



CREaTE

Canterbury Research and Theses Environment

Canterbury Christ Church University's repository of research outputs

<http://create.canterbury.ac.uk>

Please cite this publication as follows:

MacInnes, D. L., Vieira, I. and Sheriff, M. (2016) In the case of prostate cancer patients, are there advantages in cancer nurse-led follow-up? *International Journal of Urological Nursing*. ISSN 1749-771X.

Link to official URL (if available):

<http://dx.doi.org/10.1111/ijun.12112>

This version is made available in accordance with publishers' policies. All material made available by CReaTE is protected by intellectual property law, including copyright law. Any use made of the contents should comply with the relevant law.

Contact: create.library@canterbury.ac.uk



BACKGROUND

Prostate cancer is the most common cancer in men in the UK with over 37,000 new cases diagnosed in 2010 (Cancer Research UK, 2011). At present, even prostate cancer patients with low risk disease recurrence after initial treatment are offered lifelong secondary care medical follow up (NICE, 2008; DOH, 2011; Cox & Wilson, 2003). Prolonged follow up poses a serious financial healthcare burden. It has also been suggested the current form of follow up does not address patients' needs, due to a focus on the disease and not the person, and is based on a medical model approach (Kirby, 2003; Jones, 2003; Cancer Action Team, 2010; DOH, 2011).

The DH (2007) publication highlighted the fact that due to a shortage of medical staff and the high cost of their time, there is "an opportunity for specialist nurses to undertake a wider range of clinical tasks" (pg 2). **The European Commission group (2010) predicts that by 2020 there will 13% less clinician available to carry out follow up in hospitals. The NHS Improvement in 2010 comment that there is no recognised national strategy on Cancer Nurse-led follow up. However, there are more evidence emerging from satisfaction surveys and observational studies that nurse led follow up is a good alternative to the medical follow up (Milne et al, 2007; Trevatt et al, 2008; Briant-Lukosius et al, 2010; Leahy et al, 2012; Watson et al, 2014).** Clinical Nurse Specialists (CNS) were introduced to the teams to bring an holistic patient-centred approach to interprofessional team working (Calman & Hine, 1995, NICE, 2002; Castledine, 2002; DOH, 2010; DOH, 2011). It has been recognised that Clinical Nurse Specialists are the biggest catalyst of change in their teams **and perhaps in a good place to meet current changes in service provision in regards to follow up care (DOH, 2000; Castledine, 2002; Pratt, 2006; Leary et al, 2008; Academy of Medical Royal Colleges, 2009; DOH 2010; NHS Improvement, 2010).**

When reviewing the guidance on the diagnosis and treatment of men with localised prostate cancer (NICE, 2014), it is clear that current recommendations are not supported by reliable research evidence. It is admittedly based on the expert opinion and research that been conducted more than 10 years ago, concluding that no new systematic review have been conducted in the subject in recent years. Consequently, there is no clear guidance on follow up. The general advice is to offer follow up outside hospital to men with a stable Prostate Specific Antigen (PSA) after first two years of hospital based follow up (NICE, 2014; Catton et al, 2003; Cathala et al, 2003). Kirby & Kirby (2010), recognised experts in the field, suggest that shared care is not always appropriate for patients with prostate cancer to be followed up in primary care and highlighted there are management issues associated with variation in practice, duplication of care and inconsistencies with the transfer of patients to primary care. The only quoted by the NICE (2014) most up to date review is by Yao and DiPola (2003) looking at the evidence available surrounding prostate cancer follow up. They reported the basis of guidance on prostate cancer follow up rests upon a consensus based on "low-level" evidence. In their review they conclude most patients diagnosed with prostate cancer die of other causes therefore prolonged follow up for people with prostate cancer does not influence the chances of survival and is perhaps unnecessary. McIntosh et al (2009) conducted a systematic review of international guidance to identify key elements of the existing model of follow up in cancer care. The absence of high quality studies, and the inconsistencies and lack of specification in recommendations, led the authors to conclude that primary care-based follow up would require considerable effort and investment to implement posing a challenge to Yao and DiPola's (2003) suggestion to discharge this group of patients from secondary care to primary care.

It can be concluded the current evidence on prostate cancer follow up is limited and it is open to debate and interpretation, which suggests that the decision on how to organise follow up

care rests with specialist cancer teams. The only consensus of opinion among the experts appears to be that follow up can be reduced and focused more on patients who display care needs. Due to the fact there is little available evidence concerned with prostate cancer follow up the focus of this review is the follow-up care received by patients with all forms of cancer. The National Cancer Survivorship Initiative (NCSI, 2010) report highlighted that the existing pathways of care in the UK are focused on medical surveillance and follow up, with little emphasis on meeting holistic care needs. NCSI (2010) suggested the prioritisation of research should be to enhance the understanding of survivorship issues. The holistic needs assessment to elicit cancer patients' concerns was offered as a tool for more effective practice (NCSI, 2011). **Cancer Nurses, who possess necessary skills and knowledge in area of their expertise, were identified as ideally placed to carry out such assessment as a part of their ongoing care for cancer patients supporting continuity of care and meeting patients needs.**

Some patients reported they found CNSs to be more accessible, provided better support and were better able to meet their needs (Greenwood 2003; McGlynn et al 2004; Tarrant et al, 2008; Lewis et al, 2009; Milne et al 2007; Bryant-Lukosius et al, 2010; Leahy et al 2012). However, some professionals and patients have noted concerns as to whether nurses have enough knowledge and expertise to offer sufficient care and support to adequately follow up cancer patients in the community (Henderson et al, 2004; Milne et al, 2007). It is difficult to judge if nurse-led follow up adds any value as there is a lack of current research evidence to demonstrate Cancer Nurse Specialists' contribution to cancer care follow up, (Anderson, 2010). However, the few studies undertaken suggest that a nurse led service face to face or by phone might be a good alternative to conventional care. In one nurse led service, Lewis et al (2009) found that though nurses were perceived by patients to be more supportive than doctors with greater satisfaction with nurse led follow up, other health professionals didn't have confidence in a nurse led approach. Cruikshank et al (2008) noted that a nurse led

service changed the focus of consultation from focusing on physical examination to a more holistic patient centred model of care resulting in high patient satisfaction.

The role of CNS in supporting prostate cancer patients and improving their care is not well articulated in terms of patients' outcomes. With only a limited amount of current evidence, there is a need for an up to date systematic literature review to examine the nursing contribution to cancer patients' follow up care and in particular those measurable outcomes associated with good nursing care, such as: patients' satisfaction with care and quality of life, level of anxiety and depression and emotional wellbeing.

AIMS

As noted earlier, the original aim was to examine the follow up care offered to people with prostate cancer. However, the initial examination of the literature revealed there were few studies looking exclusively at this population so that the focus would be on the follow up care offered to patients with all types of cancer. The aim of this systematic review is to develop an understanding based on existing evidence of whether or not there is a difference between nurse-led follow up (NFU) versus medical follow up (MFU) in relation to cancer care. It explores outcomes directly linked to patients' care needs to enable some understanding of what can subsequently guide the development of services.

DATA COLLECTION METHODS

The overall systematic review question was: "In the case of prostate cancer patients, is Cancer Nurse -led follow-up better than medically led follow up when examining patients' satisfaction with care, quality of life, level of anxiety and depression and emotional wellbeing?" The Population Intervention and Comparison Study Design (PICOS) approach was used to guide this systematic review (Egger & Smith, 2001; Table 1). Randomised

Controlled Studies (RCTs) were selected as the study designs to be included in the review are viewed as the most reliable study approach to use to evaluate intended effects of healthcare interventions (MacInnes, 2009). Non randomised trials and observational studies were excluded.

Each paper had to include at least one of the main outcome measures to estimate the effect intervention has on a patient's quality of life, satisfaction with care, emotional wellbeing, anxiety or depression, as an inclusion criterion. Restriction to language and date of publication were applied. To ensure, all relevant studies were incorporated in the review, a decision was made to include any studies from outside the UK where it was viewed a similar health system to the UK health care system was in operation (Netherlands, Sweden and Australia).

Databases were searched from 1995 to September 2015. No earlier studies were sought as the role of Cancer Nurse Specialist was introduced following The Calman Hine Report in 1995. For the purpose of this review, secondary and primary data sources were searched using the databases detailed below as well as the reference lists of any relevant articles. Secondary sources were examined first. This included Department of Health publications surrounding cancer care (DOH, 2000; DOH 2004; DOH 2007; NHS Improvement, 2010; DOH 2011); NICE guidance on developing urological cancer services and guidance in prostate cancer (NICE 2002; NICE, 2004; NICE, 2008; NICE 2011) and Macmillan publications on cancer patients follow up care (Macmillan, 2008; Smith & Thompson, 2010; Taylor et al, 2010).

The conference abstracts were scrutinised and research proposals were noted, but not included as lacked completed data.

Primary sources of research articles were searched on selected databases: MEDLINE (1995 to September 2015), EMBASE (1995 to September 2015) and CINAHL (1995 to September 2015). The suggested search terms followed from the review question detailed in Table 1.

A flow chart details the selection process in Table 2. 21 RCTs were selected after the initial application of the inclusion and exclusion criteria. Upon closer examination of the eligibility criteria, a further 10 studies were excluded leaving 11 studies included for bias appraisal. The Cochrane Collaboration Assessment of Bias Collaboration's tool (Higgins and Altman, 2011) was used and 10 out of 11 studies were selected for data extraction. The bias assessment is detailed in Table 3.

Included studies with comparable outcomes were placed in separate tables and were compared like for like per outcome of interest at similar follow up time points. Other characteristics such as the demographic details of the participants, sample size, time from diagnoses, intervention, tools used and scoring were also noted.

Quality of life outcomes

Six studies examined quality of life outcomes all reporting continuous outcomes. European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC) was used by Faithfull et al (2001), Moore et al (2002), Brown et al (2002) and Kimman et al (2011), Functional Assessment of Cancer Therapy - General (FACT -G) by Sheppard et al (2009), European Health-Related Quality of Life (EURO QOL) by Verschuur et al (2009) and the general health questionnaire (GHQ-12) by McArdle et al (1996).

Two studies reported median data at twelve weeks of follow up Faithfull et al (2001) and Moore et al (2002), with three studies noting mean scores at three months follow up, four at six months and five at twelve months follow up (McArdle 1996; Brown et al 2002; Sheppard

et al 2009; Verschuur et al, 2009; Kimman et al, 2011). There was a problem with the Sheppard et al (2009) paper as the standard deviation was not noted in the follow up scores. It was decided to use the same values as for the beginning of the trial, as the authors suggested that an adjustment of data was made based on that score.

Patient satisfaction outcomes

Outcomes were measured by Self-assessment questioner of satisfaction with care based on Newcastle satisfaction with nursing care scale tool in Faithfull et al (2001); Moore et al (2002) used self developed, validated questionnaire; GHQ-12 and Spilberger state - trait inventory (STAI) was used by Beaver et al (2009) and Helgesent et al (2000) and Koingberg et al (2004) used The Satisfaction and accessibility scale (SaaC).

Six studies reported this as an outcome with both continuous and dichotomous data recorded. Faithfull et al (2001) and Moore et al (2002) noted outcomes at twelve weeks follow up. Beaver et al (2009), Helgesen et al's (2000) and Koingberg et al (2004) noted dichotomous data at twelve months follow-up.

Emotional Wellbeing Outcomes

Data for this outcome was available from six trials. There were three studies looking at continuous data with the median score recorded. EORTC measures were used by Faithfull et al (2001); Moore (2002); Brown et al (2002); Verschuur et al (2009); Kimman et al (2011), where Sheppard et al (2009) used global health guilty of life 12 aggregative questionnaire (GHQ12)

Faithfull et al (2001) and Moore (2002) at twelve weeks; Moore et al (2002) and Brown et al (2002) at six and twelve months. Three studies were combined using continuous with the mean data recorded at three, six and twelve months (Verschuur et al 2009, Sheppard et al

2009, and Kimman et al, 2011). The Sheppard et al (2009) data was excluded due to a lack of accurate data as only an aggregated score for this outcome was available.

Anxiety and depression outcomes

Five studies looked at anxiety and depression outcomes using hospital anxiety and depression scale tool (HADS) by Helgesen et al, 2000; Koingberg et al, 2004 and Brown et al, 2002; McArdle et al, 1996) and one study at only anxiety outcomes with help of State Trait Anxiety Scale (Kimman et al,). Brown et al (2002) and Kimman et al (2011) used continuous data and to examine levels of anxiety at six and twelve months follow-up. Hellgesen et al (2000) and Koingberg et al (2004) reported anxiety and depression outcomes at twelve and twenty - four months using dichotomous data.

DATA META - ANALYSIS

The process of meta-analysis was supported by the use of RevMen software version 5.1.7 and presented using a forest plot. Scores placed in the right hand axis represent an increase in the scores of the outcome of interest in those patients receiving the nurse-led intervention and scores placed in left hand axis show a decrease in scores of the outcome of interest in nurse-led follow up groups. Standardised Mean Difference (SMD) was used as a statistic for the measure of effect between interventions for continuous data. Hozo et al's (2005) formula helped to estimate the mean and variance from the median range, thus allowing all of the continuous data to be combined for analysis. Odds ratio (OR) was used as the effect measure when analysing dichotomous data. 95% confidence intervals were also recorded. Heterogeneity was also assessed with it being viewed as present when the p value <0.05 or I² over 75%.

RESULTS

Study Characteristics

The results are reported with forest plots used to give a graphical representation followed by a narrative explanation of the main findings. When examining the results, it was clear that heterogeneity was a problem for some of the combined findings. Forest plots have not been detailed where heterogeneity was considered a problem though the overall findings have been documented.

The total number of patients in these studies was 2166 with a mean age of 63 years (ranging from 56-78) with 831 male participants, and 757 female. There were a total of 495 identified as prostate cancer patients. The mean follow up time since completion of treatment was 20.5 months. The number of selected RCTs were small with a mean of 217 participants in each trial (ranging from 62-400). All included studies were viewed to have a low risk of bias and were acceptable for the systematic review as they reported the required outcomes and, as such, represent the best available current evidence.

Quality of Life Outcomes

The results at three months follow-up suggest a significantly increased quality of life score for patients receiving nurse-led follow-up with a mean difference of 2.88, 95% C.I.: 0.71-5.05, $p = <0.01$). However, there is a high level of heterogeneity recorded ($\text{Chi}^2 = 6.79$, $\text{df} = 2$, $p = 0.03$ and $I^2 = 71\%$) giving some cause for concern as to the variability between the study findings and consequently the amount of confidence in the overall combined result. Therefore, the findings should be interpreted with caution.

There was a slight but non-significant difference noted at six months in the combined scores between the two groups with mean difference in favour of NFU of 1.58, C.I.: -0.35 – 3.51, p

= 0.11. However, heterogeneity was also recorded when this analyses was undertaken ($\text{Chi}^2 = 14.08$, $\text{df} = 3$, $p = 0.003$).

The forest plot Table 3 shows the twelve month follow up comparison indicating little difference in the combined scores with a slight increase in the quality of life scores in the nurse-led follow-up patients, but high heterogeneity.

Patient Satisfaction Outcomes

The studies examining patient satisfaction are noted in this section at three months and twelve months. Both of the results appear to demonstrate significantly increased satisfaction with nurse-led follow-up when compared to medical follow up (Table 5 and 6). Overall, both 3 and 12 month analyses show greater satisfaction with the nurse led service, though it is heterogeneous.

Satisfaction with Accessibility by Phone

Two further studies examined a specific type satisfaction related to the patient`s perception of the accessibility of the urological service by phone and satisfaction with follow-up routines. The results indicate no difference in satisfaction between the two groups of patients (Table 7).

Emotional Wellbeing Outcomes

Six studies recorded outcomes that looked at different aspects of emotional wellbeing: role, emotional and social functioning. Three studies reported their findings using a median score (Faithfull et al, 2001; Moore et al, 2002; Brown et al, 2002), and two reported their findings by way of a mean score (Verschuur et al, 2009; Kimman et al 2011). However, Faithfull et al (2001) used GHQ12 questionnaire and presented all data apart from month 3 of follow up as

an aggregated score. Consequently this made it very difficult to combine all six studies' in 6 and 12 months of follow up for rich and more statistically significant data.

Role Functioning

In the two meta-analyses undertaken at 6 and 12 months looking at role functioning, there are no significant differences present though there was a slight non-significant increase in the NFU groups at 6 months, but results are heterogeneous (table 8 and 8a).

Social functioning

Two studies compared social functioning at 6 and 12 months. Though social functioning was slightly better in the NFU, there was high heterogeneity present (Table 9).

Emotional Functioning

A little difference was observed between two groups in emotional functioning, with slight increase in patients receiving nurse led follow up at three month (Table 10) though by the time of the six and twelve month follow-up there was a small decrease in emotional functioning recorded for this group of patients. (Table 10a and 10b). However, heterogeneity persist throughout.

Anxiety and Depression Outcomes

Anxiety outcomes were examined using continuous data at six months and twelve months follow up (Table 11 and 11a) while studies using dichotomous data were examined at twelve and twenty-four months follow-up (Table 12 and Table 12a). The findings suggest there is very little difference between the two types of follow up in the level of anxiety reported by patients with a small non-significant decrease in anxiety in the nurse led groups at six months and twelve months follow-up.

The outcomes were different at twenty-four months with a clear (though non-significant) increase in anxiety in the nurse led group.

Depression outcomes using dichotomous data were also analysed at twelve and twenty-four months follow-up (Table 13 and 13a). The combined scores indicate a non-significant increase in depression in the nurse led groups at twelve months and twenty four months follow-up.

Discussion

The main finding of this review is there is very little difference between those patients receiving nurse-led or medically-led follow-up in relation to their: quality of life; satisfaction with care; emotional wellbeing, anxiety and depression. There is some suggestion there are slightly more positive outcomes for patients receiving a nurse - led service in the early stages of follow-up but that no difference between two groups by the time of twelve months follow-up. This may be associated with adaption to life after treatment and the importance of assessment of changing needs (NCSI, 2011). The review also found that different modes of follow-up (face to face or telephone) are acceptable to patients whether the follow up is delivered by a nurse led or medically led service.

Previous work showed an absence of evidence to demonstrate the benefit of hospital based follow-up in the detection of cancer recurrence (Lydon et al, 2009; Kokko et al 2005; NICE, 2014) which indicates that efforts should be prioritised to support patients in living a relatively normal life and to optimise their social functioning validating the NCSI (2010) suggestion to reduce the number and duration of follow up visits. CNSs appear to be in an ideal position to support patients in transition to self-care. Emerging from the available evidence also appears to be the recommendation there should be a thorough assessment of

patients' concerns and a choice of follow-up care provision to patients where services are made flexible enough to accommodate their preferences (NHS Improvement, 2010).

The findings need to be examined with a degree of caution as the RCTs included in the review have small sample sizes, great variation in presentation of data or missing outcome data in the papers report resulting in a limited amount of combined evidence. The reviewed studies reflected short period of follow up making it difficult to judge the sustainability or effect of NFU long term. In addition, there were also variations between studies in patient selection, baseline cancer severity and the treatment modality received. **There are no more up to date published RCTs on the subject available, perhaps this review evidence not representative of modern practice and more up today RCT requires.** Finally, there is a possibility of publication bias due to only English language articles being included.

It is suggested that nurses have the required flexibility to develop innovative services and adapt to the different modes of follow-up to meet patients' preferences and relieve pressure on secondary care (NHS Improvement, 2010). Patients find nurses accessible and approachable, a source of information and support, who are able to co-ordinate their care in the most efficient way (DOH 2010; DOH 2010a; NHS Improvement, 2010; DOH, 2011). It appears that with adequate training and support, CNSs may be in a better position to carry out follow up and meet patients needs through ongoing holistic needs assessment.

CONCLUSIONS

The review has found the current evidence points to little difference in the outcomes of patients followed up by the two professional groups. Consequently, there is some evidence to suggest that NFU in cancer care is as safe and effective.

No strong recommendations can be drawn from this review due to the small difference between effects and low strength of evidence. However, some tentative conclusions can be drawn. Although there are low numbers of prostate cancer patients in this review, there was little variation in patients' outcomes among the studies. Due to the consistencies of the findings in different cancer groups, there is some optimism for proposing that the cancer nurse specialist in the follow-up of prostate cancer can provide equivalent care. Nurses are in a good position to offer ongoing holistic needs assessment and to subsequently meet the unmet needs of prostate cancer patients. If patients are fully informed about their follow-up care choices, Cancer Nurses Specialists can be considered a good alternative to medical follow up for people with prostate and other cancers.

IMPLICATIONS FOR PRACTICE

The lack of significant findings for the majority of the analyses indicates that more research is required to establish the effectiveness of nurse-led follow-up in cancer care, to examine whether different types of follow-up care may be effective and whether there are differences in outcomes for patients with different types of cancer. It would also be useful to examine if a holistic tool assessment could be used for outcomes such as enhancing self-care, adjustment to illness and resuming social functioning. It would be preferable if future research studies used validated, standardised tools and present comparable data to allow the data to be easily combined for future reviews.

What is known about the subject and what this paper contributes?

This systematic review adds to previous reviews by Lewis et al (2009) who looked at nurse-led versus medical follow-up for patients with cancer and Cruickshank et al (2008) who evaluated the input of specialist breast care nurses for the supportive care of women with breast cancer. Both reviews derived to similar conclusion in favour of no difference between nurse-led and medical follow up. This review included studies that were previously analysed (McArdie 1996; Helgesen et al, 2000; Moore et al, 2002; Brown et al, 2002 and Koingberg et al 2004) and new studies that were not part of any previous reviews (Faithfull et al, 2001; Shepperd et al 2009; Beaver et al, 2009; Verschuur et al, 2009 and Kimman et al, 2011). Thus contributing to the body of research evidence on the subject.