Research paper

Equal rights, equal respect: an examination of differential inpatient experience in the NHS

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What is known on this subject
- Reports from inpatient surveys indicate that, overall, most patients feel treated with dignity and respect.
- Members of certain minority groups are less likely to report that they were treated with dignity and respect while in hospital.
- There are gaps in knowledge about care experience in relation to some minority groups.

What this paper adds
- Young women, those from mixed and South Asian backgrounds, gay/lesbian women and those with a mental health condition are particularly negative about their treatment.
- The extent of negative patient experiences varies widely between hospital trusts.
- In adapting to a changing patient population, services need to become more culturally inclusive.
- Improvement should be focused on the groups identified in this paper.

ABSTRACT

In the National Health Service (NHS), patients' experiences of care episodes in acute hospital trusts are measured through the NHS patient survey programme. These surveys use large samples of patients and include questions about 'protected characteristics' as set out in the Equalities Act 2010.

Data were examined for one item in the 2011 Inpatient Survey measuring treatment with dignity and respect. They were analysed using multilevel regression models, incorporating 'hospital trust' as a random effect. Patient characteristics were entered as fixed main effects, and then as two-way interactions. The effect of allowing slope coefficients to vary for these characteristics was investigated.

More negative reported experience of being treated with respect and dignity was associated with several demographic categories, including younger people, women, those affiliated with no or 'another' religion, gay/lesbian or bisexual individuals, those who did not disclose their religion or sexual orientation, specific ethnicities and certain chronic conditions. There were significant interactions between gender and other background variables, including age, sexual orientation, ethnicity, religious affiliation and certain chronic conditions. Random slope models suggested large hospital-trust-level variation in the experience of certain groups.

The results align with previous findings but are of particular interest in relation to religion and sexuality, for which data have hitherto been unavailable. However, the extent to which these reported differences might be due to differential expectations, reporting behaviours or discrimination is not clear. The results provide a starting point from which providers can analyse practices to identify where they might give rise to differences in treatment with dignity and respect.

Keywords: chronic disease, culture, gender, inequalities, patient experience, sexuality

Introduction

There is a duty on public bodies in England, Wales and Scotland to consider how their activities and decisions affect people from specific demographic groups. Consolidating earlier legislation, the Equalities Act (2010) specifies these groups in terms of nine *protected characteristics* that, individually or together, must not be a basis for less favourable treatment. These characteristics are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, gender and sexual orientation. The Act imposes an obligation on public bodies, such as the National Health Service (NHS), to demonstrate and promote equality in terms of access to services, treatment, care and patients' experiences care. The past decade has seen patient experience and patient-centred care feature more prominently in the healthcare agenda. 'Ensuring that people have a positive experience of care' now comprises one of five domains in the NHS Outcomes Framework (Department of Health, 2011). In England, this is measured, *inter alia*, through the NHS patient experience survey programme which was introduced in 2002 and is among the largest of such programmes internationally. The programme consists of a series of postal surveys which are sent out regularly to large representative samples of service users of all NHS providers of acute and mental health services; the results inform government, commissioners, providers, regulators and the public. Surveys within the programme collect a range of demographic information on respondents, and are therefore an important tool for monitoring equality of patient experience.

It is already clear that demographic groups give different reports of their experiences of healthcare. Various studies, both in the UK and internationally, have identified differential experiences associated with a variety of patient characteristics or backgrounds (Young *et al*, 2000; Healthcare Commission, 2006; Wolf *et al*, 2012; Department of Health, 2009). Specifically in relation to the NHS Inpatients Survey, Sizmur (2011) documented more negative reported experience in various domains for women, patients in the youngest and oldest age groups, and those in certain minority ethnic groups.

Until recently, several gaps in the demographic information collected with national patient experience data prevented a thorough assessment of potential inequalities across the protected characteristics. From 2011, the NHS Inpatient Survey has asked patients about their sexual orientation and religious beliefs, but three of the protected characteristics are still not included, namely gender reassignment, marital/partnership status, and pregnancy or maternity. In fact, women admitted to hospital for management of a pregnancy were excluded from the survey.

Being treated with dignity and respect is a central element of patient-centred care, and has consistently featured in frameworks of the most important aspects of patient experience. 'Respect for the patient' is listed among the 'essential requirements of care' in the National Institute for Health and Clinical Excellence (2012) clinical guidelines on patient experience, while the NHS Patient Experience Framework (itself based on the Picker Institute's *principles of patient-centred care*) (Gerteis *et al*, 2002) requires 'respect for patient-centred values, preferences, and expressed needs, including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making' (Department of Health, 2011). Being treated with dignity and respect was also identified by Picker Institute Europe as one of the core domains of acute inpatient experience (Sizmur and Redding, 2009). It is a good predictor of overall satisfaction with inpatient care (Sizmur and Redding, 2009; Dickert and Kass, 2009; Beach *et al*, 2005). Moreover, there is evidence that being treated with respect may make a positive contribution to the outcome of treatment (Dickert and Kass, 2009; Beach *et al*, 2005). Recognising the unconditional value of patients as people appears to be an important aspect of respect from the patient's viewpoint (Dickert and Kass, 2009; Beach *et al*, 2007). In particular, it has been emphasised that the respect owed to patients in the healthcare system is independent of their personal characteristics (Beach *et al*, 2007). However, recent reports indicate that treatment with dignity and respect is not always a strong feature of patient care, particularly in the care of older patients (Care Quality Commission, 2012). One contributing factor seems to be that health services have not kept pace with the increasing number of older service users; older people's needs and circumstances do not fit well into standardised care protocols, leading to a 'right place, wrong patient' attitude on the part of staff (Tadd *et al*, 2011). The presence of dementia appears to be a specific trigger for discriminatory behaviour towards older people (Baillie and Matiti, 2013). Similarly, there is international evidence that health services regard young people as generally healthy, rather than as having particular health issues, and that they do not make age-appropriate adjustments for younger patients' health needs (World Health Organization, 2002).

With regard to other demographic groupings, evidence from the UK is more limited (Whitehead and Wheeler, 2008). However, research has uncovered lack of dignity and respect towards gay, lesbian and bisexual patients. A particular problem is that clinicians may ignore disclosures of patients' sexual orientation and continue to assume heterosexuality. Being unsure of how their disclosure will be treated, other patients decline to 'come out' (Hunt and Fish,

2008). Questions asked of patients by healthcare staff about contraceptive use may be perceived as degrading (Baillie and Matiti, 2013). Although prejudice against people with a disability, including mental health problems, appears to have declined, stigmatisation and differential treatment of those with an intellectual disability persist in the healthcare system (While and Clark, 2010). In the USA, it has been found that racial and ethnic minorities are more likely to perceive lack of cultural competence on the part of health service providers (Johnson *et al*, 2004).

Currently, most NHS patient surveys include an item that measures respect and dignity, and it was this that was identified as an important single-item domain in the Picker Institute's analysis (Sizmur and Redding, 2009). It would seem to be a good potential indicator of the extent to which individuals feel that differences and values are respected in a range of healthcare contexts. The aim of the study presented here was to analyse data for this domain with regard to the demographic information collected in the survey. There was a particular emphasis on the newly added categories of sexual orientation and religious affiliation, and on interactions between demographic groupings, but all potential differences were of interest. In each case, the null hypothesis was that the population reported no differences with regard to respect and dignity. A subsidiary research question contingent on rejection of the null hypothesis was how much variability in experience was due to differences between providers and how much was due to differences in the distribution of demographic groups within trusts.

Methods

Data

Data were derived from the national data set of the 2011 NHS Inpatients Survey of 161 acute hospital trusts. This is a postal survey that follows a standard methodology, with two reminders. The survey is sent out annually to a representative sample of patients in every acute hospital trust, for the purpose of measuring national and trust performance on various indicators of patient experience, and for informing quality improvement work within the system. The 2011 NHS Inpatients Survey was granted a favourable opinion by the National Research Ethics Service (NRES) Committee North West (Haydock), Research Ethics Committee (REC) reference 01/8/090.

Further details of the methodology can be found in Reeves and Seccombe (2008). Questionnaires were sent out to 850 eligible patients in each trust, and there were 70 863 validated responses (an overall response rate of 53%). Patient consent to participate was confirmed by completion of a questionnaire. Data were processed so as to ensure that none of the respondents were identifiable.

The research reported here was based on a secondary analysis of these existing data.

Response options for categorical questionnaire items were scaled from 0 to 100 for analysis, with 100 representing the most positive experience and 0 the most negative experience in relation to the question. The target variable was scored responses ($n = 68\,492$) to the question '*Overall, did you feel you were treated with respect and dignity while you were in the hospital?*' (see Figure 1). This item was highly correlated with an item measuring overall satisfaction with care in the sample (Pearson's $r = 0.68$). Demographic indicators available from the survey in relation to the protected characteristics are listed in Table 1. Generally, these were derived from patient responses in the final section of the questionnaire, although, in the case of age and gender, data supplied by the participating trust were substituted if the patient response was missing. In the case of age, the subdivisions were created with a view to examining the extremes of the range while maintaining sufficient numbers for analysis. Previous analysis has suggested that these ages represent disjunctions in the otherwise positive monotonic relationship between age and reported experience (Sizmur, 2011). Because not all of the respondents provided demographic information, these categories do not sum to the total number of responses.

> Overall, did you feel you were treated with respect and dignity while you were in the hospital?
>
> 1 ☐ Yes, always   score 100
>
> 2 ☐ Yes, sometimes   score 50
>
> 3 ☐ No   score   0

Figure 1 Item wording and scoring for target variable.

Table 1 Demographic indicators in the survey*

Characteristic	Subgroup	n	%
Age	< 20 years	953	1.4
	≥ 80 years	14 028	19.9
	20–79 years (reference group)	55 500	78.7
Gender	Female	37 771	53.6
	Male (reference group)	32 710	46.4
Disability	Deafness/severe hearing impairment	8343	12.9
	No hearing impairment (reference group)	56 492	87.1
	Blindness/partial sight	2909	4.5
	No sight impairment (reference group)	61 926	95.5
	Long-standing physical condition	19 992	30.8
	No physical condition (reference group)	44 843	69.2
	Learning disability	916	1.4
	No learning disability (reference group)	63 919	98.6
	Mental health condition	3199	4.9
	No mental health condition (reference group)	61 636	95.1
	Long-standing illness	19 902	30.7
	No illness (reference group)	44 933	69.3
Ethnic background	Irish	711	1.1
	Gypsy/Irish Traveller	77	0.1
	Other white	1118	1.7
	White and black Caribbean	143	0.2
	White and black African	64	0.1
	White and Asian	167	0.3
	Other mixed	89	0.1
	Indian	888	1.3
	Pakistani	519	0.8
	Bangladeshi	141	0.2
	Chinese	151	0.2
	Other Asian	229	0.3
	African	494	0.7
	Caribbean	514	0.8
	Other black	75	0.1
	Arab	64	0.1
	Other ethnic group	59	0.1
	White British (reference group)	61 223	91.8
Religion	No religion	10 240	14.9
	Buddhist	227	0.3
	Hindu	580	0.8
	Jewish	355	0.5
	Muslim	1315	1.9
	Sikh	337	0.5
	Other	706	1.0
	Prefer not to say	956	1.4
	Christian (reference group)	53 783	78.5
Sexual orientation	Gay/lesbian	506	0.8
	Bisexual	253	0.4
	Other	538	0.8
	Prefer not to say	2714	4.1
	Heterosexual/straight (reference group)	61 647	93.9

* Demographic variables have different base numbers as not every respondent answered every question.

An important consideration when analysing data of the kind considered here is how to treat missing or non-informative responses such as 'prefer not to say' (or, in some cases, 'other'). The meaning of such responses in terms of the underlying variable being measured is unclear. Aspinall (2009) shows that respondents who choose 'prefer not to say' include those who do not wish to disclose, those who cannot identify an appropriate response category applicable to themselves, and those who object to being labelled. Common solutions in other contexts would include either removing the cases from analysis or imputing values based on modal or other information, or strategies such as 'hot-deck' replacement (Andridge and Little, 2010). In this study, neither of these approaches appeared desirable, and the least bad option seemed to be to treat such data as a specific response category despite their lack of homogeneity.

Analysis

The data were analysed in a series of regression models, with the 'dignity and respect' item score as the dependent variable, and with the demographic indicators as independent variables (see Table 1). When predictors are nominal in nature (as here), the regression coefficient can be interpreted as the mean difference on the independent variable associated with presence of that characteristic compared with its absence, while controlling for other characteristics.

Initially, the model was implemented as an ordinary linear regression at the individual respondent level. This included only main effects for each demographic indicator. Ordinary regression has the disadvantage that it takes no account of the clustering of data within NHS trusts, giving rise to potentially misleading results when the impact of clustering is significant (Goldstein, 1999). The fit of this model (–2.loglikelihood) was therefore compared with that for the equivalent two-level variance components model, with 'trusts' as a random effect at level 2 and the demographics as fixed effects at level 1. Two-level models provide estimates of the extent to which patient experience varies within trusts, rather than primarily being driven by the concentration of particular groups at good or poor trusts (Lyratzopoulos *et al*, 2012). As the improvement in fit was statistically significant, all further analyses were conducted using two-level models. However, the proportion of variance accounted for by the second level was small (1.6%).

The Equalities Act is framed in terms of main effects and two-way interactions between the protected characteristics. Interaction terms were therefore each tested separately by entering them in the model while monitoring their effect on model fit. Their impact was categorised as significant ($P < 0.01$), marginally sig-

nificant ($0.01 \leq P < 0.05$) or non-significant ($P \geq 0.05$). The interactions were then evaluated according to whether they contributed to the model, whether there was a clear case for including them to aid model interpretation, and whether there were sufficient cases in all combinations to provide estimates of model coefficients. As a result, certain main effects were replaced by interactions (i.e. were subdivided) in subsequent models, with the reference categories chosen to reflect majority groups. Proxy response categories were included in the final model as control variables, in order to eliminate these as a potential alternative explanation for differential response.

It was possible that the extent of differential experience among the subgroups might vary between trusts. This would be the case, for example, if women patients reported no difference in treatment from men in some trusts and very different experience in others. A random slopes model allows for this by estimating the level 2 variation in a given effect. Terms in the model were therefore tested one by one to determine whether overall model fit could be improved by setting their coefficients to random at level 2. Where this was the case, large level 2 variance indicated large variability between trusts in the extent of differential experience.

All of the models were fitted using MLwiN version 2.2 (Rasbash *et al*, 2012). Tables of parameter estimates and other model information are available from the corresponding author on request.

Results

For main effects, the two-level variance components model was a better fit to the data than the ordinary regression model ($P < 0.001$), indicating clustering effects in the data. This suggested that to some extent the relatively good/poor experience of certain main groups was due to their being over-represented in relatively high/low-performing trusts. Two-level models were then implemented to account for this between-trusts effect. The intercept for the null two-level model with no predictors (an estimate of the unadjusted 'respect and dignity' score for the sample as a whole) was 88.1/100. With main effects for the demographic variables added, this changed to 93.8/100. The main effect coefficients relative to this value for the two-level model (with 95% confidence intervals) are illustrated in Figure 2.

These results show a distinctly more negative experience of being treated with respect and dignity for a number of demographic categories, including younger people, women, those who associated with no or 'other' religion, gay/lesbian or bisexual individuals, those who chose not to disclose their religion or sexual orientation, specific ethnic groups (primarily mixed
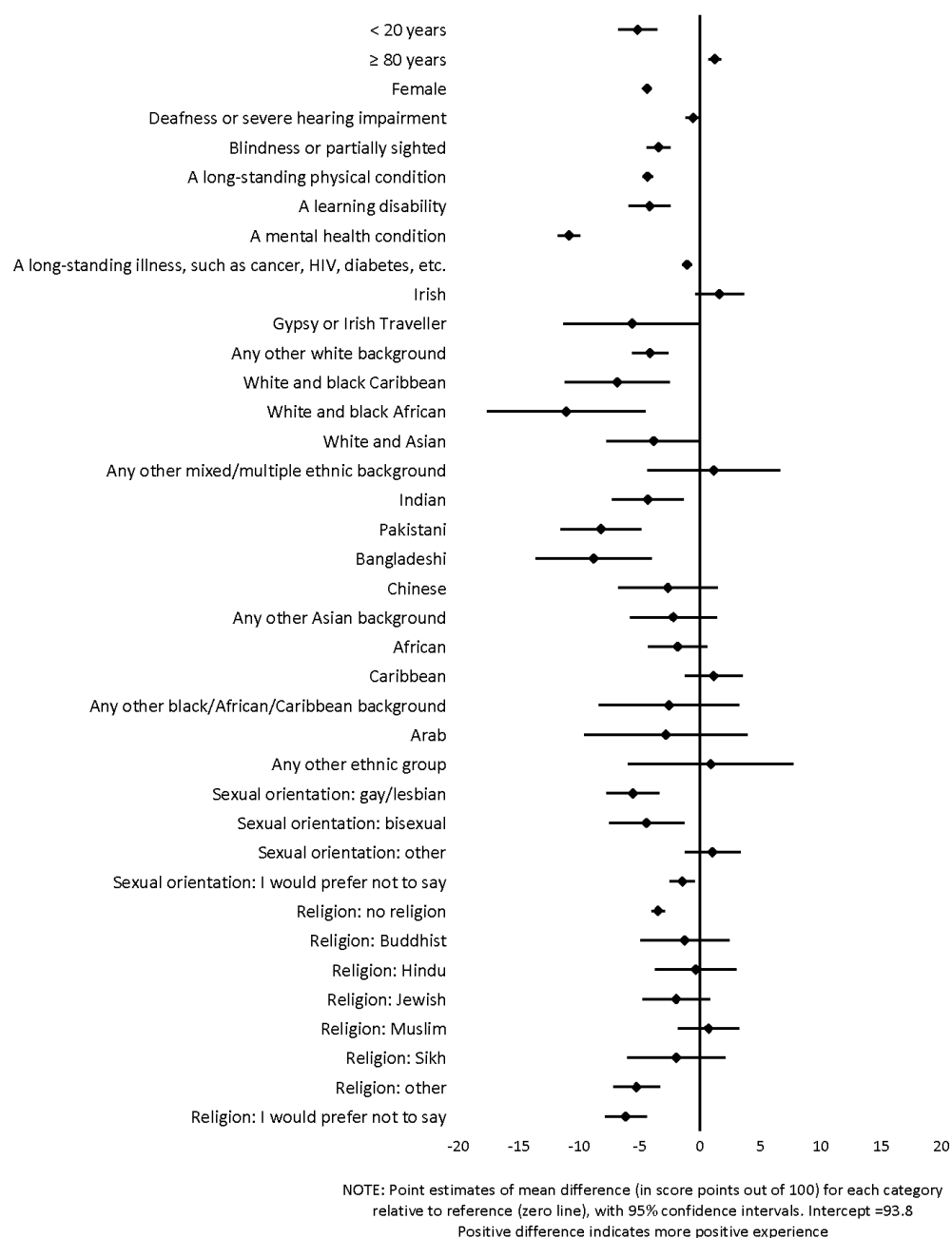
NOTE: Point estimates of mean difference (in score points out of 100) for each category
relative to reference (zero line), with 95% confidence intervals. Intercept =93.8
Positive difference indicates more positive experience

Figure 2 Main effects in variance components model.

and Asian categories) and those with specific chronic conditions (particularly mental health conditions, where results were on average more than 10 points below those for people without a chronic condition). Only those aged $\geq$ 80 years reported a significantly more positive experience than their reference. The results of preliminary testing for two-way interactions are available on request.

As a result of this assessment, main effects for 'age', 'sexual orientation', 'religion' and 'mental health condition' were subdivided by 'gender' in subsequent models. The model estimates for the variance components model including these interactions, and adjusting for proxy response compared with the patient unaided, are shown in Figure 3.

As with the main effects, these results reveal less positive reported experience for women, particularly in the youngest age group, but also now in the oldest group. The results for the religious groupings also reflect those for the main effects, but women with no religious affiliation reported more negative experience than men with no religious affiliation. Similarly, lesbians
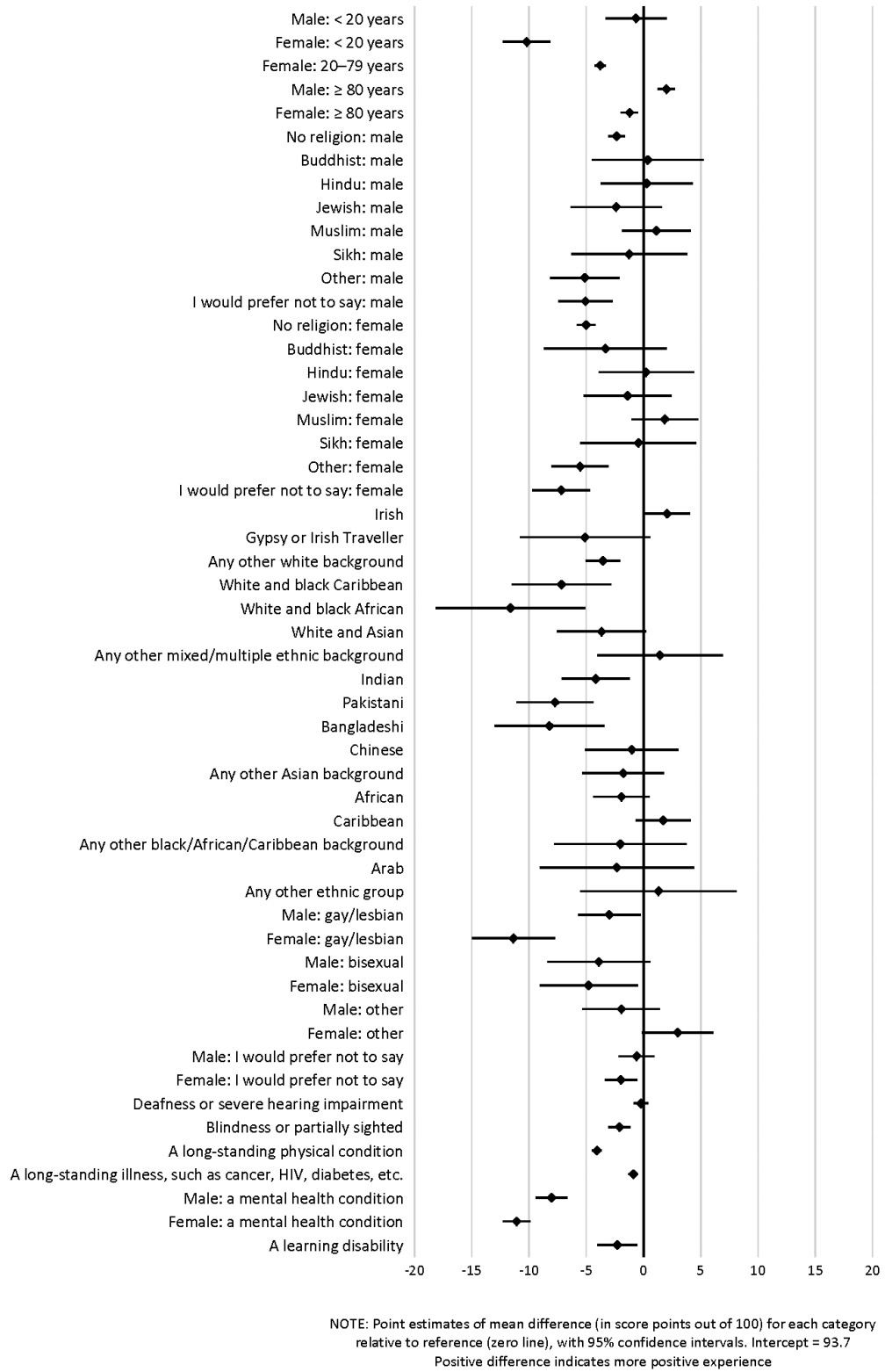
NOTE: Point estimates of mean difference (in score points out of 100) for each category relative to reference (zero line), with 95% confidence intervals. Intercept = 93.7
Positive difference indicates more positive experience

Figure 3 Main and interaction effects in variance components model.

Table 2 Variance estimates for model random slopes

Variable	Variance	Standard error
Female: < 20 years	71.8	26.6
Female: 20–79 years	2.6	1.0
No religion: female	3.1	2.8
Other: female	145.0	44.9
I would prefer not to say: female	163.5	47.0
I would prefer not to say: male	69.2	31.6
Any other white background	51.7	16.3
White and black Caribbean	264.3	105.7
White and Asian	65.3	56.0
Indian	30.5	16.1
Pakistani	31.1	21.3
Bangladeshi	221.6	100.8
Any other black background	185.2	123.5
Female: gay/lesbian	373.3	103.3
Female: bisexual	274.9	105.6
Female: I would prefer not to say	29.7	11.9
A long-standing physical condition	2.0	1.0
Male: a mental health condition	40.0	12.8
Female: a mental health condition	72.5	14.7
A learning disability	122.8	27.6

had more negative experience than gay men, and women with a mental health condition had more negative experience than men with such a condition.

Table 2 shows the estimated variances for the random slope models. These indicate how much the effect associated with predictor variables varied around the mean effects shown in Figure 3. However, the magnitudes of the standard errors show that these variances are generally poorly estimated and should not be relied upon, particularly in relation to small demographic subgroups. Nevertheless, there are a number of areas where the variance was very large, which is suggestive of wide trust-level variation in the extent of differential experience for certain groups, most notably among particular ethnic groups and women of same-sex or bisexual orientation.

Discussion

Many of these results are in line with previous examinations of differential patient experience across a range of domains (Sizmur, 2011; Lyratzopoulos et al, 2012). However, there is now evidence in relation to sexual orientation and religion that has hitherto not been available and, in addition, different experiences were revealed for men and women within each of several groupings. There were particularly striking negative reports about being treated with 'respect and dignity' from young women, women of gay/lesbian orientation and women with a mental health condition. In terms of religion, differences were small except in relation to those of no religious or 'other' religious affiliation and those who preferred not to disclose; in each of these categories, women's responses were generally more negative. In addition, those with Pakistani, Bangladeshi and mixed white and black African

ethnic backgrounds were somewhat less positive about whether they were treated with dignity and respect.

This brings us to the issue of multiple comparisons. Although some have argued very cogently that adjustments for multiple comparisons are unnecessary, inappropriate or even worse (Perneger, 1998), we recognise that this persists as a matter of concern for reviewers. Treating the study purely as a fishing expedition, and all 53 comparisons to the mean in the final model as independent tests, the study-wide error rate of 0.05 can be maintained with a Dunn-Sidak-adjusted comparison-wide alpha of close to 0.001. Even with this very conservative criterion, many of these results (and specifically those commented on here) remain statistically significant. Full details of coefficients and standard errors are available from the corresponding author.

A perennial problem with this type of analysis is whether the differences noted are due to objectively different treatment by the health service because of patients' characteristics, or whether cultural norms or expectations, or indeed reporting behaviours, are different across the different groups, and here the data are silent. This is relevant to whether there is any direct or indirect discrimination. Outside of the legal context, however, it does appear that some particular groups of patients are less likely to report a positive experience of care than others, for whatever reason, and this should be of interest in itself. Read in the context of the wider literature that suggests services are not always responsive or welcoming to minority groups, the suggestion of a deficit in 'respect and dignity' becomes more compelling. Also, some of these groups experience health inequalities (House of Commons Health Committee, 2009), and it is not clear whether these inequalities are linked to reported experience, or whether they constitute a double whammy of disadvantage. There was no 'general health' question in the 2011 survey, although the items reporting long-term or limiting conditions can be expected to act as a reasonable proxy in this analysis.

Throughout this study, patients have been classified as though the groupings have clear-cut boundaries. However, this is not necessarily the case. How people identify with constructs such as 'sexual orientation' and 'ethnicity', or indeed 'gender', can be somewhat fluid. Moreover, whether people decline to answer demographic questions may in itself depend on demographic variables, and there is evidence that some respondents misunderstood the questions and the categories provided (Taylor, 2008). There may also be an element of deliberate misreporting. It has been suggested that, over time, sensitive questions introduced into surveys may become normalised, in which case we might expect to see more accurate reporting and less use of the 'prefer not to say' option in future rounds of the survey (Aspinall, 2009).

The response rate is reasonable for a survey of this kind, but reported experience is nevertheless missing for nearly half of those invited to participate, and there was most probably differential non-response in relation to some of the protected characteristics investigated. This might have introduced an element of bias to some of the results reported here. The very limited demographic data available on non-responders preclude a thorough investigation of this issue. Neither has it been possible to eliminate a number of potential confounding factors, although it was possible to control for the differential use of proxy respondents by some groups. This is an area worthy of further examination in itself, but is beyond the scope of the present investigation.

The implications in terms of action by providers are not completely clear, but the differences reported deserve attention, and we would urge NHS providers to work with their local communities to understand their particular needs, preferences and experiences. The findings reflect a more general theme from the literature on differentiation in healthcare that patients who do not fit mainstream expectations or protocols are regarded as being 'in the wrong place' (Tadd *et al*, 2011). As the demographics of the patient population change, and healthcare resources are reorganised to accommodate future health needs, it is equally important that services become culturally as well as medically inclusive and responsive. Awareness of the specific issues raised here is hopefully a starting point from which practices and procedures can be analysed to see where they might give rise to differential experience. Where trusts have good patient involvement in their decision making, and where this patient involvement reflects a range of perspectives, this should prove helpful in delivering improvements. Chadwick (2012) provides an example of how service users can be involved in refreshing practitioners' skills and values towards upholding the basic rights of patients. This would be an ideal context for action research, with the opportunity to improve not only practice but also understanding of the nature of these reported differences. A particular priority should be the experiences of and the services provided for women who are younger, who are gay/lesbian, or who have mental health conditions, as these groups gave particularly negative reports when asked if they had been treated with respect and dignity.

Limitations of the study

This study (necessarily) suffers from the limitation of rigid demographic categories. Information was not available in relation to gender reassignment, although we would expect the number of people in the inpatient sample to whom this applied to be very small. The

study will be affected by reporting biases as well as non-response biases more generally. Although the questionnaires used to provide the data have been subject to extensive testing, including cognitive testing with people from a range of backgrounds, there is limited evidence specifically on the equivalence of meaning of questions across the different categories of respondent.

Conclusions

This secondary analysis has identified some distinct patterns in inpatients' reported experience of being treated with dignity and respect. Women generally gave less positive reports than men, and this extended across other classifications, such as age, sexual orientation, mental health and religious affiliation. Some of this differential experience was due to higher concentrations of particular demographics within trusts where experience was generally less positive, although this effect was small. There was also variation between trusts in the extent to which the experiences of particular groups differed. The reasons for the reported differences are not clear, and NHS trusts are urged to explore differential experiences and needs with their local communities in order to tackle reported inequalities.

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CONFLICTS OF INTEREST

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