THE ROLE OF ILD NURSES & PATIENT SUPPORT GROUPS: OPTIMISING CARE FOR ILD

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AIMS

This session will give insight into the evolving role of the ILD nurse within a historical context; offering an appreciation of both Specialist Clinical Nursing Practice and Advanced Practice. Within the contemporary global economic climate, challenges / opportunities will be considered of how to optimise care for ILD. The supporting role of charitable organisations will be discussed reflecting on recent reports from two UK Charities.

Clarification:

It is assumed that participants will have varied experiences of working with clinical nurse specialists and different expectations of nursing roles. Many centres in Europe are looking to introduce / develop the role of an ILD clinical nurse specialist. This summary affords some insight into the challenges of defining, developing and supporting nursing specialisation predominantly from a UK perspective. The subsequent presentation will discuss how this impacts ILD healthcare services.

Background

Nurses are central to healthcare provision and highly valued by patients particularly in the ILD specialism. In the UK, 90% of patients reported that an ILD specialist nurse was their main medical contact for IPF healthcare. Nurses provided information on IPF, patient support organisations and lifestyle advice, as well as helping patients to access medication and manage side effects [1].

Nursing roles have progressively expanded and diversified, with nurses taking on new and higher level responsibilities [2] responding to the increased demands on healthcare services. Changes to the training and roles of junior doctors has impacted nursing roles resulting in political drivers to improve healthcare quality and efficiency in service delivery [3, 4]. Nursing roles have therefore developed in order to plug gaps rather than advance nursing skills per se. Consequently ‘specialist nurses’ and ‘advanced nurse practitioners’ have emerged but there is a lack of standardisation of these roles [in the UK and Europe]. This results in a degree of confusion amongst both healthcare professionals and patients [5-9]. Is a specialist nurse and Advanced Nurse Practitioner the same thing? What level of care can a patient expect and how do these nurses work within a specialist team?

UK Case Study

On 1st December 2004 Agenda for Change (AfC) a radical reformation of UK National Health Service (NHS) grading and pay system for all NHS staff, excepting doctors, dentists and some senior managers was introduced. Its aim was to harmonise pay scales and career progression

The AfC system allocates the post to a set pay band based on aspects of the job, such as the skills required. This Knowledge and Skills Framework (KSF) is integral to the AfC system providing a
A competency based framework to evaluate NHS Jobs [10]. All staff are matched to a job profile and corresponding pay band [11].

AfC is designed to evaluate the job rather than the person in it; thereby it does not take account of the individual’s strengths. The rationale for this is to ensure equity between similar posts in different geographical areas but in reality this does not always happen. There is a perception that lower bandings are being used, particularly for the clinical nurse specialist and advanced practitioner roles and that skill sets that individuals bring to a role are not appropriately rewarded. This can impact morale and retention of nursing staff.

Progression up the scale for an individual can also be difficult, requiring that the post they are allocated to be changed substantially in order to be re-graded. This is because the structure is focussed on the position not the person who may well have developed in professional skill; become more experienced and increased their level of responsibilities beyond the scope of the post. However, an individual’s professional development beyond the scope of the post would not be regarded as sufficient for re-banding that post. This can be perceived as a barrier to career progression.

All nursing posts in the UK have to fit within this knowledge and skills competency based Framework (KSF). Meanwhile core standards for specialist and advanced nursing practice are set by the Nursing and Midwifery Council, the UK regulatory body [12]. However, the NMC do not regulate advanced practice and standardization of roles is lacking, despite the best efforts of the Royal college of Nursing and the International Council of Nurses (ICN). In practice there remains inconsistencies in the scope of practice, education provision and career progression [13-18]. This has implications for how Clinical Nurse Specialists and Advanced Practitioner nursing roles develop.

Professional bodies and the Royal colleges apply the International Council of Nurses definition of advanced nursing practice which enables a degree of common understanding and offers a foundation upon which to further develop these nursing roles (ICN 2001):

'A Nurse Practitioner/Advanced Practice Nurse is a registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competencies for expanded practice, the characteristics of which are shaped by the context and/or country in which s/he is credentialed to practice. A master’s degree is recommended for entry level.' [19]

Clinical nurse specialists (CNS) in the USA must hold a master’s degree [20]. There is a general consensus in the UK that nurses practicing at specialist level should complete a 1 year full-time degree level programme concentrating on: clinical nursing practice; care and programme management; clinical practice development and clinical practice leadership. 50 per cent theory: 50 per cent practice. Many Clinical nurse specialists in the UK have completed Master’s level of study often relating to a specialism e.g. MSc in Cardio-respiratory nursing. This level of study is not recordable on the professional register.
Only Specialist Community Public Health Nurses (SCPHN) and Specialist Practice Qualification- nurses specialising in general practice, mental health, children’s nursing, learning disability nursing and district nursing are recorded as specialists on the NMC professional register.

Moving forward practitioners will increasingly be required to demonstrate Masters level [critical] thinking [21-23]. This may lead to homogenising advanced nursing practice and clinical specialisation. There is a need to standardise the training and development of ILD clinical nursing roles and work within the limits of AFC to secure appropriate financial remuneration for clinical ILD nursing posts and enable career progression. Consideration regarding professional registration and regulation of the respiratory nursing specialism is needed. Investment in mentorship of the new ILD nursing workforce is also urgently needed to ensure retention of a highly skilled workforce and thus improve patient care at all stages of the care pathway through continuity, the application of evidence based practice and nursing led research programmes.

**ILD Nursing**

Against this background the National Institute for Health and Care Excellence (NICE) UK published a Quality statement in 2015 that:

‘People with idiopathic pulmonary fibrosis have an interstitial lung disease specialist nurse available to them.’ [24]

The rationale for this is that:

An ILD specialist nurse can ensure that people with idiopathic pulmonary fibrosis, and their families and carers, receive all the information and support they need throughout the care pathway. This includes information about investigations, diagnosis and management. Interstitial lung disease specialist nurses can sensitively discuss prognosis, disease severity and progression, and life expectancy.

This quality standard is supported by the Idiopathic pulmonary fibrosis NICE guideline [25] and requires commissioners (NHS England specialised services area teams) to ensure that they commission services from regional specialist centres that employ an interstitial lung disease specialist nurses as part of their multidisciplinary teams.

Specialist centres are developing across the UK and Europe and there is an urgent need to appoint specialist ILD nurses to newly created positions. Given the limited number of experienced well trained ILD Clinical Nurse Specialists already established in practice and the lack of robust accredited training course, such nurses will likely require training ‘on the job’ in the short term, thereby, compounding existing issues in the wider nursing profession of standardisation of role that can inform clear pathways of professional development and advancement of careers.

It is apparent that patients, service users and carers value the role of the ILD Specialist nurse but that the demand for ILD specialist nurses is greater than the supply. A UK national survey from the BLF (2015) [26] reported:
39% patients have frequent contact with an ILD specialist nurse
36% patients say they have no access at all
8 UK trusts routinely allocated patients a named ILD specialist nurse within 6 months of diagnosis

A further report from the IPF Charity Action for Pulmonary Fibrosis (2015) [27] reported that:
‘six out of ten patients reported that a specialist nurse is the best single point of contact for their care’

Specilaist nurses with specific training and experience in interstitial lung diseases are required to provide information and support to patients, their families, and carers, throughout all stages of their care. It is established that patients and care’s value this. ILD nursing is a challenging field that requires specific knowledge and communication skills. Individual patients presenting with an ILD are often complex and often have comorbidities. ILD nurses need to be able to discuss often complex test results, treatment options and other concerns that patient’s raise about their condition and for many newly appointed nurses this will require some additional training to deliver optimal care.

Given the current economic challenges in the healthcare provision specialist nursing posts are often the first to be lost with many nurses redeployed. We need to consider new ways of working, engaging with other interested parties if we are to sustain an effective and efficient model of healthcare for this complex group of ILD patients.

References


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