1

Cancer patients' respect experiences in relation to perceived communication behaviours from hospital staff: analysis of the 2012-2013 National Cancer Patient Experience Survey.

Running title: Cancer patients' respect experiences

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Abstract

Purpose: Respect experiences are poorly understood despite respect being central to professionalism in healthcare and patient well-being, and needed for optimal patient care. This study explores which patient-perceived communication behaviours from hospital staff contribute most to cancer patients' respect experiences and account for variation in their experience by socio-demographic and clinical characteristics.

Methods: Secondary analysis of data from the 2012-2013 National Cancer Patient Experience Survey of 45191 patients with a primary cancer diagnosis treated in English National Health Service trusts providing adult acute cancer services who provided data on experienced respect and dignity. Results: Both autonomy-supportive and caring/emotionally sensitive behaviours were associated with reported respect, although the latter showed stronger associations and accounted for most differences in reports of respect between patient groups. Differences in respect were found by gender, race/ethnicity, age, the presence of long-standing conditions, treatment response, time since first treated for cancer (p<.001), employment and type of cancer (p<.05).

Conclusions: The study questions the tendency to conceptualise respect primarily in terms of autonomy-supportive behaviours and shows the relative contribution of autonomy-supportive and caring/emotionally sensitive behaviours in explaining disparities in respect experiences. More attention should be paid to affective communication behaviours from hospital staff to reduce disparities in respect experiences.

Keywords: Respect; cancer patients; communication behaviours; disparities in care experiences; United Kingdom

1. Introduction

Respecting patients is central to professionalism in healthcare [1-3] and is essential to alleviate patient distress and to support optimal patient care. Yet there are indications that patient respect experiences are not optimal [4, 5]. Respect is defined as an attitude towards someone based on an evaluation of their worth, including their humanity [6]. Feeling respected thus generally means feeling worthy or valuable in interactions with others [7], often experienced as a result of others' respectful behaviours towards oneself, which may follow from them having a respectful attitude. The experience of disrespect is often associated with feelings of injustice, anger and aggression [8] and is particularly damaging to patients' emotional well-being [9]. Research indicates that respect from healthcare professionals is a primary concern for patients, shown to be one of breast cancer patients' primary demands [10]. Quigley et al. [11] also showed that reports of how often the physician "showed respect" most strongly predicted overall physician ratings. Respect experiences have also been shown to be associated with patient satisfaction, adherence to advice, receipt of optimal preventive care, seeking needed care [12, 13], illness perception [14] and trust in healthcare providers [14, 15]. Feeling respected is especially pertinent for cancer patients who are vulnerable and tend to experience high psychological stress, including fears regarding their cancer spreading and their future, lack of control, feelings of uncertainty and depression [16-17].

Despite the importance of treating patients with respect, there are disagreements in the literature around what this means in practice. The medical and bioethics literature often equates respecting patients with respecting their autonomy, although some authors recognise that respecting patients also implies recognising their value as persons more generally by paying attention to their subjective feelings and vulnerabilities [18, 19]. Rare studies have indeed indicated that key components of patient respect encompass not only support of autonomy and provision of information but also caring/emotionally supportive behaviours such as empathy, care, recognising individuality, respecting dignity and paying attention to their needs [14, 20, 21]. Treating someone with dignity likely forms part of treating someone with respect, that is as a worthy human being [22]. Respect is likely to underpin several dimensions of patient-centred communication to the extent that these communicate to the patient that s/he is a *worthy and valuable human being*. Thus, perceived respect may well play an important role in the positive influence of patient-centred communication on patient satisfaction. Patient-centredness is a complex concept that generally advocates care oriented towards the patient's needs and illness experience, but there is a lack of consistency in its definition and operationalisation; some focus specifically on understanding the patient's experience of illness, some on building rapport with the patient and others on information-giving and patient education [23]. The patient-centred approach appears likely to communicate respect, but this aspect may be overwhelmed by other important aims, such as improving understanding and retention of information and increasing satisfaction with and confidence in the treatment plan. Research is scarce into which behaviours communicate respect and the studies mentioned have tended to rely on small samples, have not specifically looked at cancer patients and have not evaluated the relative influence of primarily autonomy-supportive behaviours versus behaviours demonstrating care and emotional sensitivity on patients' experiences of being treated with respect. More generally, there is a lack of research on communication behaviours that contribute most to patients' respect experiences [24]. This understanding is necessary to maximise the likelihood that patient-centred care is perceived as respectful.

Disparities in cancer patient respect experiences in the United Kingdom (UK) have been shown to exist according to age, gender, ethnic group, deprivation level and cancer diagnosis [25] but it is not known what accounts for these. The influence of employment and clinical characteristics such as the presence of long-standing conditions, response to cancer treatment and time since first treated for cancer on respect experiences has also not been explored. It is also not known whether these characteristics influence UK cancer patients' overall satisfaction with healthcare professional communication in hospital care more generally. Using data from the 2012-2013 National Cancer Patient Experience Survey (NCPES) in England, the current study aims to (1) investigate which perceived behaviours of hospital staff contribute most to explaining cancer patients' respect experiences and (2) examine which perceived behaviours of hospital staff account for differences in respect experience by socio-demographic and clinical patient characteristics. Such investigation can help explain differences in experienced respect between patient groups and suggest more targeted interventions to reduce disparities in patients' experiences of care.

2. Methods

2.1. Participants and data

The study used data from the 2012-2013 NCPES in England run by Quality Health and commissioned by the UK Department of Health [26]. Adult patients with a primary diagnosis of cancer admitted and treated in English NHS hospitals, and discharged from September to November 2012, were sent the survey by post between January and May 2013, with two reminders to non-responders [27]. The survey covered all 155 acute and specialist NHS trusts providing adult acute cancer services and responses were collected from 68737 patients (64% response rate) [27]. Institutional ethical approval was not needed for the current secondary data analysis study.

The study analysed responses to the survey question: "Were you treated with respect and dignity by the doctors and nurses and other hospital staff?" Patients answered the question on a 4-pt Likert scale from "always", "most of the time", "some of the time" and "never". This variable was converted into a dichotomous variable with the categories "always" and "not always" to balance the groups, given that 83% of patients answered "always". Being treated with respect "most of the time" implies there were instances of disrespect so it made sense to group the "most of the time", "some of the time" and "never" categories together under the category "not always", representing some level of disrespect. This variable was also named *reported respect* for simplicity.

Patient socio-demographic and clinical variables used in the analysis included: self-reported age, gender, sexuality, employment status, presence of longstanding condition, time since first treated for their cancer, cancer response to treatment (questions 71 to 77), self-reported ethnicity (based on the 2001 Census Office for National Statistics classification, question 79) and cancer type (derived from hospital records). Age was treated as continuous because inspection of the data supported a linear increase in reported respect with age. Colorectal/lower gastrointestinal cancer was treated as the

reference category being the most frequent condition with a similar incidence in males and females. Non-meaningful responses such as "do not remember" were treated as missing.

The study selected patient reported behaviours from hospital staff that were clearly *autonomy-supportive* or clearly demonstrated *care and emotional sensitivity* and captured a range of different aspects with as little overlap as possible. *Autonomy-supportive behaviours* consisted of involvement in decisions, measured with question 20: "were you involved as much as you wanted in decisions about your care or treatment?", and provision of information, measured with question 67: "How much information were you given about your condition and treatment?" (with the response categories: not enough/the right amount/too much)

Behaviours demonstrating *care and emotional sensitivity* consisted of five variables: (1) being talked to as if not there, measured by combining answers to question 39: "did doctors talk to you as if you were not there?" and question 43: "did nurses talk to you as if you were not there?" ("yes, often" by doctor or nurse/"yes, sometimes" by doctor or nurse/"no" by neither doctor nor nurse); (2) being given privacy, measured by combining question 48: "were you given enough privacy when discussing your condition or treatment?" and question 49: "were you given enough privacy when being examined or treated?" ("yes, always" on both questions/"yes, sometimes" on either question/"no" on either question); (3) being able to discuss worries or fears, measured with question 50: "were you able to discuss any worries or fears with staff during your hospital visit?"; (4) staff doing everything to control pain, measured with question 51: "Do you think the hospital staff did everything they could to help control your pain?" and (5) the way told about cancer, measured with question 12: "how do you feel about the way you were told you had cancer?" Except where described above, for combined variables, the response categories were analysed as they were reported in the NCPES and can be found in Table 2.

2.2. Statistical analysis

Logistic regression analysis was initially used to obtain unadjusted odds ratios (with 95% confidence intervals) for univariable associations between the socio-demographic, clinical and behavioural self-reported variables and reported respect from hospital staff. Following univariable analyses, four multivariable binary logistic regression models were constructed with reported respect as dependent variable. All socio-demographic and clinical variables were entered simultaneously in Model 1 to obtain odds ratios for each background variable adjusted for the other background variables. Models 2 to 4 were hierarchical regression models used to examine the relative contribution of *autonomy-supportive behaviours* and behaviours demonstrating *care and emotional sensitivity* in explaining variance in reported respect (adjusting for background variables), and their role in explaining relationships between background variables and reported respect. In model 2, autonomy-supportive behaviours were entered simultaneously at step 1 and background variables at step 2. In model 3, caring/emotionally sensitive behaviours at step 2 and background variables at step 1, caring/emotionally sensitive behaviours at step 2 and background variables at step 3. Cases with missing data were excluded from the analyses. Analyses were carried out using SPSS 20.

3. Results

Data were available from 45191 patients who provided data on the extent to which they were treated with respect and dignity (65.7% of 68737 total respondents). Of these, 37632 (83.3%) reported always being treated with respect and 7559 (16.7%) reported not always being treated with respect. Table 1 shows participants' socio-demographic and clinical characteristics. The majority of participants were white (92.7%), female (54.5%), heterosexual (90.1%) and not employed (69.2%), and 34.5% had a longstanding condition. The mean age was 65.49 (SD = 12.57, median = 67, range = 17-102). The most common cancer type was breast cancer (23.8%), followed by colorectal/lower gastrointestinal cancer (15%) and urological cancer (12.7%). For 72.5% of participants, it had been less than a year since they were first treated for cancer and 41.9% reported that their cancer fully responded to treatment.

3. 1. Background socio-demographic and clinical variables

Unadjusted and adjusted analyses showed the odds of reported respect were lower for females, younger patients, patients who preferred not to indicate their sexuality, patients in employment, patients of Asian/Asian-British, Chinese or other ethnicity, patients with a long-standing physical condition or illness, or mental health condition, patients for whom it had been more than one year since they were first treated for cancer, and patients whose cancer did not fully or did not respond to treatment (including new cancer or cancer came back) or who were uncertain of what was happening with their cancer (see Table 1). Adjusted analyses showed patients with lung, breast, head and neck, gynaecological, skin, haematological or some other form of cancer were more likely to report respect than colorectal/lower gastrointestinal cancer patients (see Table 1).

3.2. Autonomy-supportive behaviours

Unadjusted and adjusted analyses showed involvement in decisions and provision of information significantly predicted reported respect (see Model 2 in Table 2). Patients were less likely to report respect when they agreed to some extent or disagreed that they had been involved in decisions as much as they wanted compared to when they definitely agreed with this (adjusted ORs of .33 and .20) and when they reported being given not enough or too much information compared to the right amount of information (adjusted ORs of .43 and .68). Involvement in decisions explained 11.8% (percentage derived from Nagelkerke R² in univariable analyses) and provision of information 7.1% of the variance in reported respect; together they explained 13.5% of the variance (see Nagelkerke R² for Model 2 in Table 2).

These behaviours remained significantly associated with reported respect after adjusting for behaviours demonstrating care and emotional sensitivity, with ORs of .62 and .58 for involvement in decisions and an OR of .80 for being given not enough information. The association between being given too much information and reported respect was no longer significant (see Model 4, Table 2).

3.3. Behaviours demonstrating care and emotional sensitivity

Unadjusted and adjusted analyses showed the behaviours "being talked to as if not there", "given privacy", "able to discuss fears and worries", "staff did everything to control pain" and "way told about cancer" significantly predicted reported respect (see Model 3, Table 2). Patients were less likely to report respect when they reported often or sometimes being talked to as if they were not there (adjusted ORs of .41 and .35), were not given privacy or only sometimes (adjusted ORs of .30 and .36), were not able to discuss any worries or fears with staff or only most or some of the time (adjusted ORs of .15 and .27), staff did everything to control their pain only some of the time or not at all (adjusted ORs of .22 and .09) and felt they could have been told they had cancer a bit or a lot more sensitively (adjusted ORs of .74 and .62) (see Table 2).

After adjusting for autonomy-supportive behaviours, these behaviours were still significantly related to reported respect with relevant ORs ranging from .10 to .42 for the first four behaviours and adjusted ORs of .84 and .72 for each category of the fifth behaviour (see model 4, Table 2). They were able to explain an additional 26% of the variance in reported respect (based on difference in Nagelkerke R² values between Model 4 and Model 2, see Table 2), with each individual behaviour explaining an additional 1% ("way told about cancer") to 13.1% ("able to discuss worries or fears") of the variance; "being talked as if not there" explained an additional 8.7%, "being given privacy" an additional 9.8% and "staff did everything to control pain" an additional 12% of the variance (percentages based on the difference between the Nagelkerke R² for Model 2 plus each individual caring/emotionally sensitive behaviour and Model 2). Autonomy-supportive behaviours only accounted for an additional 0.7% of the variance after adjusting for caring/emotionally sensitive behaviours (based on difference in Nagelkerke R² values between Model 4 and Model 3, see Table 2).

3.4. Reported communication behaviours explaining differences in reported respect according to patient characteristics

After adjusting for autonomy-supportive behaviours, the difference in reported respect was no longer significant for employment status but became significant between patients with urological and colorectal/lower gastrointestinal cancer (see Table 3). After adjusting for caring/emotionally sensitive

behaviours, most differences in reported respect by socio-demographic and clinical characteristics disappeared, with a few exceptions. Patients who were uncertain about their treatment response were still less likely to report respect and patients with haematological cancer were still more likely to report respect than their counterparts (see Table 3). Patients with a mental health condition were also still less likely to report respect than patients with no long-standing condition but this difference disappeared after adjusting for both types of behaviours (see Table 3).

4. Discussion

In line with past literature [14, 20, 21], but drawing on a large sample of cancer patients, the findings show that respect for patients not only entails acknowledgement of their autonomy but also, and importantly, sensitivity to their subjective experiences, such as feelings and vulnerabilities, and care and concern for their emotional well-being. Caring/emotionally sensitive behaviours from hospital staff were found to explain more of the variation in reports of respect than autonomy-supportive behaviours and accounted for most of the differences in reports of respect between patient groups. This finding emphasises that an emotionally detached approach, which may be more likely when healthcare professionals do not feel respect for the patient or adopt a more pragmatic approach to patient care, may fail to communicate respect. This is the first large quantitative study to examine which communication behaviours from hospital staff contribute most to patients' experiences of respect.

For the purpose of this study, behaviours were divided into autonomy-supportive and those showing sensitivity to feelings and care, in line with the distinction adopted in the literature. However, both types of behaviours are not strictly independent; for instance autonomy-supportive behaviours convey recognition of the patient as able to think and act autonomously and possibly some aspects of care/concern, such as for the patient's state of mind. Of note, patients were less likely to report respect when not given enough information but also when given too much information. Past research has also found that cancer patients do not want to be "over-informed" [10]. The present study suggests this may be linked to their perception that the healthcare provider does not care about their well-being.

Observed differences in reported respect by age, gender and ethnicity are consistent with past studies on cancer patients' experiences of respect [25] and overall care [28] and similar disparities in patient experience of healthcare professional communication by age, gender and/or ethnicity have been observed in the general UK patient population [29, 30]. Past studies with US general patient samples have likewise shown younger and non-White patients to be less likely to report always being treated with respect and dignity but no difference by gender [12, 13]. The current study stresses the need to also pay closer attention to cancer patients with long-standing physical conditions, mental health conditions or long-standing illness, who were first treated for cancer more than one year ago, with partial or no treatment response, in employment or preferring not to indicate their sexuality, who had more negative respect experiences after adjusting for the other socio-demographic and clinical factors.

Most disparities in reported respect were explained by patients' perceptions of hospital staff behaviours relating to emotional sensitivity and care. This was particularly the case for differences in reported respect by gender and sexuality, which is consistent with research showing female cancer patients to have stronger emotional and support needs [31]. Similarly, the data suggests colorectal/lower gastrointestinal cancer patients were less likely to report respect than patients with other forms of cancer because they reported less emotional sensitivity and care from hospital staff. Nonetheless, clear changes in odds ratios after the introduction of autonomy-supportive behaviours in the analysis suggest that autonomy-supportive behaviours also contributed to some extent to differences in reported respect by race/ethnicity and response to treatment. In addition, the difference in reported respect between patients with a mental health condition and no long-standing condition disappeared only after both autonomy-supportive and caring/emotionally sensitive behaviours were adjusted for. Patients with a mental health condition may have a greater need for personal interaction with healthcare professionals, including being treated as partners of care [32].

While the study highlights communication behaviours from hospital staff that correlate with patients' reports of respect, more research is needed to establish why some cancer patient groups report a worse

experience. Concentration in hospitals with poorer care could explain some of the differences [33]. Behaviours showing emotional sensitivity and care may be especially poor if there are high levels of staff burnout [34]. However, this is unlikely to explain all differences in reported respect since differences in patient experience of care remain after adjusting for care site [29, 33]. Differences in reported respect could be due to some patient groups being treated with less respect, possibly because of less respectful attitudes towards certain patients [24, 35] and/or to differences in patient groups' conceptions and expectations of quality care [30]. Some groups may have generally higher expectations of patient-centred care than others [14] but there may also be differences, cultural or otherwise, in the importance attached to certain expressions of respect.

The analyses are based on a very large sample and findings are likely to generalise to the whole cancer patient population since the survey was sent to patients in all acute and specialist NHS trusts providing adult acute cancer services [27]. However, only 66% of survey respondents completed the respect question. Analyses looking at differences between participants who completed the respect question versus those who did not showed the groups differed significantly on all study variables, except race/ethnicity and reports of being given privacy. Generally, groups who felt less respected in the main analyses and who reported worse treatment were more likely not to complete the respect question, except for males, non-employed and older patients who felt more respected in the main analyses but were also more likely not to complete the respect question. These analyses suggest that the number of patients reporting always receiving respect may not be as high as indicated by the results and suggest particular caution in generalising the findings to males, non-employed and older patients. Moreover, the smaller size of some groups, in particular Chinese and other and patients with a learning disability, indicates that more caution should be exercised in making conclusions about these groups. Responses to some questions might also reflect a social acceptability bias (e.g. mental health condition) and difficulties in interpretation (e.g. response to treatment). The study is also limited by the type of questions collected in the NCPES and there may be other important factors that explain respect experiences that should be investigated, such as efficiency of the healthcare system, trust in the NHS and continuity of care with hospital staff. Trust-level factors were not adjusted for

but these have been shown to minimally influence the association between patients' sociodemographic characteristics and care rating [28].

In conclusion, the study highlights the need to pay more attention to affective communication behaviours from hospital staff, because increasing their use should help improve patients' respect experiences and reduce disparities in care experiences. The strong associations between caring/emotionally sensitive behaviours and reported respect call in to question a tendency to conceptualise respect simply in terms of autonomy-supportive behaviours [18] and a primary emphasis on these behaviours [36]. Patients want to be recognised and valued as whole persons with rational capacity *and* feelings. The study presents data on communication behaviours that explain many of the disparities in reported respect, which could inform more targeted interventions to reduce disparities in care experiences and/or be used by medical and other healthcare educators to promote respectful patient care among trainee and experienced healthcare professionals. Caring/emotionally sensitive behaviours of respect can be improved through communication skills training [37]. It would be helpful to further explore, using qualitative approaches, patient perceptions of the affective behaviours identified as being strongly associated with patients' respect experiences. This could be explored across, as well as between, patient groups to facilitate delivery of respectful care.

Conflict of Interest: The authors declare that they have no conflict of interest and do not have a financial relationship with the organisation that sponsored the research. The National Cancer Patient Experience Survey 2013 dataset used can be accessed at http://ukdataservice.ac.uk.

References

 [1] Department of Health (2015) The NHS Constitution. Crown Copyright: London. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/448466/NHS_C onstitution_WEB.pdf. Accessed 2 September 2015.

- [2] General Medical Council (2015) Promoting excellence: standards for medical education and training. <u>http://www.gmc-uk.org/education/undergraduate/ undergrad_outcomes.asp</u>. Accessed
 2 September 2015.
- [3] Nursing and Midwifery Council (2015) The Code: Professional standards of practice and behaviour for nurses and midwives. NMC, London, 1-20.
 http://www.nmc.org.uk/standards/code/ Accessed 2 September 2015.
- [4] Chadwick A (2012) A dignified approach to improving the patient experience: Promoting privacy, dignity and respect through collaborative training, Nurse Educ Pract 12:187–191.
- [5] Francis R (2013) The mid staffordshire NHS foundation trust public inquiry. <u>http://www.midstaffspublicinquiry.com/report</u>. Accessed 15 July 2014.
- [6] Lalljee M, Tam T, Hewstone M, Laham, S, Lee J (2009) Unconditional respect for persons and the prediction of intergroup action tendencies. Eur J Soc Psychol. 39: 666-683.
- [7] Parse RR (2006) Feeling respected-a parse method study. Nurs Sci Q 19: 52-6.
- [8] Miller DT (2001) Disrespect and the experience of injustice. Annu Rev Psychol. 52: 527-553.
- [9] Thorne S, Oliffe JL, Stajduhar KI, Oglov V, Kim-Sing C, Hislop TG (2013) Poor communication in cancer care: patient perspectives on what it is and what to do about it. Cancer Nurs 36: 445-453.
- [10] Wright EB, Holcombe C, Salmon P (2004). Doctor's communication of trust, care and respect in breast cancer: qualitative study, Brit Med J 328: 864.
- [11] Quigley DD, Elliott MN, Farley DO, Burkhart Q, Skootsky SA, Hays RD (2014) Specialties differ in which aspects of doctor communication predict overall physician ratings. J Gen Intern Med 29: 447-54.
- [12] Beach MC, Sugarman J, Johnson RL, Arbelaez JJ, Duggan PS, Cooper LA (2005) Do patients treated with dignity report higher satisfaction, adherence and receipt of preventive care? Ann Fam Med 3: 331–8.
- [13] Blanchard J, Lurie N (2004) R-E-S-P-E-C-T: patient reports of disrespect in the health care setting and its impact on care, J Fam Pract 53: 721–30.

- [14] Clucas C, St Claire L (2010) The effect of feeling respected and the patient role on patient outcomes. Applied Psychology: Health and Well-being 2: 298–322.
- [15] Elander J, Beach MC, Haywood Jr C (2011) Respect, trust, and the management of sickle cell disease pain in hospital: comparative analysis of concern-raising behaviors, preliminary model, and agenda for international collaborative research to inform practice. Ethn Health, 16: 405-21.
- [16] Arora NK (2003) Interacting with cancer patients: the significance of physicians' communication behaviour. Soc Sci Med 57: 791-806.
- [17] Chambers SK, Girgis A, Occhipinti S, Hutchison S, Turner J, Morris B, Dunn J (2012) Psychological distress and unmet supportive care needs in cancer patients and carers who contact cancer helplines. Eur J Cancer Care 21: 213–23.
- [18] Beach MC, Duggan PS, Cassel CK, Geller G (2007) What does 'respect' mean? Exploring the moral obligation of health professionals to respect patients. J Gen Intern Med. 22: 692-5.
- [19] Dickert NW (2009) Re-examining respect for human research participants. Kennedy Inst Ethics J 19: 311-38.
- [20] Dickert NW, Kass NE (2009) Understanding respect: learning from patients. J Med Ethics 35: 419-23.
- [21] Purnell L (1999) Panamanians' practices for health promotion and the meaning of respect afforded them by health care providers. J Transcult Nurs 10: 331-9.
- [22]Macklin R (2003) Dignity is a useless concept. Brit Med J 327: 1419-20.
- [23]Mead N, Bower P, Hann M (2002) The impact of general practitioners' patient-centredness on patients' post-consultation satisfaction and enablement. Soc Sci Med. 55: 283-99.
- [24] Beach MC, Roter DL, Wang N-Y, Duggan PS, Cooper LA (2006) Are physicians' attitudes of respect accurately perceived by patients and associated with more positive communication behaviors? Patient Educ Couns 62: 347–54.
- [25] Saunders CL, Abel GA, Lyratzopoulos G (2015) Inequalities in reported cancer patient experience by socio-demographic characteristic and cancer site: evidence from respondents to the English Cancer Patient Experience Survey. Eur J of Cancer Care 24: 85-98.

- [26] Department of Health, National Cancer Patient Experience Survey, 2012-2013 [computer file] (2013), UK Data Archive [distributor]: Colchester, Essex. SN: 7400, http://dx.doi.org/10.5255/UKDA-SN-7400-1.
- [27] Quality Health (2013) Cancer Patient Experience Survey 2013. National Report: 1–167. https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013national-cancer-patient-experience-survey-reports/301-2013-national-cancer-patientexperience-survey-programme-national-report/file. Accessed 2 September 2015.
- [28] Bone A, Mc Grath-Lone L, Day S, Ward H (2014) Inequalities in the care experiences of patients with cancer: analysis of data from the National Cancer Patient Experience Survey 2011–2012, Brit Med J Open 4: e004567.
- [29] Lyratzopoulos G, Elliott M, Barbiere JM, Henderson A, Staetsky L, Paddison CJ, Campbell J, Roland M (2012) Understanding ethnic and other socio-demographic differences in patient experience of primary care: evidence from the English General Practice Patient Survey, Brit Med J Qual Saf 21: 21-9.
- [30] Mead N, Roland M (2009) Understanding why some ethnic minority patients evaluate medical care more negatively than white patients: a cross sectional analysis of a routine patient survey in English general practices, Brit Med J 339: b3450.
- [31] Clarke S, Booth L, Velikova G, Hewison J, Social support: gender differences in cancer patients in the United Kingdom, Cancer Nurs 29: 66–72.
- [32] Davey MP, Kissil K, Niño A, Tubbs CY (2010) "They Paid No Mind to My State of Mind": African American Breast Cancer Patients' Experiences of Cancer Care Delivery, J Psychosoc Oncol 28: 683-98.
- [33] Goldstein E, Elliott MN, Lehrman WG, Hambarsoomian K, Giordano LA (2009)
 Racial/ethnic differences in patients' perceptions of inpatient care using the HCAHPS survey,
 Med Care Res Rev 67: 74-92.
- [34] Maslach C, Schaufeli WB, Leiter MP (2001) Job burnout, Annu Rev Psychol 52: 397–422.
- [35] Van Ryn M, Burke J (2000) The effect of patient race and socio-economic status on physicians' perceptions of patients. Soc Sci Med 50: 813-28.

- [36] NHS executive (2001) Guidance on Commissioning Cancer Services Improving Outcomes in Upper Gastro-intestinal Cancers. Crown copyright: Department of Health, London. http://www.wales.nhs.uk/sites3/documents/362/UpperGIGuidance.pdf. Accessed 2 September 2015.
- [37] Moore PM, Rivera Mercado S, Grez Artigues M, Lawrie TA (2013) Communication skills training for healthcare professionals working with people who have cancer, Cochrane Database Syst Rev 28: CD003751.

			Unadjusted associations		Multivariable model 1, N = 33812		
Background variables	N	% "always"	OR 95% CI		OR	95% CI	
Gender			-		-		
Males	19237	84.4	1		1		
Females	24644	82.3	.86	.82; .91***	.76	.71; .82***	
Age	43469	^a 65.8; 63.8	1.01	1.01; 1.01***	1.02	1.01; 1.02***	
Sexuality		,		,		,	
Heterosexual	40718	83.3	1		1		
Not heterosexual	577	79.4	.77	.63; .94*	.84	.67; 1.05	
Prefer not to answer	1360	80	.80	.70; .92**	.81	.69; .95**	
Employment status							
Employed	12115	81.8	1		1		
Not employed	31258	83.8	1.15	1.15 1.09; 1.22***		1.01; 1.17*	
Race/ethnicity							
White	41911	83.6	1		1		
Mixed	229	78.2	.70	.51; .96*	.77	.54; 1.10	
Asian or Asian British	771	73.7	.55	.47; .65***	.57	.47; .69***	
Black or Black British	586	80.4	.80	.66; .99*	.95	.74; 1.23	
Chinese or other	199	71.4	.49	.36; .67***	.51	.37; .72***	
Longstanding condition							
No long-standing condition	27137	84.2	1		1		
Sensory impairment ^b	2986	85.7	1.13	1.01; 1.26*	1.01	.90; 1.14	
Long-standing physical condition	4604	80.3	.77	.71; .83***	.76	.70; .84***	
Learning disability	124	83.1	.92	.58; 1.48		.55; 1.51	
Mental health condition	779	77.4	.64	.54; .76***	.66	.55; .79***	
Long-standing illness	5789	81.4	.82	.76; .88***	.80	.74; .87***	
Cancer type							
Colorectal/Lower gastrointestinal	6778	81.9	1		1		
Lung	2784	82.7	1.06	.94; 1.19	1.22	1.07; 1.40**	
Urological	5730	82.5	1.04	.95; 1.14	1.02	.91; 1.13	
Breast	10761	84.6	1.21	1.12; 1.31***	1.54	1.39; 1.70***	
Head and Neck	1989	84.1	1.16	1.02; 1.33*	1.32	1.13; 1.53**	
Gynaecological	3000	82.1	1.01	.90; 1.13	1.29	1.13; 1.48**	
Skin	1208	87.8	1.59	1.32; 1.91***	1.60	1.31; 1.97***	
Prostate	2457	84.3	1.18	1.04; 1.34**	1.12	.97; 1.30	
Haematological	5283	84.4	1.20	1.09; 1.32***	1.48	$1.32; 1.66^{***}$	
Opper gastrointestinai	2700	81.3	.96	.85; 1.07	1.06	.93; 1.21	
Time since 1st treated for someon	2501	80.9	.93	.83; 1.05	1.25	1.09; 1.44***	
Time since 1st treated for cancer	22769	Q.4	1		1		
< 1 year	32768	84	1	77. 07***	1 07	91. 04***	
1-5 years	0430 2545	81.2 70.8	.02	.//, .0/***	.0/ 70	.01, .94***	
Cancon nonnan to treatment	2343	17.0	.13	.00, .03	./0	.07, .07	
Full response	18024	86.5	1		1		
Not full or no response	10734	80.5 80.8	1	62. 70***	1 68	63. 71***	
Not certain	12237	70 8	.00	.02, .70	.00	57. 66***	
Nagalkarka D2	10075	17.0	.02	.50, .00	031		
Nageikerke R-					.031		

Table 1. Background characteristics of participants, univariable analyses examining associations between background characteristics and reported respect with unadjusted odds ratios (ORs), multivariable analyses examining background characteristics simultaneously with adjusted ORs (model 1).

Note. N indicates the number of respondents in each subgroup who answered the respect question and % "always" the percentage of respondents within each subgroup who reported always being treated with respect. ^aMeans for "always" (SD = 12.44) vs. "not always" (SD = 13.10). Similar findings were observed when age was grouped into age bands. ^bRefers to deafness or severe hearing impairment, blindness or partial sight. ^cRarer Cancers, includes brain/central nervous system and sarcoma.

* $p \le 0.05$, ** $p \le 0.01$, *** $p \le 0.001$. Nagelkerke R² is a pseudo R² statistic that indicates the approximate variance in the outcome accounted for by the predictors.

Table 2. Associations between reported respect and patient-reported autonomy-supportive and caring/emotionally sensitive behaviours from hospital staff: descriptives, univariable analyses with unadjusted odds ratios (ORs), and hierarchical multivariable analyses to predict reported respect adjusting for background characteristics, with adjusted ORs.

		Unadjusted associations		Model 2, N = 33812		Model 3, N = 34721		Model 4, N = 32721		
Predictors	Ν	% "always"	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Autonomy-supportive behaviours										
Involved in decisions										
Yes, definitely	31466	89.6	1		1				1	
Yes, to some extent	9648	70.1	.27	.26; .29***	.33	.31; .35***			.62	.57; .68***
No, but I would like to have been more	1972	51	.12	.11; .13***	.20	.18; .23***			.58	.49; .67***
involved										
Provision of information										
Right amount	38034	86.3	1		1				1	
Not enough	4000	56.4	.21	.19; .22***	.43	.39; .47***			.80	.72; .90***
Too much	950	80.3	.65	.55; .76***	.69	.57; .84***			.82	.65; 1.02
Caring/emotional sensitive behaviours										
Talked to as if not there										
No	33763	89.9	1				1		1	
Yes, often	1577	69.1	.25	.23; .28***			.41	.35; .49***	.42	.35; .51***
Yes, sometimes	8758	60	.17	.16; .18***			.35	.32; .37***	.37	.34; .40***
Given privacy										
Yes, always	37206	89.3	1				1		1	
Yes, sometimes	5877	55.8	.15	.14; .16***			.36	.33; .40***	.39	.36; .43***
No	1564	43.2	.09	.08; .10***			.30	.26; .35***	.32	.28; .38***
Discuss worries/fears										
As much as wanted	24728	93.6	1				1		1	
Most or some of the time	12376	65.1	.13	.12; .14***			.27	.25; .30***	.30	.28; .33***
Not at all, but would have liked to	1313	33.7	.04	.03; .04***			.15	.12; .17***	.18	.15; .22***
No worries or fears	6229	88.7	.54	.49; .59***			.63	.56; .71***	.67	.59; .75***
Did everything to control pain										
All the time	32559	89.6	1				1		1	
Some of the time	5312	48.1	.11	.10; .11***			.22	.21; .24***	.24	.22; .26***
Not at all	493	21.3	.03	.03; .04***			.09	.07; .13***	.10	.08; .14***
No pain	6566	84.9	.65	.60; .70***			.61	.55; .68***	.63	.56; .70***
Way told about cancer										
Done sensitively	37557	86.2	1				1		1	
Should have been done a bit more sensitively	4842	70.7	.39	.36; .41***			.74	.67; .81***	.84	.76; .93**

Should have been done a lot more sensitively	2189	62.3	.26	.24; .29***		.62	.55; .72***	.72	.62; .83***
Nagelkerke R ²¹					.135 (step 1); .148	.388 (s	tep 1); .390	.395 (s	step 2); .397 (step 3)
					(step 2)	(step 2)		

Note. $*p \le 0.05$, $**p \le 0.01$, $***p \le 0.001$. In model 2, autonomy-supportive behaviours entered at step 1 and background variables at step 2. In model 3, caring/emotionally sensitive behaviours entered at step 1 and background variables at step 2. In model 4, autonomy-supportive behaviours entered at step 1, caring/emotionally sensitive behaviours at step 2 and background variables at step 3.

	Model 2, $N = 33812$		Model	3, N = 34721	Model 4, N = 32721		
Predictors	OR	95% CI	OR	95% CI	OR	95% CI	
Background variables							
Gender							
Males	1		1		1		
Females	.78	.72; .85***	.94	.86; 1.03	.92	.84; 1.01	
Age	1.01	1.01 1.01; 1.01***		1.00; 1.00	1.00	1.00; 1.00	
Sexuality							
Heterosexual	1		1		1		
Not heterosexual	.80	.62; 1.03	.95	.71; 1.28	.93	.68; 1.26	
Prefer not to answer	.81	.68; .97*	1.08	.88; 1.32 ^{e-h}	1.03	.83; 1.27 ^{e-h}	
Employment status							
Employed	1		1		1		
Not employed	1.03	.95; 1.12°	1.01	.93; 1.11 ^{f-i}	.98	.89; 1.08	
Race/ethnicity							
White	1		1		1		
Mixed	.91	.61; 1.36	.91	.58; 1.43	.99	.62; 1.59	
Asian or Asian British	.59	.48; .73***	.84	.66; 1.07	.83	.64; 1.07	
Black or Black British	1.09	.82; 1.44	1.28	.93; 1.77	1.32	.95; 1.84	
Chinese or other	.64	.43; .95*	.67	.43; 1.03	.72	.45; 1.15 ^{e,h}	
Longstanding condition							
No long-standing condition	1		1		1		
Sensory impairment ^a	1.02	.89; 1.17	1.11	.96; 1.28	1.12	.96; 1.30	
Long-standing physical condition	.82	.74; .90***	.93	.84; 1.04	.96	.85; 1.07 ^h	
Learning disability	1.25	.67; 2.34	1.11	.60; 2.10	1.67	.80; 3.47	
Mental health condition	.72	.58; .89**	.78	.61; .99*	.79	.62; 1.01	
Long-standing illness	.85	.77; .93***	.91	.82; 1.01	.93	.84; 1.04 ^e	
Cancer type							
Colorectal/Lower gastrointestinal	1		1		1		
Lung	1.27	1.10; 1.47**	1.13	.96; 1.34 ^e	1.16	.98; 1.38	
Urological	1.20	1.07; 1.35** ^d	1.08	.94; 1.23	1.14	.99; 1.31 ^e	
Breast	1.53	1.37; 1.71***	1.02	.90; 1.16	1.07	.94; 1.22	
Head and Neck	1.36	1.16; 1.60***	1.08	.89; 1.30 ^{f,g}	1.11	.92; 1.35	
Gynaecological	1.36	1.18; 1.58***	1.00	.85; 1.18 ^{e,f}	1.02	.86; 1.23	
Skin	1.58	1.26; 1.98***	1.06	.83; 1.35	1.07	.83; 1.38	
Prostate	1.03	.88; 1.20	.94	.79; 1.13	.90	.75; 1.07	
Haematological	1.51	1.33; 1.71***	1.20	1.04; 1.38**	1.23	1.06; 1.42**	
Upper gastrointestinal	1.10	.95; 1.26	1.09	.93; 1.29	1.08	.92; 1.28	
Other ^b	1.44	1.24; 1.68***	1.09	.92; 1.30 ^f	1.17	.97; 1.39	
Time since 1st treated for cancer							
< 1 year	1		1		1		
1-5 years	.88	.81; .96**	.95	.86; 1.04	.94	.86; 1.04	
> 5 years	.82	.72; .95**	.88	.76; 1.03	.92	.78; 1.08 ^e	
Cancer response to treatment							
Full response	1		1		1		
Not full or no response	.82	.75; .89***	.96	.88; 1.05	.98	.89; 1.08	
Not certain	.79	.73; .85***	.85	.78; .93***	.88	.81; .97**	

Table 3. Explaining differences in reported respect by socio-demographic and clinical characteristics: Hierarchical multivariable analyses examining the role of autonomy-supportive behaviours and caring/emotionally sensitive behaviours (models 2-4), with adjusted ORs.

Note. *p≤0.05, **p≤0.01, ***p≤0.001

In model 2, autonomy-supportive behaviours entered at step 1 and background variables at step 2. In model 3, caring/emotionally sensitive behaviours entered at step 1 and background variables at step 2. In model 4, autonomy-supportive behaviours entered at step 1, caring/emotionally sensitive behaviours at step 2 and background variables at step 3.

^aRefers to deafness or severe hearing impairment, blindness or partial sight. ^bRarer Cancers, includes brain/central nervous system and sarcoma.

^cBecame non-significant after adding "involved in decisions" or "provision of information"; ^dBecame significant after adding "involved in decisions"; ^eBecame non-significant after adding "talked as if not there"; ^fBecame non-significant after adding "given privacy"; ^gBecame non-significant after adding "able to discuss worries or fears"; ^hBecame non-significant after adding "staff did everything to control pain"; ⁱBecame non-significant after adding "way told about cancer"