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An evaluation of the role of support workers in lung cancer

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Emerging roles in lung cancer care: an exploration of the work of unregistered practitioners.

Abstract

Background: Despite the evolution of support roles in other areas of nursing practice, the use of unregistered practitioners like Support Workers (SW) to support the lung cancer nurse specialist (LCNS) is new. No evaluations of such roles exist.

Aim: To evaluate how SWs are being implemented in the UK to support LCNSs.

Methods: A mixed methods study using a survey and qualitative interviews.

Analysis: Survey responses were coded and analysed using SPSS; followed by qualitative thematic analysis of the interviews.

Findings: The findings indicate that when appropriately planned and resourced, SW roles can have a significant impact on practice and service delivery, enhance the work of the LCNS and impact positively on patient experience. SWs create opportunities for service improvement initiatives that would not otherwise be feasible.

Conclusion: This study highlights the importance of planning and training to ensure the success of SW roles.

Introduction

This paper presents findings from a mixed method evaluation of clinical support roles to explore their impact on the work of lung cancer nurse specialists (LCNS) and the organisation of care. The LCNS is an essential member of the multidisciplinary team (MDT) and a main care provider throughout the cancer journey for patients with lung cancer (UK Lung Cancer Coalition (UKLCC) 2012; Edwards 2011). Consistent access to a LCNS within the MDT is now an explicit expectation (National Institute for Health and Clinical Excellence (NICE) 2012). In addition, the UKLCC specifies standards for MDT working, many of which are reliant on the intervention and expertise of LCNSs (UKLCC 2012).

Background

Every year in the UK more than thirty thousand people lose their lives to lung cancer, accounting for 35,184 deaths in 2011 and lung cancer remains the leading cause of cancer deaths in the UK (Ryan et al 2008; Cancer Research UK 2013). Following a diagnosis of lung cancer, around 30% of patients survive for three years but fewer than 10% survive beyond five years (Roy Castle Lung Cancer Foundation (RCLCF) and National Lung Cancer Forum for Nurses (NLCFN) 2013). However, the awareness of signs and symptoms remains low and over 60% of patients are diagnosed at a stage where the goal of treatment shifts towards palliation rather than cure (RCLCF/NLCFN 2013). Consistent specialist support and advice is therefore a prerequisite as care needs and treatment options are complex.

Increasing workload and variation in access to the LCNS

Previous reviews of LCNSs indicated that as much as 12% of LCNS work was purely administrative and that variations exist across the UK in terms of their caseload, role within the MDT and how patient access differs across geographical area (Leary et al 2008; RCLCF/NLCFN 2013; Leary et al 2014). LCNS workloads do not compare favourably with CNS roles in other cancer types/sites. For example breast cancer nurse specialists have an annual new patient caseload of 79, compared to an average of 122 for LCNSs (UKLCC 2012). Macmillan, working with the DH and NHS Improvement on the National Cancer Survivorship Initiative (NCSI) identified that many survivors reported unmet needs for information and support, especially in the post treatment period (DH et al 2010); a particularly vulnerable time (UKLCC 2012). An overstretched LCNS workforce can lead to inequity of access and inconsistent support (Leary et al 2008; McPhelim et al 2009; RCLCF/NLCFN 2013). A recent study identified that workload pressures mean that some LCNSs are increasingly reliant on unpaid overtime to conduct essential work, resulting in them having to leave work undone (Leary et al 2014).

Substitution roles

The changing landscape of cancer care and escalating workloads require new roles, reshaping the traditional boundaries of registered practitioners. The NCSI and Frontier

Health determined a shortfall in the current cancer workforce, highlighting the need for cancer support roles (Frontier Health 2010; DH et al 2010). They further suggest that unregistered practitioners may be able to deliver up to 33% of cancer care if new models are developed. It is envisaged in the Macmillan Cancer Workforce Development Strategy 2010-15 that a Band 4 support role could act as a first point of contact and coordinate care (Macmillan Cancer Support 2011a). Core responsibilities for this type of SW role have been identified, providing a single point of access to help people navigate the health and social care system (Macmillan Cancer Support 2011b).

Remodelling clinical teams is essential as current approaches are unsustainable. It is against this backdrop that support roles are now emerging alongside LCNSs; however the boundaries of these new roles have not yet been defined and require clarification (Thurgate et al 2010). This study aims to identify emerging roles that support the LCNS, to reveal their main responsibilities and training needs. We aim to generate knowledge and understanding of the impact of SWs on the work of the LCNS, the MDT and implications for service delivery.

Design

This mixed methods study was undertaken in two stages, an electronic survey and in-depth interviews. The study was a collaborative initiative between Sheffield Hallam University and the NLCFN. University Ethical Committee approval was obtained.

Stage one: An electronic survey

Aims: To map the prevalence and type of unregistered roles that have emerged to support LCNSs.

Method: An electronic survey.

Sample: 198 NHS lung cancer sites were identified through the NLCFN. Contact was initiated by the NLCFN and the survey circulated to the Forum's members (n=250) who worked within those sites.

Data collection/Analysis: A questionnaire was developed with reference to related literature and expert opinion from the NLCFN. The tool was piloted with selected LCNSs (n=6). The

final questionnaire was circulated by email between July-September 2013. An information sheet was provided and involvement was entirely voluntary. Evidence based strategies were employed to increase response rates including three further reminders (Edwards et al 2008). An anonymised data set was produced using membership numbers on returned questionnaires. Descriptive analysis of the coded responses was undertaken using SPSS; free text responses were examined to identify recurrent issues.

Stage two: Interviews

Aim: To explore the impact of clinical SW roles on the work of the LCNS and how this may affect the MDT and service delivery.

Method: Semi-structured interviews by telephone.

Sample: A purposive sample of LCNSs who were supported by a SW with a clinical role were selected (n=7).

Data collection/Analysis: Consent for interview was requested within the survey and an information sheet provided to those who agreed. Interviews were digitally recorded and transcribed ad verbatim. A topic guide aided consistency and was informed by relevant literature and emerging findings from the survey. Framework Analysis was used involving a systematic process of sifting, charting and sorting material according to key themes (Ritchie and Spencer 1994). Drawing on a priori issues, a provisional thematic framework was constructed based around three principal themes: preparation and training; tasks and roles and impact. Additional mapping identified subthemes, their constituent categories and facilitated interpretation. The veracity of this thematic framework was tested through independent analysis of a sample of transcripts and wider analytic discussion with members of the research team.

Integrated findings from both stages of the study are presented here.

Findings

As only minor amendments to the questionnaire were made following the pilot, these pilot data were also included in the analysis. 65/250 questionnaires were returned (response rate

26%). As all respondents did not work with a SW, the numbers of responses and percentages quoted vary accordingly. Survey data, exploring all types of SW roles, are elaborated using interview data that focuses on the role of the clinical SW.

Roles undertaken by SWs and workload management

31% (20/65) LCNSs indicated they worked with a SW and 31 different SW roles were identified, which are summarised in figure 1.
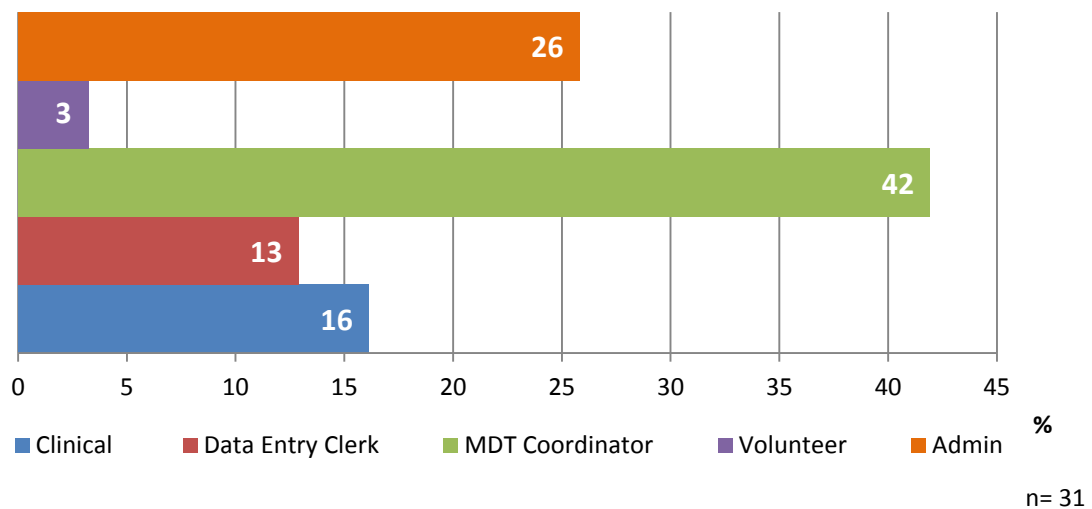

Figure 1: Roles undertaken by SWs.

Of the 31 SW roles identified, the majority had an administrative (84%: 26/31) and/or MDT Co-ordinator (42%: 13/31) rather than a clinical function. Only 16% (5/31) worked in a clinical capacity despite the ratio of patients to LCNSs being high (for interviewees a mean average was 153:1). Interviewees identified increasing workload as the main reasons for employing SWs and that tasks such as administration and paperwork could be delegated. A non-clinical role did therefore appreciably reduce this burden on the LCNS. However, persistent increases in workload were further exacerbated by increasing referral rates from improved diagnostic techniques and public health campaigns, such as persistent cough of over three weeks. Current cancer targets also fast-tracked patients with suspicious symptoms or chest X-ray to be seen within two weeks. Additional delegation by the LCNS of routine tasks involving patient contact was identified as a means to address these demands.

Clinical SW job titles

There was considerable variation in the job titles used for SWs with a clinical role; these are illustrated in the job titles related to the LCNSs who were interviewed. (Table one).

Table 1. Interviewees

Interview number	Interviewee	Relevant SW Job title
1	LCNS	Volunteer (This was a non-clinical role)
2	LCNS	Health support worker
3 and 5	LCNSs	Lung cancer clinical support worker
4	LCNS	Support worker
6	LCNS	Lung cancer care coordinator
7	LCNS	Patient care coordinator

For clarity, in the remainder of this article the title of SW is used as an umbrella term to identify any unregistered practitioner undertaking delegated duties that directly support the LCNS whereas the clinical SW has a role also involving patient contact.

Funding and salary scales

The survey identified that 90% (28/31) of SW posts identified were funded by local Trusts and that 83% (26/31) of these were permanent. However when obtaining funding for the clinical SW post, the LCNSs interviewed identified that the current financial constraints within the NHS were a significant hurdle. One strategy was to share the clinical SW role with other cancer teams, part time employment and flexible hours did offer a reasonable solution. An additional strategy was a skill mix review. Interviewee 7 described this as potentially challenging and not always something that nurse specialists considered favourably.

`At first we were quite horrified at the thought of losing a band 8 and some nursing hours, but when we thought about the care, it was absolutely the best thing ever we had done. We had a band 8 full-time, and we went to a band 7 three days, to allow for a full-time SW`. (Interview 7).

This approach offered greater flexibility to address changing workloads, but not reduce the availability of LCNSs.

Whilst management support was generally favourable, determining the appropriate salary scale for clinical SWs was more troublesome. Band 3 was often allocated to health care assistant roles; however one interviewee described how they had had to negotiate hard with managers to achieve what they considered a fairer banding, as their SW would be undertaking a range of clinical responsibilities.

`But we felt that the level they would be continually working at deserved it to be a higher band than what the healthcare assistants in general are. On the third appeal, myself and (LCNS) actually went to the appeal and explained exactly what the role would entail and that's when it was given a band 4`. (Interview 5).

Preparation and training of the SW

The survey identified that in-service training was used for 68% (21/31) of all SW roles. The use of study days and leaning packages were identified as the most cost effective means of providing in-service training. Interviewees confirmed that this approach was used for each clinical SW and included mandatory skills, supported and shared by weekly teaching by the MDT, ensuring it was not a significant burden for the LCNS. They indicated that existing Information Technology (IT) and organisational skills were imperative and that as many administrative tasks required clinical know how, additional learning must include details of the lung cancer patient's investigative and treatment experiences.

Competencies and skills

Good interpersonal and fluent communications skills were identified as the most important skill for SWs by survey respondents, 100% (63/63). Other important skills identified were knowledge of cancer treatments, 68% (42/62); awareness of side effects, 67% (41/61); the ability to prioritise care, 77% (46/60) and ability to judge when to refer to others, 89% (54/61). (Figure 2).
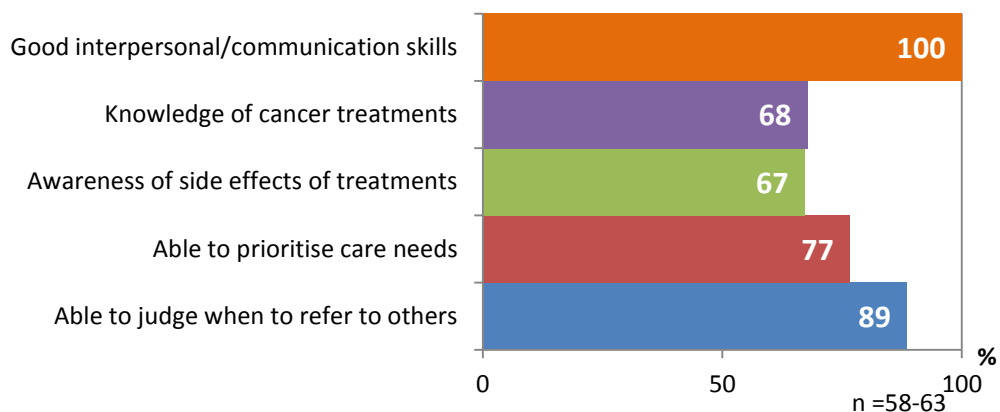
Figure 2: Essential skills of the SW

Interviewees confirmed communication skills as central for the clinical SW, displaying compassion when dealing with patients and appropriate assertiveness with staff. They further highlighted the ability to interact with people in emotionally challenging situations when offering support to patients. This required an understanding the complexities of investigative and treatment regimes and knowing when and from whom to seek support; characteristics of a good team player. Determining the limits of accountability for the clinical SW was essential, working within their comfort zone and recognising when the more advanced skills of the LCNS were needed. Psychological support, decisions regarding medication, clinical advice and symptom management remained the preserve of the LCNS as problems that appeared to be clear cut often concealed more significant issues.

`Situations which seem quite perhaps straightforward on the surface are often very complex and complicated.  Perhaps not just from sort of what's going on with the disease process and symptom management, but psychologically and emotionally`. (Interview 1).

Freeing the LCNS to practice these advanced skills required the clinical SW to take on a wider range of duties; the specific responsibilities of the clinical SW are now discussed.

Tasks and roles

Assisting with patient communication and surveillance

Interviewees reported that prioritising and triaging telephone calls for the attention of the LCNS emerged as an essential task for clinical SWs. The ability to recognise and escalate complex cases ensured that the core skills of the LCNS could be utilised to the best advantage. The clinical SW dealt with many issues independently, referring patients to other members of the MDT, checking appointments, results and arranging transport. Most importantly, providing continuity of patient communication and facilitating timely responses to telephone calls whilst the LCNS was busy was particularly valued by patients.

Patient tracking

Patient tracking activities of the clinical SW identified by interviewees included setting up data bases, checking referrals for scans, ensuring that investigations had been completed and monitoring the patient's progress through the pathway. The clinical SW identified patients recently discharged and initiated follow-up home visits by the LCNS, identified those patients at risk of breaching their care, communicated with the team and also acted as the hub for arranging MDT meetings.

Impact of the SW

Liberating professional expertise

80% (16/20) of survey respondents who worked with a SW agreed or strongly agreed that SWs reduce the pressure of work on the LCNS. (Figure 3).

Legend:
- Strongly Disagree
- Disagree
- Agree
- Strongly Agree

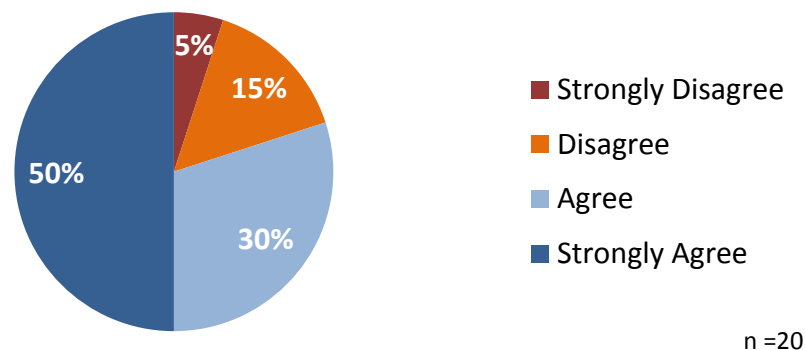Pie chart values: 5%, 15%, 30%, 50%

n =20

Figure 3: Distribution by percentage: The SW reduces pressure of work on LCNS

Interviewees acknowledged that the main impact of the clinical SW was to free the LCNS from the pressure of day to day work, ameliorating the adverse effect of increasing workload. Interviewee 4 commented on the impact of their SW:

`it's like walking through quick sand in this job, it really is, and just you're struggling to keep your head above that sinking feeling, and she's lifted us out of that, she has`. (Interview 4).

Creating opportunities for service improvement

The survey also revealed that 85% (17/20) of LCNS who worked with a SW agreed or strongly agreed that SWs allowed the LCNS to focus on core responsibilities. (Figure 4).
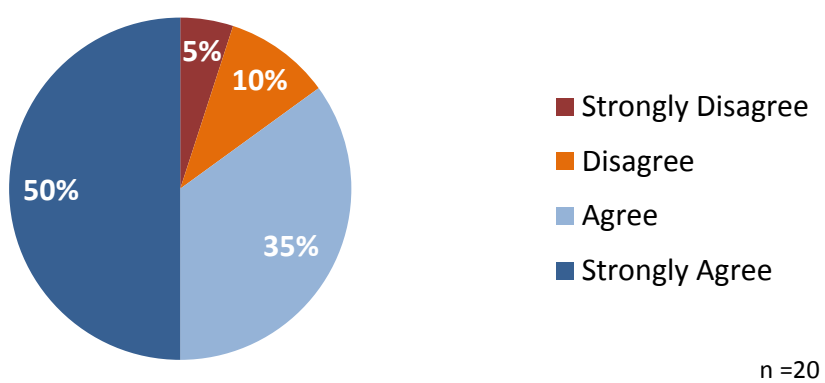

n =20

Figure 4: Distribution by percentage: Use of SW enables LCNS to focus on core responsibilities.

Furthermore, interviewees confirmed that when the clinical SW took on patient-facing roles this enabled the LCNS to more readily focus on patient focused activities, providing the opportunity to move initiatives forwards that would otherwise be difficult to progress.

`I think what had happened is that there was no focus to be able to improve the service, because they were so bogged down with like all the administration work and answering phones`. (Interview 6).

One LCNS commented that their service was now providing same day bronchoscopy following scan. The additional demands for patient support were met by the clinical SW, resulting in improved patient experience.

`The bigger picture is it has improved the pathway and it's a better quality service for the patient, which is the most important thing at the end of the day`. (Interview 5).

Other initiatives included the development of a fast-tracking service for pulmonary nodules. Increased referrals for scanning meant there was a larger cohort of patients requiring information and support; support that could be facilitated only with the assistance of the clinical SW working alongside medical staff. The provision of a new pleural service for the drainage of pleural effusions, overseen by the LCNS, was also incumbent on the availability of the clinical SW to offer patient support.

Additionally, undertaking holistic care needs assessment was problematic as documentation was lengthy and required monitoring. Time constrains had diminished its use. With the aid of the clinical SW, re-establishing this approach became feasible. Similarly, reinstating nurse-led health and wellbeing clinics relied on the assistance of a SW. Further service improvements included the development and production of detailed information packs for patients at diagnosis.

Importantly, undertaking post-surgical follow-up was also identified as an exceptionally difficult area of practice due to the complexity of each patient's journey; patient contact needed to be timely and individually structured.

`We've not been able to do our surgical follow-up without her really because we wouldn't have time; she works out the dates that we need to ring patients`. (Interview 6)

The clinical SW played a central role in providing information to LCNSs regarding the dates of surgery and discharge, organising a schedule for the LCNS to contact patients in the critical post-surgical period.

Discussion

Although the role of the LCNS is pivotal to the quality of care throughout the pathway, increasing administration and caseload act as barriers. Some LCNSs feel that work is being left undone (Leary et al 2014). The work left undone relates to essential safety and quality components of care, including pro-active case management, calling and seeing patients at set times, undertaking holistic needs assessment and attending to psychological support.

This study provides new evidence, demonstrating that SWs can play an important role in workload management. Offering administrative support frees the LCNS from routine duties. Tasks undertaken by SWs could include the construction and management of patient-data to facilitate patient tracking to provide the LCNS with the information needed for timely patient contact. Patients who have contact with a LCNS are more likely to receive treatment, with potentially negative impact on treatment uptake if contact is limited (Leary et al 2014). Effective tracking may also help to streamline the service and facilitate additional support by the LCNS following treatment when it is often problematic and the need for symptom control may be under-estimated, improving the experiences of patients (UKLCC 2012, Huhmann and Camporeale 2012, Maher 2013).

The experiences of interviewees suggest that these benefits are extended when a clinical SW role is constructed to match a particular service. The delegation of some patient facing responsibilities enables the LCNS to address individual preferences more readily and develop new services within the pathway (DH et al 2010; Maher 2013). Holistic needs assessment, a greater focus on health and wellbeing clinics after treatment and personalised care planning are emphasised by the NCSI (DH et al 2010). These initiatives are dependent on the availability of the LCNS.

Identifying core responsibilities for clinical SWs can provide a more cohesive career trajectory. When structuring new posts, traditional roles can be redefined to free funds, offsetting financial constrains. This may be challenging. However salary scales should have some consistency to justify and accord with the SW's clinical responsibilities. Given the emotive nature of the work, effective communication skills are imperative. To deal with patient enquiries the clinical SW must understand the complexities of the cancer pathway, the range of problems patients encounter and spheres of responsibility within the MDT. The triage and referral of enquiries demands some degree of clinical discretion and job descriptions should be structured around core roles, to ensure minimum standards, for example as described within the Macmillan Cancer Care Coordinator role (Macmillan Cancer Support 2011b). In-service training should be competency-led and shared by the MDT to avoid overburdening the LCNS. An important message is that the job evolves over time; flexibility permits responsiveness to local needs and enables the clinical SW to gain those skills that best support a particular cancer pathway.

Access to the LCNS is recognised as an essential standard for all patients with lung cancer and use of a SW may be one means of making this more achievable (NICE 2012; UKLCC 2012; RCLCF /NLCFN 2013).This study illustrates how a clinical SW can provide additional opportunity for the skills of the LCNS to be more effectively deployed. Delegation of some patient-facing tasks may allow the LCNS to focus on the development as well as the delivery of services, creating the opportunity for service improvement initiatives that would otherwise not be possible. Increased patient contact by the LCNS throughout the pathway can impact positively on patient experience and may help to address unmet needs, ameliorate feelings of work left undone and facilitate more individually structured care and sustained psychological support.

Strengths and Limitations

This study provides the first evidence mapping the emergence and impact of SW roles working alongside LCNS. The study is limited to a UK and lung cancer context but could form the basis of wider study in other cancers and geographical areas. Response rates were low, but standard for an electronic survey of this type. It is possible that non-responders thought they did not need to return the survey if they did not have a support role. Triangulation using qualitative data adds rigour, providing useful insight into the role of the SW and its impact on LCNSs and services.

Conclusion

This study presents first evidence on how the SW role is being implemented in the care of patients with lung cancer in the UK. Implementation should be competency led, align with recommended standards and training structured around specific care pathways. Appropriate delegation can free the LCNS to enable a more effective use of their skills, improving patient experience. The findings may therefore have significance for CNS's working in other areas of practice. Further research exploring SW roles and their impact should be undertaken to guide further development and provide insight into those roles that are the most cost effective and clinically helpful.

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