulnerable patient. Respondents reported that military nurses must have the correct clinical competencies, with skill sets aligned to working within one's scope of practice. A particular concern was caring for children, with anxiety induced from both a lack of clinical experience (Finnegan et al 2016c) and previous negative experiences. Participants found these situations extremely stressful.

The impact of the study at the time was to inform pre-deployment training and advocate the role of practice educators in the operational environment. Due to the unique nature of this research, the study built on homebased military qualitative defence research (Finnegan et al 2014c) and I published the challenges, theory and methods used to inform future studies (Finnegan 2014a, 2014b).

Current and future relevance

COVID-19 presented nurses with a multitude of challenges, and one means of assessing what is required in the present is to look to the past. Defence nurses face challenges not generally encountered at an equivalent level within civilian practice, and this study demonstrated the essence of compassion and empathy associated with an altruistic motivation to relieve suffering in the harshest of condition. The attributes historically aligned to great military nurses of previous generations were empirically demonstrated as intact in the current workforce, which is particularly poignant in the International Year of the Nurse and the Midwife.

The characteristics identified in our study have been demonstrated in nurses during the COVID-19 pandemic, and there is clear synergy with global workforce demands. Popular descriptions of nurses 'battling' the virus and 'being on the front line' are used to describe healthcare delivery.

The findings from our study identified that certain themes and categories could be polarised, depending on the circumstances. Nurses focused on their scope of practice, civilian colleagues were intrigued by the leadership skills, while patients and public focused on personal attributes. However, the power of nursing as a profession is built on the amalgamation of these elements to provide the unique characteristic and value of the profession. The research provided military nurses with a framework for a realistic personal development plan to build on their strengths and identify limitations. Also, it supplied selection panels with an additional tool to help the recruitment process and presented a prompt to focus on all the components of being a military nurse, and not just one area, for example, physical fitness.

Given the increasing global migration of nurses, it was hoped this paper could encourage similar occupational models. Due to the sample, the findings were UK-focused, but these nurses were deployed with equal numbers of colleagues from the United States and evidence suggests that lessons learned from War Zone nursing have international military and civilian implications. However, as an emerging model, readers were advised to treat the findings with some caution.

The American Academy of Nursing's Military and Veteran Family's expert panel are working with the RCN's defence forum and nursing academics to further develop nursing research. In 2020, this will be showcased in international events (Westminster Centre for Research in Veterans, 2020), with 14-16 of the conference papers scheduled to be published in a high standard peer review journal in April 2021.

As the only international armed forces nursing-led qualitative research study undertaken during the Afghanistan and Iraq conflicts, this article was an important historical resource. Significant medical advancements have been achieved by translating clinical lessons learned on the battlefield into civilian healthcare. The serious poly-trauma injuries of the Afghan conflict featured orthopaedic problems,

including amputations and associated injuries such as burns (Jansen et al 2012) and traumatic brain injuries (Taylor et al 2012, Trauma Brain Foundation 2016). Yet the exemplary Bastion Hospital healthcare provision (Care Quality Commission 2012, Stockinger 2012) played a part in saving lives where previously patients would have died (Hodgetts 2012). These experiences informed the development of the National Institute for Health Research/Ministry of Defence-funded Surgical Reconstruction and Microbiology Research Centre (2015) and the Scar Free Foundation (2020). In mental health, clinical and nursing initiatives such as assertive outreach, community-based care, crisis intervention (Artiss 1997) and group psychotherapy (Harrison and Clarke 1992) have their origins in the world wars. The

lessons learned from the battlefield, can have significant positive influences on military and civilian nursing on a truly international scale. The study demonstrates that despite the ethical and geographical challenges, that quality information can be collected in the harshest of terrains. The originality of the study is embedded in the United Nations' sustainable development goals of producing evidence to inform good health and well-being and shaping quality education.

By collecting empirical data to inform educational programmes, clinical practice and policy, nursing researchers can help prepare the future generation of nurses. Placing nurses first, with a model that focuses on the requirements of a good nurse, has the potential to lead to better patient care, and improve the quality of their workforce experiences.

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The Person-centred Nursing and Person-centred Practice Frameworks: from conceptual development to programmatic impact

by Brendan McCormack (FRCN 2014)



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The development of the Person-centred Nursing and Person-centred Practice Frameworks has spanned over 20 years of research, practice development and evaluation activities. The original framework published in 2006,

was developed for use in the intervention stage of a large quasi-experimental project that focused on measuring the effectiveness of the implementation of person-centred nursing in a tertiary hospital setting (McCormack and McCance 2006).

Development of a framework for person-centred nursing

Abstract

Aim This article presents the development and content of a person-centred nursing framework.

Background Person-centred is a widely used concept in nursing and healthcare generally, and a range of literature articulates key components of person-centred nursing. This evidence base highlights the links between this approach and previous work on therapeutic caring.

Methods The framework was developed through an iterative process and involved a series of systematic steps to combine two existing conceptual frameworks derived from empirical studies. The process included the mapping of original conceptual frameworks against the person-centred nursing and caring literature, critical dialogue to develop a combined framework, and focus groups with practitioners and co-researchers in a larger person-centred nursing development and research project to test its face validity.

Findings The person-centred nursing framework comprises four constructs – prerequisites, which focus on the attributes of the nurse; the care environment, which focuses on the context in which care is delivered; person-centred processes, which focus on delivering care through a range of activities; and expected outcomes, which are the results of effective person-centred nursing. The relationship between the constructs suggests that, to deliver person-centred outcomes, account must be taken of the prerequisites and the care environment that are necessary for providing effective care through the care processes.

Conclusion The framework described here has been tested in a development and research project in an acute hospital setting. While there is an increasing empirical base for person-centred nursing, as yet little research has been undertaken to determine its outcomes for patients and nurses. The framework developed can be described as a mid-range theory. Further testing of the framework through empirical research is required to establish its utility for nursing practice and research.

Citation

McCormack B, McCance T (2006) Development of a framework for person-centred nursing. *Journal of Advanced Nursing*. 56, 5, 1-8. doi: 10.1111/j.1365-2648.2006.04042.x

Link

onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2648.2006.04042.x

Introduction and background

The 2006 version of the Person-centred Nursing Framework (PCNF) was derived by combining the conceptual framework that I had developed (McCormack 2001, 2003) focusing on person-centred practice with older people and Tanya McCance's (2003) framework that focused on patients' and nurses' experience of caring in nursing. Our first joint publication (McCormack and McCance 2006) – the article that underpins this article – set out the processes involved in developing the framework. More significantly, the specific shared philosophical underpinnings that enabled two conceptual frameworks to be combined into one theoretical framework were described. This shared philosophical starting point enabled us to set out the key aspects of what it means to be a 'person' that were consistent with a philosophy of human science and embraced key human science principles of freedom, holism, relationality, time and knowledge (McCance and McCormack 2017). A diagram of the original PCNF can be found in our original publication, and as shown, comprised four domains:

1. Prerequisites focus on the attributes of the nurse.
2. The care environment focuses on the context in which care is delivered.
3. Person-centred processes focus on delivering care through a range of activities.
4. Expected outcome is the result of effective person-centred nursing.

Each domain had several constructs that enable users of the framework to engage in a systematic consideration of the key elements of person-centred nursing and its complexity. The pictorial representation of the framework was deliberately chosen to reflect that complexity. We wanted to show that achieving person-centred outcomes is not something that happens through a particular intervention or indeed a meaningful moment of care, compassion or kindness. Instead, person-centred nursing outcomes are achieved through systematically attending to each of the domains (prerequisites, care environment and care processes), working towards the achievement of person-centred outcomes for a person, people or populations. From the outset, we described the PCNF as a mid-range theory, which is a theory generated through research and used as an evidence base to develop practice or interventions for practice. We made explicit its place on the continuum of theory development in our follow-on publication

(McCormack and McCance 2010), where we drew on the seminal work of Fawcett (1995).

The exposure of the PCNF to nursing communities internationally following its publication in 2006, resulted in much critical debate about the domains and constructs, and its general applicability in practice. This was helpful and to be expected as the work was published at a time when models and theories of nursing were far from fashionable, 'armchair' theorising was scorned on (McKenna 2005), and nursing-specific knowledge was sacrificed at the altar of evidence-based practice. However, this period also represented a time in nursing and healthcare where a focus on modernising and improving practice through a variety of implementation science and quality improvement methodologies were being promoted and given a lot of attention.

We chose to integrate the PCNF with the international work we were engaged with – practice development – making explicit that the ultimate outcome from practice development was the creation of effective person-centred cultures (McCormack et al 2013). This integrated approach resulted in the international adoption of the framework and a desire for it to reflect multidisciplinary and interprofessional practice more explicitly. This challenge has been continuously responded to.

Influence and impact

Since the publication of the original PCNF, we have continued to revise and develop it (McCormack and McCance 2010, McCance and McCormack 2017) resulting in the development of a multidisciplinary version: the Person-centred Practice Framework (PCPF) (McCormack and McCance 2017, 2019a). Despite these revisions, the fundamental building blocks (the domains), and the key elements (the constructs), have remained stable over time. They have been refined to reflect increased engagement with the framework and its implementation in a variety of contexts. However, with the emergence of the PCPF as the most adopted framework among multidisciplinary and interprofessional teams, the most recent iteration of the PCNF reflects its firm location in the meta-paradigm of nursing (Fawcett 1995) and its recognition as a model of nursing (McCormack and McCance 2016). While today, the majority of our work and those of collaborators adopt the PCPF, we have always remained committed to contributing to the ongoing development of nursing-specific knowledge, and so we chose to

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develop a revised PCNF in 2019 (McCormack and McCance 2019b).

The PCPF has now been translated into 10 languages (Dutch, German, Danish, Norwegian, Portuguese, Spanish, Mandarin, Slovenian, Swedish and French) and tested in multiple healthcare contexts in more than 22 countries, with the framework and associated tools/instruments appealing to a wide range of stakeholders. Research and development undertaken with international partners in the United Kingdom, Sweden, Norway, Finland, the Netherlands, Spain, Portugal, the Republic of Ireland, Australia, South Africa, the United States and Canada, has resulted in the development of five evaluation instruments and through various implementation studies with these and other international partners, we have identified key outcomes from the implementation of person-centred practice (Slater et al 2009, 2017, Wilson et al 2020).

In nursing home settings, implementation studies have resulted in improvements to the care environment, greater resident satisfaction, improved staff well-being, reduction in falls and reduced use of psychotropic medications (McCormack et al 2010, Buckley et al 2014, Mekki et al 2017). In acute care settings, evidence of better engagement between staff and patients as well as improved retention of staff, greater job satisfaction and staff wellbeing have been identified (McCance et al 2008, Parlour et al 2014, Hahtela et al 2015, Laird et al 2015). In palliative care, the evaluation of practice development programmes has shown improvements in regulator quality indicators, as well as improvements to the quality of the care environment, better and more effective staff communication, increased staff development, and better retention of staff (Yalden et al 2013, McCormack et al 2018, Haraldsdottir et al 2020).

An international programme of work leading to the development and testing of eight person-centred nursing key performance indicators (KPIs) also offers a mechanism to measure aspects of person-centred practice (McCance et al 2012). The eight KPIs align to the processes in the PCNF. Tanya McCance has led the development of a set of measurement tools to accompany the KPIs (McCance and Wilson 2015). The eight KPIs and measurement tools have been tested through a series of international implementation studies in a range of clinical settings (McCance and Wilson 2015, McCance et al 2015, 2016).

Findings from these studies confirmed that using the eight KPIs generated evidence of patient experience that facilitated engagement of nurses to develop person-centred practice, contributing to an enhanced care experience.

Current and future relevance

This unrelenting attention to theory development in person-centred nursing and healthcare could be considered 'overkill' in paying attention to issues that, for some people, are routine everyday current practice. It is precisely that tension that challenges all of us in the development of person-centred nursing and healthcare practices, in learning about person-centredness and in embodying it in everyday work. 'We do it but we don't call it that' is a retort that is familiar to all of us and it challenges us to use language describing person-centred practice to demonstrate its uniqueness, worthwhileness and transferability across contexts.

The 'we do it but we don't call it' mantra among practitioners, academics and researchers leads to a view that person-centredness is a nebulous concept, devoid of clear definition and something that can be substituted with other concepts such as compassionate care and dignified care. While there are (a few) clear definitions of person-centredness and person-centred nursing/healthcare, the use of the term 'person-centred' and its derivations without offering any definition is prolific in published research and does little to help practitioners develop a clear understanding of person-centredness and the elements on which they need to focus.

There is also a tendency to focus exclusively on the service-user at the centre of care and decision-making. While nobody could object to such an important focus, it is only part of the story. We have always contended that it is immoral for an organisation to expect high-quality, evidence-informed, person-centred care to be provided to service-users without an equal focus on the personhood of staff and their well-being (McCormack and McCance 2010, 2017). We have challenged the dominance of focusing on person-centred care provided to, with and for service-users/families at the expense of staff well-being. This values-informed position has been reinforced through the systematic development, implementation and evaluation of the PCNF and PCPF, and is now a more accepted focus in many quality improvement activities. It remains the case, though, that the person-centredness of

care providers is placed at a lower level of importance and significance to that of service users – and this has been abundantly evident during the COVID-19 pandemic.

For person-centredness to become more normalised in nursing and healthcare discourse, there is a need for thought-leaders, strategic planners, managers and decision-makers to stop using the ‘it’s too difficult to define’ and ‘we do it anyway’ arguments to defend organisational cultures that are non-conducive to the achievement of person-centred care for service-users; but instead, strive to make sense of what person-centredness could look like for all people in an organisation. For too many managers, an obsession with ‘quick-fix’ solutions means that the time needed to achieve such clarity is sacrificed at the altar of expediency.

Person-centred practice needs to be understood as a concept that is embedded in every strategy and policy that shapes healthcare planning and delivery. It needs to be based on conceptual and theoretical frameworks that are inclusive of all people and that clearly articulate how these concepts are to be embedded in everyday practices at macro, mezzo and micro levels.

If healthcare organisations are committed to developing person-centred cultures for all people, we need decision-makers to think about how they create opportunities for all people to have spaces ‘to be’ with others, and explore opportunities for increasing connections that further develop person-centred practices. Developing complex systems is not the answer, but neither are simple quick fixes to complex problems.

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Learning disability liaison nurses: the provision of compassionate, person-centred care for people with learning disabilities accessing acute hospital care

by Michael Brown (FRCN 2015)



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The publication that underpins this article (Brown et al 2016) arose from research on equality of access to acute hospitals for people with learning disabilities. It presents findings from a large study involving four Scottish NHS boards and 11 acute hospitals.

The study had 100 participants, comprising families, carers and health professionals with direct experience of the contributions made by learning disability liaison nurses. We identified the outcomes achieved by the nurses and their contribution to the provision of person-centred and compassionate care in the acute hospital setting.

The work to improve acute hospital care for people with learning disabilities has continued for around 20 years, during which time there have been many developments. The work started in 1997 and was a

collaboration with Dr Juliet MacArthur, who is now chief nurse for research and development with NHS Lothian.

At the time, I was a practice development nurse in Lothian Primary Care NHS Trust, and Juliet was in a similar role in the then Western General Hospitals NHS Trust. We established the first learning disability liaison nurse role in 1999 in the Western General Hospital Acute NHS Trust, Edinburgh. The role was an innovative response to the often complex health needs and the frequency of access to acute hospitals of people with learning disabilities.

The focus of the role was to provide people with learning disabilities and their families access to additional support and education, before and during hospital attendance and admission and at discharge.

The perspectives of stakeholders of intellectual disability liaison nurses: a model of compassionate, person-centred care

Abstract

People with learning disabilities have a high number of comorbidities, requiring multidisciplinary care, and are at high risk of morbidity and preventable mortality. The effective provision of compassionate, person-centred care is essential to prevent complications and avoidable deaths. The aim and objectives of the study were to investigate the experiences of patients with learning disabilities, their family, carers and health professionals regarding the role of learning disability liaison nurses and the delivery of compassionate, person-centred care and from this, to propose a model of person-centred care embedded in these experiences.

A qualitative design was adopted with interpretative phenomenological analysis for data analysis. Semi-structured interviews and focus groups were conducted. Data were analysed with a focus on compassionate, person-centred care elements and components. Themes were modelled to develop a clinically meaningful model for practice.

The themes identified were vulnerability, presence and the human interface; information balance; critical points and broken trust; roles and responsibilities; managing multiple transitions; 'flagging up' and communication. The findings provide the first 'anatomy' of compassionate, person-centred care and provide a model for operationalising this approach in practice. The applicability of the model will have to be evaluated further with this and other vulnerable groups.

Citation

Brown M, Chouliara Z, MacArthur J et al (2016) The perspectives of stakeholders of intellectual disability liaison nurses: a model of compassionate, person centred care. *Journal of Clinical Nursing*. 25, 7-8, 972-982. doi: 10.1111/jocn.13142

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Introduction and background

The care and support of people with learning disabilities have seen significant policy changes in many developed countries across the world. Internationally, the term used is 'intellectual and developmental disabilities', and in the UK, 'learning disability'. Long-stay institutions across the UK have closed during the past 30 years, brought about by a policy shift towards care and support in the community, seeking to maximise autonomy, independence and social inclusion of people with learning disabilities (Scottish Government 2000). It is important to appreciate, however, that most people with learning disabilities have always lived at home with their families. Some lived in congregated institutional settings.

Alongside these developments, life expectancy has increased significantly over the past 100 years and today many people with learning disabilities live into older age (Dolan et al 2019). The number of children with intellectual disabilities has also increased due to a range of factors, including improved survival rates due to developments in neonatal and child healthcare (Heuvelman et al 2018). These children and young people are surviving into adulthood, however life expectancy for many may be 20-30 years shorter than the general population, particularly for those with the most complex of care needs (Scottish Government 2013). Many children, adults and older people with learning disabilities experience a range of complex, co-existing physical and mental health conditions and behaviours that can be challenging (Hughes-McCormack et al 2018). Physical health conditions are common and include, for example, respiratory disorders, gastric conditions and neurological disorders (Emerson et al 2016). Mental ill-health is also common by way of for example, depression and anxiety disorders (Hughes-

McCormack et al 2017). Many have communication disorders that can have a negative impact on health-seeking behaviours (Chinn and Rudall 2019). As a result of their complex health conditions, people with learning disabilities are frequent consumers of all aspects of care services, including health (Kalseth and Halvorsen 2020).

Our collaboration began following a complaint and investigation regarding the care of a patient with learning disabilities admitted for treatment and care. The outcome of the investigation was a request from the two nurse directors in acute and primary care for a review and update of the local policy, Care of the Mentally Handicapped Patient, the existence of which was largely unknown by staff in the trust. Following the review of the policy, it became apparent that significant work was required to address the needs of people with learning disabilities and make service improvements.

We audited and identified patient care journeys into, within and out of acute hospital care. We reviewed national policies, reports and research evidence and it became apparent that people with learning disabilities accessed all clinical areas of acute care. Many accessed specific clinical areas such as respiratory, gastroenterology, neurology and dental services in greater numbers due to the extent of their health needs. Many were identified in emergency care and unscheduled care services, out-patients and day surgery and investigation units as well as in-patient units.

Influence and impact

The idea of developing the learning disability liaison nursing role was to ensure that people with learning disabilities and their families, carers and health professionals in acute care had access to a learning disability nurse with the knowledge, skills and expertise of

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the needs of the population. This was in the wider context of the distinct and complex health conditions experienced by many people with learning disabilities and their need to access assessment, treatment and investigations in acute hospitals (Glover et al 2019). Additionally, all public bodies had, and have, a legal duty to make 'reasonable adjustments' for all people with disabilities by complying with legislation to enable access to public services. The role was seen as a way to help achieve compliance (Heslop et al 2019). Following a review of the limited available research evidence, it became evident that the health needs of the population of people with learning disabilities were high, often unidentified and unmet and, yet access to additional support was limited (Burke and Heller 2017). Families gave accounts of being left to provide all but technical healthcare. Professionals in acute care described limited previous education on the specific needs of people with learning disabilities, with many lacking in the confidence and skills necessary to respond (Hemm et al 2015).

The first large long-stay institution for people with learning disabilities to close in Scotland was Gogarburn Hospital, on the outskirts of Edinburgh. As part of the closure programme, a service development fund was available, and Juliet MacArthur and I developed a funding proposal for the first learning disability liaison nursing role to be based at the Western General Hospital. Funding was secured for a two-year post, with the first postholder, Maria Rigg, appointed in 1999.

Implementing a new role in a large and busy acute hospital environment was challenging. However strategic support from Mrs Alex Harvey, nurse director at the Western General NHS Trust, was important. Dr Linda Pollock, nurse director in primary care, helped to facilitate the establishment of the role. The focus of the role was on the provision of additional support before, during and at the point of discharge for people with learning disabilities and their family, and education and support for health professionals in acute care.

A range of other initiatives were also tried, which met with varying success. These included a face-to-face education programme on the needs of people with learning disabilities for acute care professionals, and establishing a network of link-nurses in key clinical areas in the trust. These met with limited success due to the inability of the trust to release

colleagues from their day-to-day role to attend education sessions, and the turnover and internal movement of the link-nurses in the organisation. We envisaged that the role would work with agencies, such as primary care, specialist learning disability and social care services, to undertake pre-attendance planning and communication with the relevant part of acute care to plan and coordinate the attendance or admission. The focus on attendance was important because of the move towards day investigations and procedures and admission, where clinically indicated. During attendance and admission, the focus of the role was on information sharing, communication and care coordination, and facilitating the identification and implementation of reasonable adjustment, necessary throughout the care episode (Redley et al 2019). The liaison nurse also provided short education sessions on specific support and care needs of individual patients with learning disabilities.

The findings from the study showed that, from the stakeholder perspectives, liaison nurses were able to provide additional support at a time when people with learning disabilities and their families were at their most vulnerable. Families highlighted the importance of the presence of the liaison nurse in providing the 'human interface', helping to make care more compassionate and person-centred. Families described previous care episodes in acute care where their trust and confidence in 'the system' had been broken, and they were overwhelmed by decision making and the volume of information provided. Liaison nurses' knowledge of the needs of people with learning disabilities, and of the acute care organisation and systems, led to enhanced communication and information. They had the opportunity to flag up specific care needs and issues. An important finding was that the liaison nurse followed and tracked people with learning disabilities throughout the care journey, which was seen as critical by families when they were transferred within departments and units in the acute hospital. This further promoted person-centred care.

Current and future relevance

The study was the first to research the outcomes achieved by learning disability liaison nursing in the acute care setting and the contributions the role made to compassionate, person-centred care and support. The findings enabled the development of a definition of compassionate, person-centred care in

the acute care context and enabled the development of a new model to support the application in clinical practice. Further posts were established in Lothian, including at Royal Infirmary of Edinburgh, The Royal Hospital for Sick Children and St John's Hospital.

Since the establishment of the first post in Edinburgh, similar roles have been introduced across Scotland, the rest of the UK and Ireland.

The research findings have attracted national and international attention. From a policy perspective, the role has been identified within a range of policy initiatives as necessary to support and facilitate access to acute hospital care for people with learning disabilities. The work of the leading charity Mencap has been influential in campaigning to improve the care and support of people with learning disabilities in the acute hospital setting (Mencap 2007, 2012).

The concerns highlighted by Mencap led the Department of Health in England to hold a review that led to the report, *Healthcare for All?*, which recommended the establishment of learning disability liaison nursing roles in all acute hospitals (Department of Health 2008). The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CiPOLD) also recommended the need for additional support to be put in place (Heslop et al 2014). The role has prompted other researchers to investigate acute hospital care and liaison nursing roles (Hall et al 2014, Tuffrey-Wijne et al 2014, Northway et al 2017). The model has been recommended by the World Health Organization (WHO) as an example of best practice (WHO 2010).

With the ageing population of people with learning disabilities and the increasing number of children living into adulthood with complex health needs, our follow-on research has focused on health transitions. The main focus of the transition study was on young people with complex physical learning disabilities.

Those with complex neurodevelopmental disabilities, mental ill-health and behaviours that challenge are also populations that require specific research attention. A Scotland-wide study was completed at the end of 2019 on the transition from child to adult health services for young people with complex learning disabilities (Brown et al 2019). The role of the learning disability liaison nurse was cited by some participants as central to facilitating the smooth and effective transition between services (Brown et al 2020).

Since 1997, we have undertaken three research studies, published numerous papers and reports and have presented on the subject at conferences, workshops and seminars (Brown et al 2012, MacArthur et al 2015). The learning has also been integrated in education programmes for pre-registration nursing students in Scotland.

Given the range of issues affecting people with learning disabilities in acute hospital care, the development of the role should be seen as only part of the solution, not the whole solution. Improvements are also required in areas such as the education of health professionals of the distinct needs of people with learning disabilities, pre-admission planning, care pathways and admission and discharge policies, to highlight a few. Internationally, most nurses are educated and prepared with core competencies and skills which should, in theory, prepare them to meet the essential needs of all patients, including those with learning disabilities.

Irrespective of how nurses are educated and prepared, the need to improve care and support cannot be dependent on the existence of a learning disability specific pre-registration pathway. All nurses need to focus on reducing the health inequalities experienced by people with learning disabilities, promoting equality of healthcare access and health outcomes, in the context of social justice and protecting human rights.

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Death, dying and emotional labour: still relevant after all these years

by Daniel Kelly (FRCN 2016)



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The paper I have chosen to underpin this article is now 20 years old and was written following a clinical career in acute oncology, hospice care, as well as supporting young people with AIDS/HIV. In each setting I had witnessed how challenging it was to introduce palliative care when active treatment and cure were the main focus.

As a result, I developed an interest in what happens when (usually younger) people are

dying in places we would think of as high-tech settings. This influenced other research that I undertook with children and young people undergoing cancer treatment, most of whom were seriously ill and some of whom faced the transition to end of life care. Some of this work is referred to below.

The paper also acquired renewed relevance in 2020 in the context of the COVID-19 pandemic and the high mortality rates in people admitted for intensive care.

Death, dying and emotional labour: problematic dimensions of the bone marrow transplant nursing role?

Abstract

Bone marrow transplantation (BMT) is an established intervention for a range of conditions, including those of a serious, life-threatening nature such as leukaemias. The experience of those who fail to respond to such aggressive treatment, however, or those who die as a result of treatment-induced complications, remains under-researched. In this paper, we argue that despite the relatively high mortality associated with BMT, cultural, biological and professional factors contributed to a lack of attention to issues of death and dying and emotional labour in BMT settings.

Technological, biomedical and quality of life discourses that characterise much of the BMT literature are problematic and, we argued, serve to disadvantage those who will not survive such procedures. In addition, the provision of effective palliative care in BMT settings remains open to review through further research and development. As a first step, we argued that the role of nursing needs to be reconceptualised in BMT to allow key humane concerns such as suffering and the emotional labour of care to be explored and better understood.

Citation

Kelly D, Ross S, Grey B, Smith PB (2000) Death, dying and emotional labour: problematic dimensions of the bone marrow transplant nursing role? *Journal of Advanced Nursing*. 32, 4, 952-960. doi: 10.1046/j.1365-2648.2000.t01-i-01561.x

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Introduction and background

The way death and dying are managed in hospital settings has interested me since my earliest days of working in oncology as a newly registered nurse in Edinburgh. I had witnessed many patients undergoing aggressive cancer treatment only to succumb to their disease

eventually, and I became aware of the impact that this situation could have on the clinical staff around me, hence the link with emotional labour. At the time, I had read about this as a concept developed by the sociologist Arlie Hochschild in her book *The Managed Heart* (1983). In daily practice, I was struck by the

Acknowledgement

The publication that started this career-long interest has been cited well and has stood the test of time. I must also acknowledge my colleagues Pam Smith, Sharon Ross and Ben Grey who contributed to the original paper and helped to shape its content

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emphasis placed on effective communication by all members of the oncology team. I had also seen this approach espoused in other clinical areas, of course, but in oncology this seemed to be more overt and it had a powerful impact on me and probably shaped my whole career.

The culture of oncology seemed less hierarchical and nurses were valued and their views about patients were heeded. This was not always the case in other clinical areas where I had worked. I can still recall conversations with certain patients, often young, who were referred to our unit having already undergone extensive cancer surgery. They were being admitted to our medical oncology unit to receive aggressive chemotherapy and radiotherapy, sometimes high dose with bone marrow rescue. There were several complex treatment regimens that we administered intravenously which could last for several weeks and most, to varying degrees, were associated with side effects that affected all aspects of life: hair loss, severe mucositis, debilitating nausea and vomiting, unrelenting diarrhoea, as well as neutropenia and the associated life-threatening risk of sepsis.

I began working with Pam Smith in 1999, who was then based at London South Bank University, when I was appointed to lead nursing research at University College London NHS Trust. She had a long-standing interest in emotional labour, and we agreed to join forces with colleagues who were also interested in the unmet support needs of patients undergoing BMT for leukaemia. We sat down and shared data from a study that she was working on concerning the emotional demands of nursing, which had included nurses working in BMT settings (Smith and Grey 2000).

The result was a partly polemical paper that sought to argue against focusing only on the technical aspects of disease and treatments (such as the emphasis placed on daily blood counts) to the detriment of emotional support. The main argument was that nursing in such high-tech environments should be reconceptualised to acknowledge more openly, the impact of high patient mortality rates on the emotional needs of patients and families, and also the impact on nurses, who must present a face that all is well (Kelly and Smith 2016). As the one group of professionals who work most closely with such patients over prolonged periods of time, nurses witness death and loss on a regular basis. We argued that the focus on technical skills alone risked

overshadowing the need to focus on humane or empathic dimensions of care, but we also emphasised the centrality of nursing overall (Kirby et al 2014).

If emotional support remained an unrecognised dimension of the nursing role, we suggested that the nursing role had become 'problematic' and the culture of high-tech settings should be questioned to allow new insights and ways of working to be developed.

Influence and impact

I remember that the paper caused quite a stir at the time as some thought we were criticising expert colleagues. I sent copies of the paper to the haemato-oncology unit and offered to present it at seminars, and could quickly see by the reaction of some colleagues that there were issues they recognised as relevant.

Over the years, the paper has continued to be cited and I have been invited to address the topic on several occasions with haemato-oncology professionals, most recently in Adelaide in 2015. I believe this paper did strike a chord and the questions we raised have not gone away. This is despite the improvement in cancer treatments over the past 20 years with stem cell transplants, haematopoietic growth factors and a growing range of new, targeted agents improving clinical outcomes. However, some cancer diagnoses, such as pancreatic cancer or acute myeloid leukaemia, remain challenging in terms of cure, and mortality rates remain high. In this context, the central message of the paper remains pertinent.

Empathy and relational approaches to end of life care, wherever such care is provided, are fundamental to patient-centredness. A recent systematic review and meta-analysis demonstrated that empathic consultations can have positive clinical benefits, including the reduction of pain and anxiety levels and the enhancement of patient satisfaction (Howick et al 2018). Therefore, our argument for better awareness of these aspects of nursing care has endured and there now is a more solid evidence base on which to develop innovative practice.

In the paper, we also referred to the work of Isabel Menzies-Lyth (a social scientist and psychoanalyst) who focused on nursing in her research, and described the instincts evoked through close contact with seriously ill or dying people with what she called 'primitive' anxieties: 'Nurses are confronted with the threat and the reality of suffering

and death as few lay people are. Their work involves carrying out tasks which, by ordinary standards, are distasteful, disgusting and frightening' (Menzies-Lyth 1988).

One of the arguments we made was that increasing detachment from such anxiety-provoking events can lead to decreased levels of empathy (Haque and Waytz 2012). This has implications for the quality of a patient's experience and suggests that healthcare professionals may need to adapt and balance some degree of emotional detachment with empathy to benefit themselves and their patients. There is known to be a link between levels of emotional burnout and empathy in health professionals (Wilkinson et al 2017). For nurses who care for the acutely ill people and do not 'regulate' their emotional distance from patients, too much empathy is also a key risk factor for emotional burnout (Firth-Cozens and Cornwell 2009).

Our main call at the time was for more attention to be paid to these issues in high-tech environments, and for more awareness and research to be devoted to them by nurses. It is pleasing to see the evidence that has been added to what was a limited evidence base.

The original 2000 Journal of Advanced Nursing paper led to other research on end of life topics that I have returned to over the years, including one that explored the transition to end of life for children undergoing treatment for leukaemia (Nelson et al 2017). This project attracted particular attention and was featured in Nursing Standard, emphasising the emotional aspects of the process for children, families and healthcare professionals (Trueland 2017).

I have also written more about the needs of adolescents and young adults facing the end of life (Kelly et al 2012). Other projects have focused on children with leukaemia and how to carry out research into their communication and emotional support issues in clinical settings (Bryan et al 2019). I have also conducted systematic reviews (Edwards et al 2014) and was invited to join other teams doing similar work (Williams et al 2011). I produced additional papers on different aspects of the same issue, including treatment futility in intensive care (Kelly 2005) and the emerging culture of specialist oncology services for young people (Cable and Kelly 2019).

In 2004, I published an ethnographic evaluation of the first specialist unit that had been established for adolescents with cancer in the UK (Kelly et al 2004). We set out to

describe the emotional component of care carried out in what was then, a unique age-appropriate setting. This work was cited by the Teenage Cancer Trust in their Blueprint of Care to guide future service developments, including end of life care standards (Teenage Cancer Trust 2012). I also produced an editorial on the controversial topic of euthanasia for young people as a result of the law being changed in different countries of Europe (Kelly 2014).

Current and future relevance

The original Journal of Advanced Nursing paper that examined the link between death, dying and emotional labour captured the situation as I saw it in 2000. It built on my own clinical experience as well as those colleagues I had heard talking about their workplace, where patients died but the provision of emotional support could be less than optimal. This was not because people did not care about what was happening, but often because the culture of where they worked was difficult to change.

In the intervening years there have been ongoing calls for better integration of supportive and palliative care into intensive cancer treatment services. In haematological cancers especially, there are still challenges to be overcome and medical specialists continue to call for more service innovations that can actually work successfully in the clinic (Niscola et al 2018). The way people with cancer are treated (in an emotional sense) is now considered a key component of healthcare quality, alongside patient safety and clinical effectiveness. This provides us with new ways to 'problematise' the everyday work of cancer nursing and to question whether and how the emotional needs of patients can be met in services that are increasingly under strain. The voice of nursing must be central to shaping future developments.

Fast forward to the pandemic situation of 2020 where COVID-19 has meant that deaths in hospitals have had to be managed on a massive scale in intensive care settings around the world. The challenge from our original paper to recognise the emotional labour and supportive dimensions of nursing when caring for people who are severely ill has not diminished, but has instead become even more pertinent.

We have witnessed unrelenting pressures on nurses and healthcare teams working with COVID-19 patients that have magnified the need for humane support, especially when

families had to be excluded from the final hours of a loved one's life. The images on our TV screens of clinical staff covered from head to foot in personal protective equipment serves to emphasise the need for the human touch, and there were many accounts of this provided by nursing colleagues. In this, the International Year of the Nurse and the Midwife, we can

take considerable pride in the accounts of colleagues who have actively engaged in the emotional labour of end of life care by supporting each other, as well as patients and their families, regardless of where they work. It is our responsibility to ensure that they, in turn, receive the recognition and support that they deserve.

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Babies don't come with an instruction manual

by Ruth Oshikanlu (FRCN 2017)



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New parents often do not feel prepared for their role and wish their baby would come with an instruction manual. Most parents want to parent well, regardless of the situation they find themselves in. With some insight into the reasons why their babies act the way they do, parents can tune in to their baby, find out what babies need, meet their needs well and enjoy parenting. My book, *Tune In To Your Baby*, aimed to enable expectant

and new parents to enjoy raising happy and healthy infants without sacrificing their personal needs.

In the book, I shared my personal journey and professional insights to assist parents in discerning and satisfying their baby's needs. The aim of *Tune In To Your Baby* was to facilitate parents in choosing who they want to be, and what they want to do to enjoy parenting their baby from the point of conception through to toddlerhood.

Tune In To Your Baby: Because Babies Don't Come with an Instruction Manual

Abstract

Tune In To Your Baby was born out of my difficult experiences during pregnancy. These experiences included spending almost five months hospitalised to prevent the loss of my baby, and a relationship breakdown. Despite professional experience as a midwife, on discharge from hospital with a preterm baby, I was extremely anxious about how to meet my baby's needs. This book was the result, written in response to my clients' needs. The book comprises six chapters and an appendix, with chapter titles created from expressions I had uttered myself while pregnant or as a parent.

Citation

Oshikanlu R (2012) *Tune In To Your Baby: Because Babies Don't Come with an Instruction Manual*. CreateSpace, Scotts Valley CA.

Link

www.tuneintoyourbaby.com/my-book

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Introduction and background

The conception of *Tune In To Your Baby* occurred while I was working as a health visitor based on the Isle of Dogs, which is a part of London with gross economic disparities. My caseload included many vulnerable families whose children were subject to child protection plans or other safeguarding interventions. I also provided health visiting support to affluent mothers, many of whom were older, professional women, who were sometimes very anxious even after having attended National Childbirth Trust antenatal classes. They had higher expectations of the health visiting service and attended

clinics on a weekly basis, but frequently required reassurance from their health visitor because they lacked confidence in their parenting ability.

On one particularly memorable day, I visited three new mothers who were distraught, anxious and stressed after reading a parenting book with a very prescriptive approach, which had encouraged new parents to get their babies in a routine from birth onwards. The women who followed this approach reported feeling exhausted because they tried to meet all the prescribed expectations, yet their babies still did not settle and cried excessively. I provided all three women with evidence-based guidance

RESOURCES

Department of Health's
Family Nurse Partnership
programme
fnp.nhs.uk/about-us/the-programme

Virtual Mamahood
www.tuneintoyourbaby.com/virtual-mamahood

on responsive feeding and the need to feed newborn babies frequently because their stomachs are small and the effects of excessive crying on a baby's stress levels. This helped them to ascertain their baby's needs, to better read their baby's emotional states, and understand their baby's cues and respond to them better.

At the end of the day, I experienced a form of epiphany and set myself a goal to write a book that would be different from any other parenting book I had read. This would use my professional and personal experiences, incorporate my midwifery and health visiting expertise, use a strengths-based, solution-focused, non-prescriptive approach, and would span from conception to preschool.

At the time of writing the book, my clinical experience encompassed 19 years of service provision as a nurse, midwife and health visitor. I was also a family nurse at the Department of Health's Family Nurse Partnership programme, a nurse-led, intensive home visiting parenting programme for first-time young mums and their families. In addition, I was trained as a life coach and in cognitive behavioural therapy, neurolinguistic programming and goal mapping – a system that employs whole-brain thinking to learn how to set goals, to take action and achieve success. My master's dissertation focused on the role of the health visitor in promoting parental-foetal attachment in prospective parents.

From my practice as a midwife and health visitor, I found that women frequently expressed the wish that their babies had arrived 'with an instruction manual'. Hence, I wrote the book as a bespoke resource for parents to encourage them to understand their baby, mainly because each baby is unique but general advice can be helpful. Many of the women I provided care to shared experiences similar to my own difficult personal experience of pregnancy and early parenthood and, like me, did not know how best to handle them. This lack of knowledge could result in perinatal anxiety and depression.

An additional rationale for penning the book was the emerging evidence about the importance of the care a baby receives from conception to the first two years of life, referred to as the 1001 Critical Days (Leadsom et al 2013). Advances in neuroscience highlight the crucial relationship between early brain development and outcomes later in life. Research has indicated that a

baby's brain develops in response to what he/she experiences throughout this early period of gestation. As such, it is essential to ensure a child's environment and experience – both inside and outside the womb – are pleasurable and nurturing as the foundation blocks of life are then being laid (Gerhardt 2014). Therefore, love for self and baby are stressed as vital ingredients throughout the book. It was written from the woman's perspective to allow for a greater sense of authenticity. However, the reader is also encouraged to enlist the support of her partner and other individuals of significance.

New parents often struggle to adjust to the changes in their role. This appeared especially difficult for first-time parents who usually sought information from books, magazines and the internet, as well as taking advice offered by family, friends and health professionals. These sources of advice, however, often conflicted and could cause further confusion. The pressure to get things right further compounded these problems, created further anxiety for new parents and added stress to them and to their baby. New parents would frequently voice concerns about the normal things that their baby did such as crying as a way of communicating, but interpreted it as a negative reflection of how well they were parenting. Social media also created additional challenges, with pressure on new parents to appear to be living the perfect life.

Influence and impact

The book encourages bonding and parent empathy from the point of conception. It is intended to help mothers ease their new baby's transition to the outside world and is intended as a comprehensive guide. Written in a conversational style, it draws the reader in, encourages self-reflection, enables mothers to identify their feelings, to consider the impact on the baby's emotions, and includes ways to support their baby to thrive. The book is full of inspiring quotes, helpful tools and techniques drawn from my life's work. The reader is invited to work through the baby manual contained in the appendix, and is also provided with a list of useful online references and websites.

The book was developed into a parenting programme commissioned by numerous NHS primary care trusts, to help serve the needs of vulnerable families. Post-publication, I delivered lectures in several universities and presented at international conferences

about parenting and parental-foetal attachment. I was featured in podcasts and video interviews. The book continues to be well distributed in many countries including Germany, United States, Australia, Canada and New Zealand. I delivered workshops in several African countries on perinatal and infant mental health. It was featured in professional journals such as *Community Practitioner* (Fisher 2013) and the *Journal of Health Visiting* (Oshikanlu 2016).

The book aligns with the Healthy Child Programme (Public Health England 2015), which supports parents from pregnancy through the first five years, incorporating the new integrated '4-5-6 model': four levels of service, five health reviews, and six areas where health visitors have the highest impact on the health and wellbeing of children aged 0-5 years. The book addresses four of the six high impact areas: parenthood and early weeks; maternal mental health; breastfeeding; and healthy two-year-olds and getting ready for school. Many health professionals believe that most parents require more than five reviews over five years: Northern Ireland, Wales and Scotland provide seven, nine and eleven mandated contacts respectively (Institute of Health Visiting 2017).

The book attempts to bridge the gap in service provision by encouraging parents to take control of their lives as parents in line with the Marmot Review (2010), which set out the evidence of inequalities in health and the social determinants of health in England, and proposed six high level policy objectives in order to take action on the social determinants of health. It aims to enable expectant and new parents to develop healthy relationships with their baby, promotes awareness of bonding and attachment, maternal and infant mental health, and therefore aims to improve health outcomes for parents and babies.

I share a range of suggestions to engage the process of reflective questioning while supporting parents to generate their own solutions. Many readers have reported *The Baby Manual* in the back of the book encouraged them to challenge their assumptions and take action; it improved their parenting confidence and enabled them to become more attuned to their baby by putting themselves in their child's shoes and then meeting their needs with the wisdom of a parent. Realising that another gap existed in service provision for women who had undergone assisted conception or

previous pregnancy loss, I created a parenting programme from conception onwards and currently work as a pregnancy mindset expert, providing new parents with therapeutic support. In response to the COVID-19 pandemic, these programmes are continuing but are now being delivered virtually.

Current and future relevance

My book aims to promote perinatal mental health by encouraging expectant mothers, new mothers and mothers of toddlers to connect with their thoughts and feelings and to process them safely. Perinatal mental health problems affect between 10 and 20% of women during pregnancy and in the first year after birth. According to an analysis published in 2015, the cost of these mental health problems to society of each one-year cohort of births in the UK is £8.1 billion (Bauer et al 2015). Mental illness directly affects women, but also has an adverse impact on their children. The effects may take a variety of forms, including risks to healthy development in early life, with consequences that may in some cases extend throughout the life course. Mental illness may exist before pregnancy of course, or develop or become exacerbated during the perinatal period. In many instances, these problems stem from early traumatic experiences with pregnancy or childbirth, an ideal opportunity for improvement.

My book supports matrescence, the developmental transition to motherhood and growth as a mother. This enables the expectant or new mother to explore her relationship with her sense of self, as well as relevant others, and signposts her to seek professional help when necessary to address unresolved concerns. Healthy parenting, I have suggested, can be attained when mothers gain greater awareness of their emotions, maintain the focus on the child, and, as a result, may become more empathic to their children.

Recognising that brain development begins in utero, my book promotes activities that support neurological development of babies from conception onwards. It is known that as early as five weeks after conception, neurons begin to form, divide, and multiply. Additionally, the second trimester has been found to be the most active period of neuron proliferation in which 250,000 neurons are created each minute (Ackerman 1992). It is also known that the potential of life-long impact is associated with the exposure to adverse childhood experiences such as

maternal stress, anxiety or depression, difficult relationships with partners, or an external trauma such as life stressors, bereavement or poverty (Anda et al 2006).

When a woman becomes a mother, she must learn to manage diverse social roles alongside parenting. If this is not managed properly, it may lead to fractures in other social relationships. The book has sections that discuss stress and how it can be managed effectively. It employs a trauma-informed approach to parenting from the point of conception. Trauma-informed care is defined as practices that promote a culture of safety, empowerment and healing. It encourages parents to focus on the present, using mindfulness and transactional analysis to enable parenting choices.

During the COVID-19 pandemic, fertility clinics were closed and changes made to the delivery of health visiting services, as many frontline health visitors were redeployed to acute settings or other specialist areas in the community such as district nursing (Fisher 2020). The reduced number of health visitors meant that those who remained were focused on providing services to the most vulnerable children and their families. This resulted in many pregnant women and new mothers not being seen in a timely manner, causing many to feel unsupported, stressed, worried, anxious or isolated; and therefore, more vulnerable.

In response to the COVID-19 pandemic and the resulting crisis from reduced health visiting services, I developed an online platform called Virtual Mamahood. The platform enables pregnant women and new mothers to connect

with an expert midwife or health visitor virtually to receive professional support and enjoy their pregnancy without fear; help manage their anxiety, maintain emotional wellbeing and raise happy and contented babies. In addition, the online platform supports community building, enabling women to share their fears, help manage their anxiety and preventing maternal isolation.

Women continue to delay starting a family until they are financially secure, which may mean they are older and could experience difficulties with conception. Having to juggle competing priorities of demanding work expectations, family life, and perfectionism as a parent, especially if they have excelled in other areas in life, may lead to higher levels of stress. Some women may also experience maternal isolation due to a lack of family support or distant familial relationships and networks. Other women may experience poverty, domestic abuse or mental health problems, all of which could impact on a smooth and enjoyable transition into motherhood.

My book aims to empower women to explore unresolved issues, to process them and to seek personal and professional help as early as possible to help prevent problems from escalating. The book is written as if a health visitor is present with parents at all times, but only a telephone call away if more help is required. I believe that when mothers are in tune with themselves, they are more likely to tune in to their baby's needs and so raise healthy, happy babies with improved life outcomes, good health and a lifelong sense of wellbeing.

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Public Health England (2015) *Rapid Review to Update*

Remembering nursing policy research: a bibliometric study of published nursing research

by Michael Traynor (FRCN 2019)



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In August 1996, I started work at the newly created Centre for Policy in Nursing Research. It was an initiative proposed jointly by Christine Hancock, then general secretary of the Royal College of Nursing, and Nick Black, professor of health services research at the London School of Hygiene and Tropical Medicine, and funded by the Nuffield Trust. The centre was located in the school's Health Services Research Unit. The director

was Anne Marie Rafferty. Though I think it is accurate to say that it was the UK's first centre set up to examine research policy in nursing, our work carried on a tradition of the Nursing Policy Studies Centre at Warwick University, established by Professor Jane Robinson and Phil Strong, who had worked at the School of Hygiene before his death in 1995. One of our pieces of work was a bibliometric study of published nursing research, and it is that article that underpins this article.

Endogenous and exogenous research? Findings from a bibliometric study of UK nursing research

Abstract

Aims This article uses the findings of a recent bibliometric analysis of published UK nursing research to ask whether the field is characterised by a fundamental split between two underlying areas of research interest. These can be termed 'endogenous' and 'exogenous'. The former term describes research which tends to be concerned with problems and issues to do with nursing as a profession; the latter is concerned with problems and issues centring around the nursing of patients.

Design and methods Articles in the Wellcome Trust's Research Outputs Database (ROD), a database of UK biomedical research, were analysed. Nursing articles published between 1988 and 1995 numbered 1,845, just less than 1% of the total articles in the ROD.

Results Analysis of the subfield identified that nursing research was atypical of biomedical research in several ways. One difference was that usually in biomedical research there is a general correlation between numbers of funders acknowledged in an article, and of authors, and esteem of the journal in which an article appears. In nursing, there was a tendency for highly esteemed articles to have fewer authors and be less likely to have acknowledged funding. However, the apparently endogenous and exogenous articles have quite different characteristics. This article explores this apparent difference and possible reasons for this difference, and will briefly compare nursing research with some other newly emerging social and academic groups.

Conclusions Thinking of nursing research outputs in this way can provide insight into the existence of different reward systems influencing nurse researchers. However, it is impossible to draw too confident a differentiation without reading each individual article and making judgements about whether they are 'endogenous' or 'exogenous', a practice generally beyond the scope of bibliometric practice.

Citation

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Introduction and background

The Centre for Policy in Nursing Research set out to promote research in nursing, based on an investigation into the state of research in the profession. We produced a series of working papers, with black covers and clever typographical devices that once prompted Nick Black to ask, rather hesitantly, whether there was something wrong with one of our computers. Our third working paper was a bibliometric analysis of published nursing research based on articles that had appeared between 1988 and 1995 (Rafferty et al 2000).

This foray into bibliometrics, which I had never heard of, came as a result of a meeting with Grant Lewison who ran the Research Outputs Database at the Wellcome Trust. Through a fortuitous combination of the School of Hygiene's reputation, and Anne Marie Rafferty's natural networking and relationship-forming abilities, we had the privilege of meeting and sometimes going on to work with an impressive range of scholars. I noted at the time that the field of work of these scholars and their personal style usually had an obvious match. The radically relativist Steve Woolgar, for example, was ironic, self-reflexive and funny over the dinner table. Others, whose work was no less excellent but far less subversive, seemed more 'straight down the line'.

The Wellcome Trust had invested in the Research Outputs Database as part of an effort to see how far funders' investment in research had resulted in publications. This was a database of published biomedical research accessible to computerised searching, which at the time was something of a novelty. It had been set up in 1993 by the Unit for Policy Research in Science and Medicine (PRISM) at the Wellcome Trust. It was made up of the Science Citation and the Social Sciences Citation indices focusing on UK-based biomedical publications.

As of mid-1999, the database contained about 275,000 articles (Dawson et al 1998). Grant worked with us to see what the tool could reveal about the character of published nursing research. Although a colleague in the school mischievously likened the ROD project to trainspotting (the apparently pointless practice of noting and recording train numbers on station platforms, not the film of the same name, which is rather more exciting), I was impressed with the insights that all this counting could fuel.

We started our collaboration with Grant in 1997 by working with him to develop a nursing filter for use with the database. This was a small piece of computer programming that interrogated the database with a combination of keywords and journal titles. The aim was to retrieve as many articles that represented 'genuine' nursing research as possible while excluding false positives. Because it was vital to agree what we meant by nursing research, we included research on topics likely to be of relevance to nurses and which was likely to have been carried out by nurses. We considered that this would capture activities that might build up the knowledge base available to nurses as well as research capacity in the profession. We agreed a list of nursing journals along with a range of keywords that we thought could describe the main fields of work. We focused on the following characteristics of the articles we retrieved:

- » The number of articles published, their proportion of all published biomedical research, trends in the numbers of publications.
- » Subject, for example mental health, elderly care, nurse education, based on our examination of their titles.
- » Co-authorship, based on the numbers of authors.
- » Potential impact, based on surveys of nursing researchers and practitioners regarding the relative importance of the leading journals to research and practice.
- » Citations, based on a sample of articles in the leading journals.
- » Funding, based on the sources of support acknowledged in the articles or implicit from their addresses.

The filter identified 2,584 articles, so these 'nursing' publications represented a very small proportion of all biomedical UK publications. However, comparing the two periods 1988-1991 and 1992-1995, we could see a significant growth in the field. In fact, the number of nursing journals also grew in and just after this period. Mental health was by far the most published topic area followed by articles on the education of nurses. This latter field more than doubled in size between the two periods.

Journal impact factors and the citation counts of individual publications are commonplace today. In our study we tried to assess the 'impact', in terms of citation, in the different topic areas that we had identified.

The process was not straightforward and involved two surveys of perceived esteem of our range of nursing research journals, because in these journals the usual patterns of citation noted in scientific publication do not pertain, or did not at that time. We devised a weighted esteem factor based on formal measurement along with the results of our surveys (Lewison 2002).

It appeared that theoretical issues predominated in the high esteem journals, such as the *Journal of Advanced Nursing*. In the 13 subjects with the highest esteem factors, the mean number of authors did not appear related to esteem factors. Neither did likelihood of funding. Many of the subjects associated with high esteem factors were the least likely to include an acknowledged funding source and the general tendency was an inverse relationship. This is in stark contrast to biomedical publication, where the three factors more usually coincide (Dawson et al 1998).

One of the advantages of interdisciplinary research is the possibility of new insights from across disciplinary fields. The aspect of our findings that we chose to focus on was an apparent distinction between two fundamental categories of research interest in the subfield. It was Grant Lewison, to the best of my memory, who first tentatively named these categories 'endogenous' and 'exogenous', the former term describing research which tended to be concerned with issues to do with nursing as a profession, the latter concerned with the nursing of patients.

In our sample, the topics most strongly associated with high esteem journals tended to be 'endogenous', for example 'theory and models' or 'profession and professional issues', while topics associated with esteem factors below the mean for all topics tended, unexpectedly, to be 'exogenous', for example 'geriatrics/elderly care' or 'quality of life'. We also noted that these two groups of articles had contrasting characteristics in addition to those already discussed.

The endogenous articles appeared to have:

- » A rapid growth in output (mostly more than double between 1988-1991 and 1992-1995).
- » Fewer authors per article (56% having only a single author).
- » Appeared in highly esteemed journals.
- » Much less chance of obtaining external funding (typically 20% or less).

The exogenous research by contrast appeared to have:

- » A lower rate of growth in output.
- » More authors per article (61% multi-authored).
- » Articles in lower rated journals.
- » More chance of being externally funded (typically 40% or more).

Influence and impact

For me, the most interesting part of this project was our speculation on possible causes for this inverted characteristic of published nursing research. We came up with three explanations and I suspect all of them applied, and still apply today. The first is the observation that endogenous research is cheap. It does not tend to require reagents, equipment or the salaries of large teams. In addition, it seems more likely that research funders will prioritise research that promises direct effects on patient outcomes than investigations into the philosophical foundations of nursing work.

Our second speculation was that the stimulation for much journal submission emerged from a combination of a pressure on university employees to publish (nursing had moved into the university sector only recently in the UK), and desire for the work done in PhDs and other research degrees, themselves possibly done as a response to nurse education's new home, to see the light of publication – hence the tendency to individual authorship. One of our previous working papers had shown the large growth in PhD work done by nurses during this period.

Finally, and perhaps most interestingly, we wondered whether an endogenous preoccupation reflected the identity formation of an emerging group, in this case nursing in the academy. We asked whether research activity that focused on the characteristics of nursing and of nurses themselves provided a medium and an arena for consciousness raising and self-definition for the profession, or at least for groups within it, such as those working in universities. We drew parallels between this and similar drives in other disciplinary and social groups.

My involvement in this piece of work, and my work in the centre, as a whole, taught me two, possibly contradictory, lessons. The first is that there can be value, sometimes immense value, in simply counting what had not been counted before. This can reveal trends, differences, disadvantage and discrimination. But at the same time, I came away from this

research, and have the strongest memories of this project, which we completed more than 20 years ago now, with the conviction that it is the interpretation of the results of the counting that is what gives this potentially train-spotting activity its meaning and significance.

The interpretation and speculation are always hazardous because they return into the research activity the investigators' prior knowledge, beliefs and positionality. Nevertheless, it is the speculative explanations that contribute to informed debate and sometimes, the development of a major field of intellectual and cultural work. Finally, this piece of research is an example of the synergy that was found between our particular desire to map and contribute to an understanding of nursing research and the then emerging technical ability to subject computerised publication databases to relatively complex analysis.

Current and future relevance

Some years after this project, we undertook, also with Grant Lewison, an update of this analysis. We found that published nursing research had begun to more closely resemble biomedical research. Perhaps, this can be understood as the discipline moving towards some concept of maturity. Since our work was published, many other bibliometric analyses of nursing research have emerged from different countries and regions in the world. An internet search on this topic reveals nearly one million hits, however, the objectives of such studies are not always clear. Sometimes they have been undertaken for similar reasons to our own, that is, to evaluate the development of an emerging discipline (Godin 2005).

Bibliometric studies can help the global nursing research community to assess and monitor the character of research published by nurses, its contribution to global health and its development as a significant global profession.

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Postscript

In the 22 articles in this collection the Fellows have contributed material on a diverse range of topics, settings, and conditions across the human lifespan from birth to death. Practice, theory, policy, history, research and education themes are all covered. But it is important to note that while we are delighted with the contributions, these represent only an exemplar of the work of each Fellow, and of RCN Fellows more generally. What we hope is that this insight into their work will encourage readers to dig deeper into the wider contribution of those who have contributed to this collection and also the many others who are listed in the RCN Roll of Honour.

Finally, we hope that when reading these accounts, you might feel stimulated to pick up and address some of the challenges offered by the Fellows in carrying forward their work. Since this is the Year of the Nurse and the Midwife there is no better time to start or continue your own journey towards Fellowship and helping to shape the future of nursing.

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