Is a larger specialist nurse workforce in cancer care associated with better patient experience? Cross-sectional study **(Short title: Cancer Specialist Nurses and Patient Experience)**

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Objectives: To assess whether variation in the provision of cancer specialist nurses in England is associated with variation in positive experiences of care by patients undergoing treatment for cancer.

Design: Cross sectional study using routinely collected national survey data.

Setting: English acute hospital NHS trusts

Participants: Patients with a primary diagnosis of cancer who attended hospital as an inpatient or outpatient day case in the first three months of 2010 in 158 NHS trusts who responded to a national survey (n=67,713, response rate 67%)

Main Outcome Measures: Patient perceptions of coordination of care, quality of information provision, emotional support and support for symptom management.

Results: Patients of trusts that had the fewest patients per specialist nurse were more likely to report that people treating and caring for them worked well together (adjusted odds ratio 1.08, 95% Confidence Interval 1.01 - 1.15 p=0.02), and enough emotional support during ambulatory treatment (1.15, 1.01 - 1.32 p=0.04) but were no more likely to report being given the right amount of information (0.96, 0.88 –to 1.05 p=0.38) when compared to patients in trusts with the most patients per specialist nurse. Breast cancer patients undergoing chemotherapy in the trusts with fewer patients per specialist nurse were more likely to report good support for control of side effects from chemotherapy (1.34, 1.02 to1.75, p=0.03).

Conclusions: Cancer patients' experiences of care coordination and emotional support are better in trusts with more specialist nurses. The absolute differences are small and further research must investigate whether particular roles or service configurations are

associated with better experience.

Introduction

Specialist nurses are identified as having a key role in delivering quality care to patients undergoing treatment for cancer. (1-4) In England, cancer specialist nurses fulfill a role intended to enhance coordination of care and provision of information as well as to provide emotional support and supportive interventions (e,g. symptom control) for patients with cancer.(1) Support for expansion of the specialist nurse workforce is strong, with patient and national clinical advisory groups calling for all cancer patients to have access to a specialist nurse and significant emphasis was placed on the function of specialist nurses in delivering a national plan for improving the quality of cancer care. (2-4) Although specialist nursing roles have been in existence for some decades in the UK, there remain significant variation in patients' access to specialist nurses . (5, 6) Many posts are initially funded by a national cancer charity, Macmillan Cancer Support, in the expectation that the NHS will continue funding. However, further expansion and investment is threatened by cost containment measures, with surveys suggesting significant job insecurity among post holders.(7)

Given the diverse groups of patients and varying roles adopted by specialist nurses, current evidence is insufficient to be certain that a broad policy of investment in the workforce as a whole will deliver the intended goals of improved coordination, communication, emotional support and supportive interventions for symptoms. Equally the consequences of a policy of disinvestment are uncertain. There are several trials focusing on defined therapeutic interventions delivered by specialist nurses for specific groups of patients, most notably for those with breast and lung cancer. (8-11) However,

there are no assessments of the impact of incorporating specialist nurses into the workforce outside such trials. In acute general care, analysis of associations between staff nurse to patient ratios and patient outcomes using administrative data have been used to estimate the impact of structural workforce changes, such as an increase in the number of registered nurses in hospitals. These studies have shown associations between improved care quality and a larger and more skilled nursing workforce and have influenced policy and legislation setting minimum nurse staffing levels.(12, 13) No equivalent evidence exists to guide policy for specialist nurse staffing.

In 2010 a national survey of cancer patients' experiences of care was undertaken in England by the NHS National Cancer Action Team. (14) This survey explored a broad range of issues and included items concerning areas where specialist nurses might improve care. Results from this survey showed that patients who reported that they had access to a clinical nurse specialist also reported that they were more likely to be provided with information and given choices about their treatment. (14) However, there is variation in the provision of specialist nurses by tumour group, and the relationship could be confounded. It is also unclear if the variation is in any way related to the size of the available workforce as opposed to more general variation in service configuration. Furthermore, while the associations reported from the survey are important, they are primarily related to a functional process (e.g. provision of written information) as opposed to the desired outcome (successful delivery of information titrated to need). In this study we use these secondary data to look for evidence of an association between the size of workforce relative to the number of patients and patient experiences in order to

explore whether the hypothesized benefits of providing more specialist nurses for people with cancer are realised.

Methods

We used two existing data sets for this study. The National Cancer Patient Experience Survey was sent to all adult (16+) patients with a diagnosis of cancer (ICD 10 codes C00-C99, D05 excluding C44) who attended one of 158 NHS trusts (inpatient or outpatient) between 1st January 2010 and 31st March 2010. (14) The data were obtained from the UK data archive. Responses were received from 67,713 people (response rate 67%). Cases with demographic information, but without survey responses relevant to our analysis were excluded reducing the sample size to 67,043. The data set also contains patient demographic and diagnostic information including ICD10 code and tumour site derived from administrative sources. The number of patients per trust was defined by the survey population, which is equivalent to the number of unique adult patients (aged 16 and above) with a primary cancer diagnosis and who attended the trust as inpatient or day case in the first quarter in 2010.

From the Patient Experience Survey, we identified items which match the overall goals of the specialist nurse workforce as stated in the policy and policy related documents cited above(1-4): that is coordination, information, emotional support and supportive interventions. We chose items that were overall summaries of relevant experience wherever possible. The final set of items was agreed by reaching a consensus among the research team. We did this without direct reference to the previously noted associations

between patient report of having access to a specialist nurse and patient experience so as to avoid biasing our selection to those items most likely to favour the specialist nurse. In addition to questions about access to a specialist nurse we used three general items, applicable to all patients, which asked about whether the team caring for the patient worked well together, whether they felt like they were treated as a 'set of symptoms' rather than a whole person (*coordination),* and whether or not they were given the right amount of information (*information / communication*). Additionally we used items which asked about *emotional support* and support to control side effects of chemotherapy and radiotherapy (*supportive interventions*) [see table 1 for precise wording]. These items were asked in relation to patients attending outpatient care only.

In all cases we compared the most favourable response with others response categories and omitted responses which did not have a clear evaluative element. For example, we judged that the response 'I have not tried to contact him or her' was not an evaluation of the experience of contacting a specialist nurse.

We obtained details of the specialist cancer nurse workforce from the 2010 Census of Cancer Specialist Nurses in England. (15) A survey of directors of nursing was undertaken in April 2010. They were asked to give whole time equivalents (WTE) and area of practice of all cancer specialist registered nurses (including but not restricted to job titles such as nurse practitioner, consultant and specialist) in NHS pay bands 6 to 9 (that is excluding newly qualified junior registered nurses). Nurses specialising in palliative care and community nurses were excluded. Staffing was operationalised as

patients per whole WTE specialist nurse. For a planned sub-group analysis focusing on specialist nurses for breast cancer and patients with breast cancer, we calculated patient per specialist breast cancer nurse ratios. For this analysis, we assumed that the number of patients in the sample with breast cancer was an unbiased estimator of the number in the target population, as we were unable to identify the diagnoses of non-responders. To assess the relationship of experience with staffing we divided the sample into three equal sized groups of trusts based on staffing levels (tertiles). We chose this approach because we did not wish to assume a simple linear relationship but had no external norms to draw on that we could use set thresholds for the analysis and to base assessments as to whether a given level of staffing was high or low. The existing literature simply illustrates the wide variation that exists(6). A low staffed trust had >43.1 patients per WTE, medium 43.1 to 30.1 patients per WTE and a high staffed trust had< 30.1 patients per WTE specialist nurse. Low staffed trusts were used as the reference category.

Trusts were fitted as random effects to compute odds ratios with 95% confidence limits for the effect of staffing in a binary generalized linear mixed regression model. To control for differences in the patient population several control factors were included in the analysis: gender (except for a breast cancer sub group analysis – see below), age (as a quadratic term), deprivation value (the square root of the index of multiple deprivation centile), the primary ICD 10 cancer group and whether patients had attended for surgery, radiotherapy or chemotherapy (based on responses to the survey). Cases with missing values were omitted from the analysis. The sample size available for analysis varied from 66,339 to 15,201 (table 1). All analyses were conducted with R 2.13 (16) and lme4 (17)

statistical software.

Results

The characteristics of the sample are show in table 1. Detailed descriptive analysis has been published in the full report of each survey. (15, 18) Overall, eighty four percent of patients answered 'yes' to the question "Were you given the name of a Clinical Nurse Specialist who would be in charge of your care?". Most patients reported positive experiences for all the questions we considered, although only 59% responded that the people caring for them worked well together (table 2). There was considerable variation across trusts for most variables. For example, overall 87% of patients felt that they were given the right amount of information, which was the most positive rated item, but trust level responses ranged from 75% to 96%.

The odds of being given the name of a specialist nurse were significantly higher in trusts with medium (adjusted odds ratio [OR] 1.09, 95% confidence interval [C I] 1.02 to 1.16) and high specialist nurse staffing (OR1.11, CI 1.03 to 1.21) compared to those with low staffing. Patients were more likely to report that they find it easy to contact their specialist nurse in these trusts (OR 1.10, CI 1 to 1.22 and OR 1.21, CI 1.08 to 1.35) (table 3).

High levels of specialist nurse staffing were significantly associated with reports of better experience on some, but not all, items (table 3). In trusts with high levels of specialist nurse staffing patients were more likely to report that professionals worked well together

to provide best possible care (OR 1.08, CI 1.01 to 1.15) and that they received enough emotional support (OR 1.15, CI 1.02 - 1.29, and OR 1.15 CI 1.01 - 1.32). However, high levels of nurse staffing were not significantly associated with patient reports of being treated as a set of cancer symptoms (OR 1.04 , CI 0.96 - 1.12) given the right amount of information (OR 0.96, 95% CI 0.88 - 1.05) support for symptom control for people undergoing chemotherapy (OR 1.13,CI 0.98 to 1.30) or radiotherapy (OR 1.04, CI 0.88 to 1.22). (Table 3)

As most specialist nurses focus on people with a particular cancer type we undertook a sub-group analyses exploring the association between experiences for women with breast cancer and the number of breast cancer specialist nurses. We restricted this analysis to breast because it was the most common type of cancer in our sample and because of the low number of patients and nurses for other tumours in most centres . Results were similar to those for the sample overall (Table 4) although associations were typically stronger and there was a significant association between high levels of breast specialist nurse staffing and perceptions of support for symptom control for those undergoing chemotherapy (OR 1.34, 95% CI 1.02 to1.75).

We conducted several sensitivity checks. We repeated the analysis dropping seven trusts whose staffing levels were at the extremes of the distribution, which did not significantly change the models or conclusions. We repeated the analysis with staffing as a standardized continuous measure (mean=0, sd=1) without detecting any significant changes to the models. Because there appeared to be some association between trust sizes

and staffing levels, with larger trusts having fewer nurses per patient, we assessed models with the number of beds per trust as a proxy for trust size, however likelihood ratio tests showed that size did not contribute to the fit in any of the models tested.

Discussion

This is the first study to explore whether greater provision of specialist nurses in the workforce is associated with the intended goal – that is improved coordination, information and supportive care for patients. Our results show that some, but not all aspects of patient experience in these areas were better where there were more specialist nurses. Patients in trusts with better specialist nurse staffing, that is those with fewer patients per specialist nurses, were more likely to be given the name of a specialist nurse and to find it easy to contact them. They were also more likely to feel that the clinical team worked well together. They were more likely to feel that they were given enough emotional support while undergoing treatment and patients with breast cancer were more likely to feel that staff did everything possible to control side effects of chemotherapy. However, we did not find evidence that patients were more likely to feel they received the right amount of information and the absolute magnitudes of the differences we found are small. The largest (unadjusted) absolute difference was a 5.9% difference in the number of patients with breast cancer reporting they were given enough emotional support between high and low staffed trusts (73.9% vs 68%).

This is a cross sectional study and so no causal inference can be made. Inevitably observational studies such as this suffer from large amounts of nuisance variation and a low “signal to noise” ratio for the relationships of interest. We used an existing survey

with items that were not designed to explicitly explore the hypothesised effects of specialist nurses. Nonetheless, we were able to select items from the survey which were relevant to the core functions outlined in policy documents and many of the relationships observed are plausibly associated with the work of specialist nurses even though the items may be insensitive measures of the relevant experiences.

It is likely that there are other unmeasured factors in the organization and deployment of staff which are associated with both better specialist nurse staffing and better patient experience. One possibility is the so called 'magnet effect', where a number of organisational characteristics including leadership and management of the clinical (nursing) team, positive relationships between nurses and doctors and support for education and training of nursing staff are associated with both better staffing and better patient outcomes. (19) However studies exploring these characteristics simultaneously in other clinical settings suggest that there is an independent effect for staffing, albeit one which interacts with other organizational factors. (20, 21)

The expected impacts of increasing the specialist nurse workforce in cancer care are ambitious and important. This study demonstrates that such a strategy may be associated with benefits when routinely implemented. While the absolute magnitude of the associations we observed is small, the experiences measured are important and likely to reflect wider benefits for patients. In addition to the intrinsic importance attached to a feeling of continuity, proper coordination of care has been linked to improved outcomes including quality of life(22) and failures of coordination and resulting discontinuities are

associated with adverse events. (23) Although the influence of psychosocial support on treatment outcomes for cancer care is unclear(24) emotional support is intrinsically important to patients and can reduce psychological morbidity. (25)

Nonetheless the value of the small differences we observed is unclear. If the association was presumed to be causal and fully reflecting the benefit of higher specialist nurse staffing it seems unlikely that an economic case could be made for increasing staffing based on these findings alone. Previous research has shown benefits associated with therapeutic interventions delivered by specialist nurses(8, 9) but has not explored the global effects of introducing large numbers of specialist nurses into the workforce. There is evidence of substantial variation in the roles of specialist nurses across trusts and between disease groups. (5, 6, 26) Many nurses in the census may be delivering little direct patient care. In the United States, clear distinctions are made between 'clinical nurse specialists', who coordinate care but generally do not deliver direct interventions, and other advanced practice nurses (for example nurse practitioners) who do. (27) There is no parallel system of registration and protection of these titles in England, which means that job title (recorded in the census) does not clearly indicate the actual role a nurse takes.

The national survey showed that patients who said that they had been given the name of a clinical nurse specialist were far more likely to be given information on self-care support and treatment side effects for example, although we found no association between the size of the specialist nurse workforce and perceptions that patients had been given the

right amount of information. This may be because the global question we selected, about the quantity of information, does not directly assess the quality of communication and provision of understandable information. However, in the absence of a clear summative question on the successful transmission and comprehension of useful information, some uncertainty must remain which warrants further investigation.

The findings of this study have their most direct relevance to policy in the United Kingdom where the goals of expanding the specialist cancer nursing workforce are clearly articulated and widely supported. However, the development of the multi-disciplinary cancer workforce to improve outcomes is not unique to this setting. Specialist nursing roles are being adopted globally (28) and cancer care is a frequent focus for the development. For example the Australian Government and Cancer Australia supported the National Cancer Nursing Education project which identified competencies for specialist cancer nurses which would match the goals intended for nurses in the UK. (29) Across Europe there is evidence of a growing role for cancer nurse specialists, but like the UK there is variation in the size and deployment of the workforce both between and with countries. (30)

Conclusion

These findings indicate that care coordination, supportive care and especially emotional support for patients with cancer, are better in trusts with more specialist nurses, although the relationship with information remains unproven. This study cannot be used to identify optimal staffing levels, but further investigation is warranted to explore service

configurations and nurse specialist roles that may be associated with improved experiences. There is a risk that reducing specialist nurse input, especially where it involves direct patient, care may lead to poorer patient experience.

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