



Self-reported competence in long term care provision for adult cancer survivors: A cross sectional survey of nursing and allied health care professionals



S. Faithfull^{a,*}, Carol Samuel^b, Agnieszka Lemanska^a, Clare Warnock^c,
Diana Greenfield^c

^a School of Health Sciences, Faculty of Health & Medical Sciences, University of Surrey, Guildford GU2 7TX, UK

^b University of Surrey, UK

^c Weston Park Hospital, Sheffield, UK

ARTICLE INFO

Article history:

Received 31 January 2014

Received in revised form 17 August 2015

Accepted 1 September 2015

Keywords:

Workforce planning

Training needs

Late effects

Competences

Nurses

Rehabilitation practitioners

Cancer

Survivorship

ABSTRACT

Background: Cancer survival is increasing as patients live longer with a cancer diagnosis. This success has implications for health service provision in that increasing numbers of adults who have received cancer therapy are requiring monitoring and long-term health care by a wide range of practitioners. Given these recent trends there is a need to explore staff perceptions and confidence in managing the consequences of cancer diagnosis and treatment in cancer survivors to enhance an integrated cancer service delivery.

Objective: This study examines the self-reported perceptions of competence in nurses and professionals allied to medicine providing survivorship services caring for adults after cancer treatment in both secondary and primary care.

Design: A cross sectional survey of the adult cancer workforce using a self-assessment tool for assessing confidence in providing long-term cancer patient management. This study was a health service evaluation.

Setting: The study was conducted within the United Kingdom.

Participants: Respondents were 618 health care professionals of these 368 were specialist adult cancer nurses in oncology and the community setting and 250 cancer allied health professionals.

Method: The survey tool was developed with experts in cancer management, nurses professionals allied to medicine such as physiotherapists and dieticians, educationalists, patient groups as well as health service managers. Competence was assessed in 4 domains clinical practice, symptom management, care co-ordination and proactive management. Perceptions of training needs were also ascertained. Data were collected using an Internet survey distributed through cancer services, community settings and professional institutions.

Results: In total 618 practitioners who responded were providing services for adults' 1-year post cancer therapy. Practitioners felt confident in managing psychosocial care and communicating with patients. Deficits in self-reported confidence were found in long-term medications management, care planning, long-term and complex symptom management, for those providing dimensions of care coordination and proactive care. Differences in confidence were seen between practitioner groups. Community nurses felt less skilled in managing adult cancer patients long-term.

* Corresponding author. Tel.: +44 01483 682568.

E-mail address: s.ffaithfull@surrey.ac.uk (S. Faithfull).

Conclusions: Nurses and allied health professionals self-reported confidence, in managing all areas of care for adult cancer survivors, is variable with deficits in important areas of practice. Despite this being a small proportion of practitioners who are working in cancer care, those responding had perceived gaps in knowledge and educational needs. In providing cancer aftercare there is a requisite shift to proactive care, supported self-management and collaborative management if patient's long-term consequences of cancer and its treatment are to be addressed.

Implications for practice: If health care providers are to transform cancer survivor services then investment is required in education and capability planning across nurses, allied health professionals in both the hospital and the community setting.

© 2015 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

What is already known about the topic?

- Increasing numbers of adult cancer survivors are requiring long term follow up and clinical services to meet chronic illness as a consequence of cancer and its treatment.
- Survivorship care is being delivered by teams of healthcare professionals across both secondary and primary care.
- Increasingly survivorship is being addressed in cancer undergraduate and postgraduate curricula for nurses and professions allied to health.

What this paper adds

- Oncology nurses perceive they have skills to manage long term adult cancer patient follow up, whilst community nurses had the lowest confidence in managing care.
- Deficits in confidence were found across professional groups in long term medications management, care planning and complex symptom management.
- Innovative approach to adult cancer follow up requires making effective use of the workforce ensuring the right skills and education are available to provide safe and effective care.

1. Background

In Europe today the number of people surviving cancer is increasing with 46.2% of all those diagnosed living 10 or more years beyond initial treatment and for some cancers, such as breast and prostate cancer, this is substantially higher (Berrino et al., 2007; Brenner, 2002). By 2030 it is projected that there will be more than 4 million cancer survivors within the UK population (Maddams et al., 2009) and 13.7 million in the USA with 59% of survivors 65 years or older (Siegel et al., 2012). Traditionally the term survivor has been used to describe those who have no detectable disease having completed cancer treatment. However, this interpretation is being challenged by the increasing number of people receiving on-going cancer therapy for many months to years (Ganz et al., 2012). This development has led to a broader definition of a survivor as those people living with and beyond a cancer diagnosis and

treatment (Bell and Ristovski-Slijepcevic, 2013). The National Coalition for Cancer Survivorship identifies that individuals “from the time of its discovery and for the balance of life, an individual diagnosed with cancer is a survivor” (p 10) (Leigh, 2007). Survivorship covers the physical, psychosocial and economic issues of cancer, beyond the diagnosis and treatment phases. The National Cancer Survivorship Initiative in the UK (DH et al., 2010) also championed survivorship care and led to the recovery package, which triages adult survivor's needs and promotes care across both secondary and primary health care sectors. Developments in Europe have similarly raised awareness of survivor's requirements and introduced rehabilitation initiatives that utilise skills of a wide range of practitioners allied to medicine (McCabe et al., 2013). Recognising this future extended trajectory of cancer management is challenging (Stricker et al., 2011) as it covers caring for those who have completed initial treatment and have no active disease, as well as those with advanced but not terminal disease (Maher and McConnell, 2011). This breadth of definition has been recognised at a policy level for continuity of services for cancer survivors, but has not addressed how to develop these, specifically the educational requirement needed by healthcare professionals across both primary and secondary care. There is increasingly a wide range of healthcare providers and staff groups delivering care for adult cancer patients and this workforce will need to be responsive to future diverse care needs (Landier, 2009).

Health care systems for cancer historically have been organised for acute illness episodes and treatment delivery rather than the prevention and management of chronic illness problems, which can arise as a consequence of the disease or treatment. Symptoms can emerge many months to years after completion of therapy (Arriagada et al., 2009) and evidence is emerging of the increased risk longer term of comorbidities (Elliott et al., 2011). Men and women with breast, prostate and colorectal cancers have a higher incidence of osteoporosis, diabetes and heart failure than age matched controls (Khan et al., 2011). In addition new emerging cancer therapies have a range of late effect profiles with possible cardiac toxicities (Lenihan et al., 2013; Monsuez et al., 2010; Pachman et al., 2012) that may develop later in life. Providing services to prevent, detect and manage these consequences has been identified as a

priority for long-term cancer care and cancer recovery packages in the UK (DH, 2012), Europe and USA (Rowland et al., 2013). The traditional hub and spoke model of cancer services provided with centres of excellence for therapy and longer term follow up at regional centres is being challenged. Despite the focus of secondary services primarily on diagnosis and treatment, in the UK, survivors have more inpatient episodes, within the first year of care, but also significant hospital activity 1–5 years after diagnosis, compared to those without cancer (Maddams et al., 2011). Economic constraints are increasing demands on service provision and the need for cost-effective and efficient services have challenged the extent of secondary care provision for cancer survivors and highlighted the need for new models of follow-up care (Virgo et al., 2013). Notwithstanding increased secondary care utilisation there has been a clear shift to primary care provider models of cancer services and commissioning of health and wellbeing approaches with a focus on chronic illness and multiple morbidity management (Watson et al., 2011) as well as rehabilitation (Goransson, 2011; Rix, 2011). This range of services is termed a cancer recovery or survivorship package, it is stratified according to risk; for example the likelihood of an individual developing health problems as a consequence of their disease and treatment, with actual and potential needs determined (McCabe et al., 2013). At its centre the survivorship package provides: holistic needs assessment, treatment summary and care plan, cancer care review and health and wellbeing clinics with physical activity, education, information and financial advice (Berlinger and Gusmano, 2011; DH et al., 2010; Harley et al., 2012; McCabe et al., 2013). To implement this package there is a need for well-trained and competent staff to provide care for adults across the multiple health care agencies.

Understanding the complexity of the consequences of cancer and its treatment requires competence in risk assessment, early detection of late-effects, health promotion and complex interventions. There are a number of systematic reviews on efficacy of specialist nurse interventions in managing cancer patients (Corner, 2003; Sussman et al., 2011). These identify that nurse provision leads to improvements in chronic health problem management and increases patient knowledge and self-management. Such evidence has been utilised to promote nurse-led care and care co-ordination roles as components of breast cancer services (Eicher et al., 2012) and more widely in other cancers. A much smaller set of studies and reviews has examined community practitioner's roles in cancer survivorship care (Cooper et al., 2010) and survivorship care provision by allied health professionals (Robb, 2011). Studies of patients have found that they are uncertain of the skills of their primary care provider in managing their care and continue to have a reliance on secondary specialist providers (Chubak et al., 2014). Increasingly survivorship is being included in undergraduate and postgraduate nursing cancer curricula (Ferrell et al., 2003) but it is also important to capture specialist staff perspectives of their own ability to determine if there is a need to expand education. The objective of this health service evaluation was to provide an analysis of workforce

capability across sectors to inform future service provision and training requirements.

1.1. Service evaluation questions

- What clinical services are being provided in community and secondary care settings, by nurses and allied health professionals for adult cancer survivors?
- What consequences of cancer and its treatment do nurses and allied health professionals feel confident in managing and what are the gaps?
- What are the perceived skills and training needs of health care practitioners in providing long-term adult cancer care?
- What are the differences in perceived skills, confidence and training needs, in adult cancer survivorship, of oncology nurses, community nurses and allied health professionals?

2. Health service evaluation methodology and design

Needs based approaches to workforce planning require the explicit exploration of population healthcare requirements, for example the level of unmet needs in the cancer patient population, against the workforce knowledge and skills to be able to address such future health care needs (Hall and Meija, 1978). The evidence and scope of patient unmet needs in cancer aftercare has identified some significant gaps in both physical, psychosocial and lifestyle management. Evidence in the experience of care PROMs survey of England (Corner et al., 2013) as well as in large population data sets (Elliott et al., 2011) report that cancer aftercare and support for self-management could be improved. However, we know less about what skills staff require in managing current cancer survivor's healthcare issues and how we match those skills to these emerging models of care. Forecasting of future supply demand requires modelling patients' needs against specific competency and capability in order to ensure workforce plans are fully integrated with future service strategy (National Audit Office, 2001).

Study data were collected through a cross sectional national survey using the "Caring for patients living with and beyond cancer competence tool". This survey tool was developed especially for this project through a participatory approach using the literature, national guidelines, patient and health practitioners and service providers. The study was conducted in 2011–2012 and piloted in the Autumn of 2010. As a health service evaluation the study did not require NHS ethical approval. This paper follows the STROBE guidelines on reporting observational studies (Elm et al., 2007; Gallo et al., 2012).

2.1. Sample

The survey was disseminated via UK cancer services, community forums, rehabilitation networks and the Queens Nursing Institute a charity for community nurses that provide networking and professional opportunities. The targeted groups were oncology, community nurses and allied health professionals. The inclusion criteria for

the sample were nurses and allied health care professionals who were providing specialist care provision for cancer patients at least 1 year after treatment completion. At the time of the survey there were an estimated 1800 clinical nurse specialists working in the UK (Trevatt and Leary, 2010). The proportion of those nurses working in follow up and adult cancer survivorship is unclear and knowledge about practitioner population and response rate for this study is not possible to report. Survey invitations were drafted by the research team with the survey link and circulated via the institutions, to allow for anonymous survey completion there were no traceable links used. Often such surveys have a poor response rate so reminders were sent via the networks, which increased data capture, but data reflects a small proportion of the workforce.

2.2. Survey instrument

Study data were gathered using the survey tool “Caring for patients living with and beyond cancer competence tool”. The tool measures the self-reported competence of practitioners in areas of adult cancer survivorship management and was designed to reflect 4 dimensions fundamental to caring for adults living with and beyond a cancer diagnosis. These include; clinical practices, symptom management, care co-ordination and proactive management. Sample demographics, current training and future training needs were also included in the survey. Psychometric properties of this tool are currently being evaluated. The tool was developed through a literature search of role requirements; expert panel development to create content validity and expert practitioner feedback from oncology, community and allied health professionals, patients, educators and service managers also reviewed the tool for construct validity. The tool has 10 items; including clinical practice 6 item scores focused on services provided and routine care planning for adult survivors. Symptom management includes 2 items on confidence in managing 20 symptoms commonly seen after cancer treatment. This is a Likert type scale, with items reflecting, “strongly agree” to “strongly disagree” in relation to practitioner’s confidence to manage such symptoms. Items 8–10 covered care co-ordination and proactive care management using a 1–10 scale of how easy the role tasks were perceived. The tool was piloted over 2 months with 6 health care professionals in both secondary and community settings, changes to the tool were made including the addition of more survivorship services in the questionnaire (for final tool see Supplementary Materials).

Supplementary material related to this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.ijnurstu.2015.09.001>.

2.3. Data analysis

Study analysis were carried out using descriptive statistics using the statistical package SPSS (v19). Likert scale data were summarised, the strongly agree and agree data were merged to show means. Data were analysed for total respondents and the differences in subgroups of

oncology, community nurses and allied health professionals.

3. Results

3.1. Demographic and training

The resulting sample consisted of 618 practitioners 368 nurses (227 oncology, 141 community nurses) and 250 professionals allied to medicine. The majority of those who completed the questionnaire had more than 20 years been registered as health care professionals, so were experienced practitioners (Table 1). Of those who reported on post registration qualifications 37.7% ($n = 233$) had degree level training and 21.7% ($n = 134$) postgraduate qualifications. The analysis showed that advanced communication courses were the most frequently undertaken, with 21.2% ($n = 53$) of allied health professionals and 16.3% ($n = 37$) of oncology nurses. Over 18.4% ($n = 46$) of allied health professionals and oncology nurses (19.4% $n = 44$) had undertaken additional courses or study days, which were tumour specific while only 2.8% ($n = 4$) of the community nurses. However, 11.3% ($n = 16$) of the community nurses had received education in palliative care compared with 9.6% ($n = 24$) of the allied health professionals and 4.4% ($n = 10$) of the oncology nurses. In contrast survivorship or late-effects training was relatively rare across all three subgroups (3.9% $n = 24$) as was psychosocial education and training (2.6% $n = 16$). Data from 618 respondents is included in each of the tool dimensions in the analyses. Percentages are reported with missing data identified.

3.2. Clinical practice dimension

To report the comparison of types of services provided by practitioner’s frequency data is reported in Table 2. Over 80% ($n = 493$) of respondents provided one or more services for patients’ 1 year following cancer treatment. Specific management of symptoms as a result of cancer treatment was the most frequently reported clinical practice with 57.6% ($n = 356$) practitioners providing this service to their patients. Reassuring patients about their health and emotional support was also high with 56.8% ($n = 351$) of practitioners, while 51.6% ($n = 319$) provided lifestyle and nutrition advice and 45% ($n = 278$) the opportunity to talk to staff that understood a cancer diagnosis. Clinical practice involving the long-term management of medications for cancer patients was comparatively low with 14.9% ($n = 92$) of the respondents involved in this activity. Overall 33.3% ($n = 206$) respondents provided telephone follow up with a larger proportion of oncology nurses 45.4% ($n = 103$) and 30% ($n = 75$) of allied health professionals. Oncology nurses were more likely than the other two practitioner groups to provide triage services with 38.8% ($n = 88$) doing so. Only 23.3% ($n = 144$) of the practitioners were providing reviews and assessment of patients 12 months after cancer treatment.

3.3. Perceived confidence and skills in symptom management

Across all the groups most practitioners felt they had skills to manage certain symptoms (Table 3) for example

Table 1
Respondent demographics.

	Allied health professionals		Community nurses		Oncology nurses		ALL	
	%	N	%	n	%	n	%	N
<i>Age groups</i>								
20–30	8.4	21	1.4	2	2.6	6	4.7	29
31–40	16.4	41	11.3	16	15.4	35	14.9	92
41–50	21.6	54	24.8	35	29.5	67	25.2	156
51–60	10.4	26	15.6	22	18.1	41	14.4	89
60+	0.8	2	1.4	2	0.9	2	1.0	6
Non respondents	42.4	106	45.4	64	33.5	76	39.8	246
<i>Years since qualification</i>								
Average number of years qualified	16.9	21.7	21.4	20				
<i>Qualifications hold</i>								
Undergraduate	36	90	34.8	49	41.4	94	37.7	233
Postgraduate	21.2	53	19.9	28	23.3	53	21.7	134
<i>Courses and study days relevant to cancer care undertaken in the past 2 years (n = multiples as participants could identify more than 1 course)</i>								
Advanced communication	21.2	53	2.1	3	16.3	37	15.0	93
Survivorship/late-effects	4.4	11	0.7	1	5.3	12	3.9	24
Tumour specific	18.4	46	2.8	4	19.4	44	15.2	94
Psycho-social	2.8	7	1.4	2	3.1	7	2.6	16
Clinical skills	2.8	7	9.2	13	2.2	5	4.0	25
Palliation	9.6	24	11.3	16	4.4	10	8.1	50
Total number of participant's	250	141	227	618				

Values are shown as a percentage of (n) for each practitioner subgroup.

fatigue (71.5% $n = 301$), anxiety and depression (66.9% $n = 282$) or general pain (66% $n = 278$). Symptoms such as nausea and vomiting (60.3% $n = 254$) breathlessness (58.1% $n = 245$) or bone and joint pain (53.9% $n = 227$) were symptoms more than half of the practitioners felt they had skills in managing for adult cancer survivors. Fertility issues (15.2% $n = 64$), impotence (15.6% $n = 66$) and cardiac effects (15.9% $n = 67$) were late-effects that the smallest number of practitioners felt they had skills to manage. There were differences in symptom management skill perception between the subgroups for managing all symptoms except fatigue, cardiac effects and memory problems.

3.4. Care coordination and proactive care

The majority 78.9% ($n = 315$) of respondents felt confident in referring patients to the multi-disciplinary team (Table 4). Areas of confidence in care co-ordination were in items of independently reviewing and assessing patients, informing and discussing long-term health effects and recognising the potential for late-effects in their client group. In creating individualised long-term plans of care only 39.8% ($n = 159$) of practitioners felt confident. In the proactive care dimension respondents felt confident in recognising psychosocial problems, effectively teaching self-management and self-monitoring and providing psychological interventions. Areas

Table 2

Comparison of the practitioner groups providing clinical practice to adult cancer patients following their cancer treatment. Values are shown as a percentage of (n) for each practitioner group.

Dimensions of clinical Practice	Allied health professional		Community nurses		Oncology nurses		All	
	%	n=	%	n	%	n	%	N
Review and assessment after 12 months	19.2	48	9.9	14	36.1	82	23.3	144
Checks for cancer recurrence	5.6	14	6.4	9	31.3	71	15.2	94
Telephone follow-up	30	75	19.9	28	45.4	103	33.3	206
Screening advice for cancer patients	6.8	17	5.7	8	20.7	47	11.7	72
Triage and referral to the physician	6	15	12.8	18	38.8	88	19.6	121
Reassure patients about their health and emotions	44.4	111	58.2	82	69.6	158	56.8	351
Long term medications management for cancer therapies	4.8	12	17.7	25	24.2	55	14.9	92
Symptom and side effect management of cancer treatment	51.6	129	52.5	74	67.4	153	57.6	356
Nutritional, exercise and lifestyle advice	54.4	136	51.1	72	48.9	111	51.6	319
Opportunity to talk to staff who understand a cancer diagnosis	34	85	41.8	59	59.0	134	45.0	278
Missing data	20.0	50	24.8	35	17.6	40	20.2	125
Total	250	141	227	618				

Table 3

Perceived skills of all respondent in managing symptoms as consequences of cancer and its treatments.

Dimensions of symptoms management	Strongly agree/agree combined							
	Allied health professionals		Community nurses		Oncology nurses		All	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>N</i>	%
General pain	61	38.4	77	86.5	140	80.9	278	66.0
Bone and joint pain	56	35.2	61	68.5	110	63.6	227	53.9
Lymphedema	51	32	43	48.3	63	36.4	157	37.2
Skin problems	36	22.6	64	71.9	103	59.5	203	48.2
Fatigue	107	67.3	60	67.4	134	77.4	301	71.5
Breathlessness	99	62.3	63	70.8	83	48	245	58.1
Weight gain	62	38.9	41	46.1	98	56.6	201	47.7
Limb mobility	90	56.6	25	28.1	55	31.7	170	40.3
Sleep problems	55	34.6	51	57.3	99	57.2	205	48.6
Bowel/urinary	31	19.5	65	73.0	95	54.9	191	45.3
Nausea/vomiting	37	23.3	78	87.7	139	80.3	254	60.3
Cardiac effects	19	11.9	17	19.1	31	18.0	67	15.9
Neuropathy	60	37.7	44	49.4	69	39.9	173	41.0
Loss of libido	11	6.9	13	14.6	54	31.2	78	18.5
Impotence/sexual	8	5.0	13	14.6	45	26.1	66	15.6
Fertility issues	7	4.4	2	2.2	55	31.8	64	15.2
Hot flushes	20	12.6	21	23.6	70	40.4	111	26.3
Menopause	14	8.8	18	20.2	62	35.8	94	22.3
Anxiety/depression	90	56.6	65	73.0	127	73.4	282	66.9
Memory problems	55	34.6	32	36.0	50	28.9	137	32.5
Missing data	91		52		54		197	
Total	250	141	227	421				

where respondents were less confident were in providing complex symptom management for severe symptoms (27.3% $n = 109$), reviewing medications and advising patients on potential medication effects (29.6% $n = 118$).

The majority of practitioners identified a training need around the knowledge of long-term health effects of cancer treatment (Table 5). This was highest in the community nurses who expressed the greatest need for training (80.3% $n = 61$). The top 5 areas defined by respondents were; knowledge of long-term health effects of cancer treatment, managing the psycho-social aspects of long-term cancer

survival, self-management techniques, long term consequences of cancer in older age and co-ordinating long-term follow up. Nurses both in hospital, community alongside allied health professionals saw training in survivorship as a priority for further training.

3.5. Comparisons across practitioners

The differences in the proportion of each group's answers were compared (Tables 1, 3, and 5) and analysed descriptively for the services they provided against

Table 4

Levels of confidence expressed by all respondents in performing specific tasks associated with care coordination and proactive care in adult cancer survivors.

Dimensions of care co-ordination	Confident		Unsure		Not confident	
	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>
Recognise psycho-social problems	62.7	250	28.8	115	8.5	34
Review and assess independently & then consult with clinician	62.4	249	26.3	105	11.3	45
Independently review and assess	52.9	211	32.6	130	14.5	58
Inform & discuss potential long term health effects of treatments	49.9	199	36.6	146	13.5	54
Review medications & advise patients on potential effects	31.1	124	39.3	157	29.6	118
Refer patients to the multi-disciplinary team	78.9	315	12.5	50	8.5	34
Effectively teach self-management & self-monitoring	50.1	200	37.6	150	12.3	49
Dimensions of proactive care						
Recognise symptoms associated with late effects	48.9	195	42.1	168	9.0	36
Create individualised long term plan of care	39.8	159	44.6	178	15.5	62
Provide psychological support	57.6	230	31.3	125	11.0	44
Provide symptom management for mild to moderate side effects	57.6	230	31.1	124	11.3	45
Provide complex symptom management for severe symptoms	30.1	120	42.6	170	27.3	109
Recognise the potential late effects of my client group	54.4	217	32.6	130	13.0	52

* Significance as measured by a z-test to compare proportions of practitioners expressing confidence or lack of confidence in managing long-term cancer patient health service activities.

Table 5
Priority of training requirements of healthcare professionals involved in the long-term management of adult cancer patients.

	Allied health professionals		Community nurses		Oncology nurses		ALL	
	n	%	n	%	n	%	N	%
Knowledge of long term health effects of cancer treatment	90	65.7	61	80.3	95	66.4	246	69.1
Managing psycho-social aspects of long term cancer survival	87	63.5	43	56.6	98	68.5	228	64.0
Self-management techniques	86	62.8	39	51.3	76	53.1	201	56.5
Long term consequences of cancer treatments in older age	71	51.8	47	61.8	69	48.3	187	52.5
Coordinating long term follow up	57	41.6	43	56.6	82	57.3	182	51.1
Tests and investigations	57	41.6	52	68.4	64	44.8	173	48.6
Endocrine effects of cancer treatment	48	35.0	40	52.6	70	49.0	158	44.4
Prevention & management of cancer induced bone loss & joint pain	65	47.4	40	52.6	64	44.8	169	47.5
Potential cardiac effects of chemo & hormone therapies	55	40.1	45	59.2	64	44.8	164	46.1
Assessing/managing pelvic problems post-surgery/radiotherapy	29	21.2	31	40.8	40	28.0	100	28.1
Cancer surgeries & effects on physiological & functional processes	67	48.9	34	44.7	48	33.6	149	41.9
Co-ordinating long term follow up	57	41.6	43	56.6	82	57.3	182	51.1
Rehabilitation	88	64.2	27	35.5	50	35.0	165	46.3
Diet/lifestyle	49	35.8	25	32.9	52	36.4	126	35.4
Benefits of exercise	51	37.2	20	26.3	44	30.8	115	32.3
Medications management and adherence	35	25.5	35	46.1	37	25.9	107	30.1
Assessment of sexual dysfunction and fertility	34	24.8	29	38.2	70	49.0	133	37.4
Assessment & screening for cancer patients longer term	38	27.7	36	47.4	62	43.4	136	38.2
Telephone follow-up techniques	42	30.7	24	31.6	73	51.0	139	39.0
Long term consequences of cancer treatments in older age	71	51.8	47	61.8	69	48.3	187	52.5
Return to work issues	68	49.6	24	31.6	68	47.6	160	44.9
Finance and benefits	32	23.4	24	31.6	57	39.9	113	31.7

perceptions of confidence. There was a difference between the professional groups in all but one of the services that they provided which would reflect the difference in practitioner roles and service provision. The exception was nutritional, exercise and lifestyle advice, which was provided by over half of respondents in each professional group and in which overall 51.6% ($n = 319$) of practitioners felt they had skills. The oncology nurses had a consistently (across all but one question) higher proportion of practitioners declaring the skills to provide the range of clinical practice identified in the survey than the other two groups. Community nurses and allied health professionals were comparable in the range and type of services they provided. However, when taking only these two groups into account, allied health professionals were more confident than community nurses in carrying out review and assessment after 12 months and telephone follow-up. Community nurses had a higher proportion of practitioners than allied health professionals in the following categories: triage and referral to the physician, reassure patients about their health and emotions, and long-term medications management for cancer therapies. Overall, in the tasks there were differences found between groups with a higher proportion of oncology nurses more confident that they could perform tasks around the management of cancer patients' long-term.

4. Discussion

The analysis presented here is the first study that evaluates the readiness of the UK nursing and allied health professional workforce to meet the emerging service requirements for managing cancer as a long-term condition. Oncology nurses were more likely to be providing

late-effects or follow up services for cancer patients 12 or more months post cancer treatment and felt confident in their clinical practice. Community nurses and allied health professionals were also providing chronic symptom management and rehabilitation for adult cancer survivors long-term. Differences were found between the professional groups in how confident they felt in managing consequences of cancer treatment and this was often related to the clinical practice they provided and increased when focused on specific client groups.

Study limitations were that this data reflected perceptions of a small number of nurses and allied health professionals who provide overall cancer care within the UK and may reflect the views of those who have an interest in survivorship care. All health care practitioners responding to the survey identified strengths and weaknesses, but perceptions of skills do not reflect the actual competence of practitioners and further work is required to research how perceived and actual skills impact on patient outcomes. However, there were significant gaps in perceived skills identified across all three groups for areas such as medications management, care planning, complex symptom management, assessment and review of late-effects.

Areas where practitioners expressed a need for more training were around the knowledge of long-term health effects, psychosocial care and self-management techniques. Providing interventions for emotional and psychosocial distress in survivors was common practice as was highlighted in the finding that fear of recurrence, anxiety and depression were commonly managed by all practitioners. Although the recognition of psychological care has grown the management remains sporadic (Fallowfield and Jenkins, 2015) and often psychological services are limited (Newell et al., 2002) this may be reflected in survey

responses. It should be recognised that this was a self-selected group of practitioners and reflects their own self-assessment of confidence. Despite these limitations the service evaluation generated important findings to inform workforce development and future training requirements.

Specialist nurses have been identified as important for the quality of service provision and for cancer survivors (Corner et al., 2013). Analysis of patient experiences, in the UK, suggests that specialist cancer nurse access leads to improvements in patient care coordination, emotional and self-care support (Griffiths et al., 2013). Expansion of the clinical nurse specialist role in long-term follow up has been advocated. Substituting or supplementing existing health professional roles can provide the same quality of care (Laurant et al., 2010) but this also needs to be understood in the context of skills and training needs of staff. While this study did not set out to review the experience and practice of specialist nurses this data suggests that there are areas that oncology nurses feel less confident in managing. In some areas of adult cancer care, allied health professionals are substituting for or supplementing doctors by providing packages of care. This includes physiotherapists and therapy radiographers (Laurant et al., 2010). Such innovative models of changing professional roles are emerging as a new emphasis on team and shared care. Physical care such as symptom management was the most prevalent activity of all participants; however symptoms such as sexual, fertility issues and libido were areas where respondents felt less confident. This may reflect the finding that few of the practitioners reported confidence in recognizing symptoms associated with late-effects. It may also be influenced by a more general lack of expertise and practice in assessment for pelvic symptoms and concerns that has been identified in previous research (Faithfull and White, 2008; White et al., 2011). Despite the importance of psychosexual problems and patients reported needs this was only identified as an area of training need by 37.4% ($n = 133$) of practitioners. Oncology nurses had concerns about their ability to assess long-term consequences, plan long-term care or manage complex symptoms and medications for patients. These chronic illness skills are rarely covered within oncology nurse training (Ferrell and Winn, 2006) but are essential for nurse-led clinics and cancer patient review (Farrell et al., 2011) as the complexity of comorbidity extends as new treatments emerge.

While the findings highlighted areas of training need and service development for oncology nursing they also identified significant concerns about the preparedness of community nurses to play an increased role in primary care led models of care delivery for cancer patient follow-up. In most areas of the survey community nurses were less confident in being able to recognise symptoms associated with late-effects and identified greater training needs and had received less investment in their training requirements despite their on-going role in cancer patient management. Only a small number of the community nurses had undertaken advanced communication skills compared to 30–50% of the other health professionals. These deficits may reflect the relatively recent move to primary care provider adult cancer service provision

within the UK but needs to be addressed if these new shared care models are too be successful.

Most studies of long-term follow-up of cancer patients in the community have been of primary care practitioners and have identified that General Practitioners (GPs) provide on-going screening and co morbidity management for cancer survivors (Hewitt et al., 2007; Khan et al., 2010). Bober et al. (2009) in a survey of US community based practices found that 47% of clinicians felt they were inadequately prepared for delivery of care to cancer survivors. This is reflected in the UK in a survey of clinicians on follow up after cancer treatment, 81% of cancer experts and GPs felt that late-effects expertise in primary care was insufficient and limited the ability to provide comprehensive care in the primary care setting (Greenfield et al., 2009).

Integrating coordinated survivorship across into community care does require additional health resources and commitment from health care practitioners (Lin and Donehower, 2010). A US study of primary care practitioners found that information transfer from oncologists and secondary care could improve the confidence of primary care health professionals and subsequently the care coordination of patients after cancer treatment (Merport et al., 2012). A recent study found that fewer than half of US comprehensive cancer centres provided treatment summaries and less than two thirds survivorship care plans (Forsythe et al., 2013). Although such tools have been introduced within the UK their use is unclear and there is still substantial work to be undertaken for this information to disseminate from secondary care to the community practitioner. The skills and confidence reported by community nurses in relation to survivorship and late-effects care could complement those of the oncology nurse. Community nurses need confidence in the treatment summaries and care plans so as to understand the long-term consequences of cancer treatment. Implementing these tools could raise awareness of the long-term care needs of cancer survivors and improve community nurses confidence in providing care to this group of patients. Allied health professionals in the study reported a high level of confidence in managing symptoms but felt less skilled in areas of self-management and care planning. Allied health professionals have a key role in rehabilitation and providing preventative management for survivors such as exercise and dietary advice to prevent potential chronic illness (Robb, 2011; Thorsen et al., 2011). This may reflect that in this study allied health professionals wanted more training on rehabilitation and self-management techniques rather than reflecting a lack of skills.

The current model of providing specific interventions to treat acute illness episodes and a single disease is no longer a model that works for cancer as a long-term condition since many of the symptoms and conditions are interconnected (Virgo et al., 2013). To be effective cancer aftercare needs to shift to a culture that is chronic illness focused with self-management and lifestyle advice as the core of provision (Robb, 2011; Thorsen et al., 2011). This is particularly the case as much of the co-morbidity described by cancer patients in aftercare emerges over

time when they often have little access to specialist support (Corner et al., 2013). Our study has shown that current long-term survivorship services and levels of perceived confidence among nurses and allied health professionals are variable between professional groups and individual practitioners. Most practitioners' levels of confidence increased for symptoms or concerns relevant to their own client group. Areas of low confidence understandably included the more latent treatment consequences related to emerging therapies such as cardiac toxicity, in this area, there was a substantive confidence gap. Only a small proportion of cancer patients need assistance with complex late-effects but the findings suggest that the skills to assess and the ability to manage such complexity is held by a relatively small number of practitioners, mostly oncology nurses. The old adage "you don't know what you don't know" resonates with the lack of knowledge regarding risks of possible future treatment consequences potentially hampering "anticipatory care". Patient surveys in the UK (Corner et al., 2013) continue to report the absence of early interventions to investigate and treat serious on-going physical problems as a result of cancer treatment this would suggest that there is indeed a need for staff training in this area. This also highlights the need for improved care pathways for re-entry into specialist care.

5. Conclusion

Innovative approaches to adult cancer follow up such as; open access clinics, patient self-referral, telephone follow-up and primary care models are spreading as the need for survivorship aftercare grows. Whilst there is utility in such models they are highly dependent on the workforce being prepared to embrace change and work across agencies in an integrated way. This health evaluation identified gaps in perceived confidence and skills for practitioners who were providing these services across both secondary and primary care. This calls for a review of healthcare competencies to complement such services for patients within both cancer and community care. This is especially important in that new models emphasise and maximise the effectiveness of a range of health care workers within cancer care. It is imperative to use a framework of competence for standardisation and quality improvement; this would assist managers and commissioners in describing current roles and understanding requirements for workforce development. Making effective use of the workforce also means ensuring the right mix of essential, specialist and leadership skills to provide safe adult survivorship care.

Acknowledgements

We would like to thank the members of Consequences of Cancer And its Treatment (CCAT) groups for providing expertise in review of the questionnaire. We also acknowledge the contribution of Carole Farrell, Paul Trevatt, Dr Charles Campion-Smith for reviewing the questionnaire and giving feedback. We would also like to thank the nurses and

allied health professionals who took the time to complete the questionnaires and made this study possible.

Conflicts of interest: None declared.

Funding: This health service evaluation was funded by a grant to the University of Surrey from Macmillan Cancer Support as part of the National Cancer Survivorship Initiative (DH, 2010–2011).

Ethical approval: Not required.

References

- Arriagada, R., Averbeck, D., Dahl, A.A., Darby, S., Fosså, S., Friberg, S., Polgár, C., de Vathaire, F., 2009. OECI workshop on late side-effects of cancer treatments. *Eur. J. Cancer* 45 (3), 354–359.
- Bell, K., Ristovski-Slijepcevic, S., 2013. Cancer survivorship: why labels matter. *J. Clin. Oncol.* 31 (4), 409–411.
- Berlinger, N., Gusmano, M., 2011. Cancer chronicity: new research and policy challenges. *J. Health Serv. Res. Policy* 16 (2), 121–123.
- Berrino, F., de Angelis, R., Sant, M., Rosso, S., Lasota, M., Coebergh, J., Santaquilani, M., 2007. Survival for eight major cancers and all cancers combined for European adults diagnosed in 1995–99 results of the EURO CARE-4 study. *Lancet Oncol.* 8, 773–783.
- Bober, S., Recklitis, J., Campbell, E., Park, E., Kutner, J., Najita, J., Diller, L., 2009. Caring for survivors. *Cancer* 115 (18 Suppl.), 4409–4418.
- Brenner, H., 2002. Long-term survival rates of cancer patients achieved by the end of the 20th century: a period analysis. *Lancet* 360, 1131–1135.
- Chubak, J., Bowles, E., Tuzzio, L., Ludman, E., Rutter, C., Reid, R., Wagner, E., 2014. Perspectives of cancer survivors on the role of different health-care providers in an integrated delivery system. *J. Cancer Surviv.* 8, 229–238.
- Cooper, J., Loeb, S., Smith, C., 2010. The primary nurse practitioner and cancer survivorship care. *J. Am. Acad. Nurse Pract.* 22, 394–402.
- Corner, J., 2003. The role of nurse-led care in cancer management. *Lancet Oncol.* 4 (10), 631–636.
- Corner, J., Wagland, R., Glaser, A., Richards, M., 2013. Qualitative analysis of patients' feedback from a PROMs survey of cancer patients in England. *BMJ Open* 3, e002316.
- DH Macmillan Cancer Support, NHS Improvement, 2010. National Cancer Survivorship Vision. pp. 80.
- DH, D.o.H., 2012. Quality of life of cancer survivors in England: Report on a pilot survey using patient reported outcome measures (PROMS). National Institute for Health Research, London, pp. 1–76.
- Eicher, M., Kadmon, I., Claassen, S., Marquard, S., Pennery, E., Wengstrom, Y., Fenlon, D., 2012. Training breast care nurses throughout Europe: the EONS postbasic curriculum for breast cancer nursing. *Eur. J. Cancer* 48, 1257–1262.
- Elliott, J., Fallows, A., Staetsky, L., Smith, P., Foster, C., Maher, E., Corner, J., 2011. The health and well-being of cancer survivors in the UK: findings from a population survey. *Br. J. Cancer* 105, S11–S20.
- Elm, E.V., Altman, D.G., Egger, M., Pocock, S.J., Gøtzsche, P.C., Vandenbroucke, J.P., STROBE Initiative, 2007. Strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *BMJ* 335 (7624), 806–808.
- Faithfull, S., White, I., 2008. Delivering sensitive health care information: challenging the taboo of women's sexual health after pelvic radiotherapy. *Patient Educ. Couns.* 71 (2), 228–233.
- Fallowfield, L., Jenkins, V., 2015. Psychosocial/survivorship issues in breast cancer: are we doing better? *J. Natl. Cancer Inst.* 107 (1), dju335. <http://dx.doi.org/10.1093/jnci/dju335>.
- Farrell, C., Molassiotis, A., Beaver, K., Heaven, C., 2011. Exploring the scope of oncology specialist nurses' practice in the UK. *Eur. J. Oncol. Nurs.* 15 (2), 160–166.
- Ferrell, B., Virani, R., Smith, S., Jurazek, G., 2003. The role of oncology nursing to ensure quality care for cancer survivors: a report commissioned by the National Cancer Policy board and Institute of Medicine. *Oncol. Nursing Forum* 30 (1), E1–E11.
- Ferrell, B.R., Winn, R., 2006. Medical and nursing education and training opportunities to improve survivorship care. *J. Clin. Oncol.* 24 (32), 5142–5148.
- Forsythe, L.P., Parry, C., Alfano, C.M., Kent, E.E., Leach, C.R., Haggstrom, D.A., Ganz, P.A., Aziz, N., Rowland, J.H., 2013. Use of survivorship care plans in the United States: associations with survivorship care. *J. Natl. Cancer Inst.* 105 (20), 1579–1587.

- Gallo, V., Egger, M., McCormack, V., Farmer, P.B., Ioannidis, J.P.A., Kirsch-Volders, M., Matullo, G., Phillips, D.H., Schoket, B., Stromberg, U., Vermeulen, R., Wild, C., Porta, M., Vineis, P., 2012. STrengthening the Reporting of OBServational studies in Epidemiology: Molecular Epidemiology STROBE-ME. An extension of the STROBE statement. *J. Epidemiol. Community Health* 66 (9), 844–854.
- Ganz, P.A., Earle, C.C., Goodwin, P.J., 2012. Journal of Clinical Oncology update on progress in cancer survivorship care and research. *J. Clin. Oncol.* 30 (30), 3655–3656.
- Goransson, P., 2011. Developing and integrating a cancer rehabilitation process in order to achieve a patient focused and coherent cancer care at hallnds hospital Halmstead: a pilot project. *Psycho-Oncology* 20, 154.
- Greenfield, D., Absolom, K., Eiser, C., Walters, S., Michel, G., Hancock, B., Snowden, J., Coleman, R., 2009. Follow-up care for cancer survivors: the views of clinicians. *Br. J. Cancer* 101 (4), 568–574. <http://dx.doi.org/10.1038/sj.bjc.6605160>.
- Griffiths, P., Simon, M., Richardson, A., Corner, J., 2013. Is a larger specialist nurse workforce in cancer care associated with better patient experience? Cross-sectional study. *J. Health Serv. Res. Policy* 18 (Suppl. 1), 39–46.
- Hall, T., Meija, A., 1978. *Health Manpower Planning: Principles, Methods, Issues*. WHO, Geneva.
- Harley, C., Pini, S., Bartlett, Y., Velikova, G., 2012. Defining chronic cancer: patient experiences and self management needs. *BMJ Support. Palliat. Care* 2, 248–255.
- Hewitt, M., Bamundo, A., Day, R., Harvey, C., 2007. Perspectives on post treatment cancer care: qualitative research with survivors, nurses and physicians. *J. Clin. Oncol.* 25 (16), 2270–2273.
- Khan, N., Mant, D., Carpenter, L., Forman, D., Rose, P., 2011. Long term health outcomes in a British cohort of breast, colorectal and prostate cancer survivors a database study. *Br. J. Cancer* 105, S29–S53.
- Khan, N., Mant, D., Rose, P., 2010. Quality of care for chronic diseases in a British cohort of long term cancer survivors. *Ann. Fam. Med.* 8 (5), 418–424.
- Landier, W., 2009. Survivorship care: essential components and models of delivery. *Oncology* 23 (4 Suppl. Nurs ed.), 46–53.
- Laurant, M., Harmsen, M.M., Wollersheim, F., Sibbald, H., Grol, B.R., 2010. *Revisions of Professional Roles and Quality Improvement: A Review of the Evidence*. The Health Foundation, London.
- Leigh, S., 2007. Cancer survivorship: a nursing perspective. In: Ganz, P.A. (Ed.), *Cancer Survivorship: Today and Tomorrow*. Springer, New York, NY, pp. 8–13.
- Lenihan, D., Oliva, S., Chow, E., Cardinale, D., 2013. Cardiac toxicity in cancer survivors. *Cancer* 119 (11 Suppl.), 2131–2142.
- Lin, J., Donehower, R.C., 2010. Make quality cancer survivorship care possible in the era of workforce shortage. *J. Oncol. Pract.* 6 (1), 52–53.
- Maddams, J., Brewster, D., Gavin, A., Steward, J., Elliott, J., Utley, M., Moller, H., 2009. Cancer prevalence in the United Kingdom: estimates for 2008. *Br. J. Cancer* 101 (3), 541–547.
- Maddams, J., Utley, M., Moller, H., 2011. Levels of acute health service use among cancer survivors in the United Kingdom. *Eur. J. Cancer* 47 (14), 2211–2220.
- Maher, J., McConnell, H., 2011. New pathways of care for cancer survivors: adding the numbers. *BJC* 105, S5–S10.
- McCabe, M., Faithfull, S., Makin, W., Wengstrom, Y., 2013. Survivorship programs and care planning. *Cancer* 119 (11 Suppl.), 2179–2186.
- Merport, A., Lemon, S., Nyambose, J., Prout, M., 2012. The use of cancer treatment summaries and care plans among Massachusetts physicians. *Support. Care Cancer* 20 (7), 1579–1583.
- Monsuez, J.J., Charniot, J.C., Vignat, N., Artigou, J.Y., 2010. Cardiac side-effects of cancer chemotherapy. *Int. J. Cardiol.* 144 (1), 3–15.
- Newell, S.A., Sanson-Fisher, R.W., Johanna, S.N., 2002. Systematic review of psychological therapies for cancer patients: overview and recommendations for future research. *J. Natl. Cancer Inst.* 94 (8), 558–584.
- National Audit Office, 2001. *Educating and Training the Future Health Professional Workforce for England*. National Audit Office, London.
- Pachman, D.R., Barton, D.L., Swetz, K.M., Loprinzi, C.L., 2012. Troublesome Symptoms in Cancer Survivors: Fatigue, Insomnia, Neuropathy, and Pain. *J. Clin. Oncol.* 30 (30), 3687–3696.
- Rix, B., 2011. A national strategy for cancer rehabilitation and palliative care in Denmark. *Psycho-Oncology* 20, 236.
- Robb, K., 2011. Addressing consequences of treatment – The role of rehabilitation. *Eur. J. Cancer* 47, S61–S62.
- Rowland, J., Kent, E., Forsythe, L., Loge, J., Hjorth, L., Glaser, A., Mattioli, V., Fossa, S., 2013. Cancer survivorship in Europe and the United States: where have we been, where are we going, and what can we learn from each other? *Cancer* 119 (Suppl. 11), 2094–2108.
- Siegel, R., Naishadham, D., Jemal, A., 2012. Cancer statistics. *CA Cancer J. Clin.* 62 (1), 10–29.
- Stricker, C., Jacobs, L., Risendal, B., Jones, A., Panzer, S., Ganz, P., Syrjala, K., McCabe, M., Baker, K., Miller, K., Casillas, J., Rosenstein, D., Campbell, M., Palmer, S., 2011. Survivorship care planning after the institute of medicine recommendations: how are we faring? *J. Cancer Surviv.* 5 (4), 358–370.
- Sussman, J., Howell, D., Bainbridge, D., Brazil, K., Pyette, N., Abbasi, S., Whelan, T., 2011. The impact of specialized oncology nursing on patient supportive care outcomes. *J. Psychosoc. Oncol.* 29 (3), 286–307.
- Thorsen, L., Gjerset, G., Loge, J., Kiserud, C., Skovlund, E., Flotten, T., Fossa, S., 2011. Cancer patients' needs for rehabilitation services. *Acta Oncol.* 50 (2), 212–222.
- Trevatt, P., Leary, A., 2010. A census of the advanced and specialist cancer nursing workforce in England, Northern Ireland and Wales. *Eur. J. Oncol. Nurs.* 14, 68–73.
- Virgo, K., JL, B., Glaser, A., Horgan, D., Maher, J., Brawley, O., 2013. Health care policy and cancer survivorship. *Cancer* 119 (11 Suppl.), 2187–2199.
- Watson, E., O'Brien, R., Campbell, C., Weller, D., Neal, R., Wilkinson, C., Rose, P.W., Prostate Cancer Follow-Up Study Group, 2011. Views of health professionals on the role of primary care in the follow-up of men with prostate cancer. *Fam. Pract.* 28 (6), 647–654.
- White, I., Allan, H., Faithfull, S., 2011. Assessment of treatment-induced female sexual morbidity in oncology: is this a part of routine medical follow-up after radical pelvic radiotherapy? *Br. J. Cancer* 105 (7), 903–910.