

‘In their own words’: Capturing the voices of older women from Black and minority ethnic (BME) backgrounds in order to understand their perceptions of dignity and care with dignity, with a focus on social care

Summary Report – SCRA1012

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Introduction

Research evidence indicates the need for studies that explore the salience of dignity from older people's perspectives, and that capture what care with dignity means to them. In order to capture the expectations and experiences of older women, the research team worked with community researchers (CRs) to record the views of older Black and minority ethnic (BME) women, producing digital stories and pictures, and an analysis of the data gathered via the interviews. Also important in building the picture of care expectations and experiences were the perceptions of providers of social services that were gathered via an all-Wales survey.

Study aims

1. To contribute to current conceptual and theoretical debates on dignity in social care relations
2. To capture the perceptions of dignity, and care expectations of older, community dwelling women, with a focus on those aged 50 and older
3. To explore service providers' perceptions of dignity, and of the care experiences and expectations of older women of minority ethnic backgrounds, and to identify the resources available for them to draw on.

Methods

Survey of service providers

A survey design was applied using a purpose-developed questionnaire to capture service providers' perceptions. This design is common in studies and evaluations of health and social care services, and was thought to be best suited to measure and compare the views and opinions of service providers in this study. A questionnaire was used to collect data, informed by the literature on good quality of care for older people, by policy documents on dignity in care, and by advisory meetings with stakeholders. Two dignity indicators relevant to caring for older people in community-dwelling settings were addressed: care and support requirements, and effective communication. The questionnaire consisted of 35 questions addressing seven areas:

1. demographics
2. information on respondents' organisations and practices
3. understanding of the concept of dignity
4. perceptions of how older women from BME backgrounds viewed the care or support they received
5. perceptions of how older women from BME backgrounds felt they were understood when talking about their care and support requirements
6. perceived barriers to, and facilitators of, service provision
7. examples of effective practices and services.

The questionnaire was available in online and paper formats. Most questions were closed, with a few open ones allowing respondents to add free text. The content and face validity of the questionnaire were piloted with a group of 12 people who had expertise in older people's issues, questionnaire design or statistics. The questionnaire was refined using feedback received on aspects of its content, readability, flows, layout and technique.

Semi-structured interviews and story-capture with older women

The aim was to capture the immediacy and complexity of real lives, and how the participants interpreted the world and made sense of their place within it. Semi-structured interviews were conducted with participants. Drawing on relevant literatures, the knowledge and experience of the research team (comprising university- and community-based researchers), and reflections on the preliminary engagement work with older women from the selected target groups, an interview schedule was developed and piloted. The interview schedule covered participants':

- experience of growing older
- understanding of dignity (what it was, what it 'looked and felt like')
- ways of acknowledging other people's self-worth
- perceptions of care, experiences of care, and perceptions of 'good' or high-quality care
- views on how needing extra care and support affects their lives and sense of self
- social care needs

- awareness and uptake of sources of social and other support.

A small number of women agreed to have digital stories or pictures produced. These were rooted in their transcripts, developed in partnership with the participants, and captured by two experienced community film companies (StoryWorks and Davies Community Films) that joined the research team.

Sample and sampling

Participants – survey of service providers

People eligible for the study were those in Wales who (i) delivered hands-on care or support to older people (50 years and older) living in their own homes, (ii) supervised others delivering such services, or (iii) managed such services. This included people delivering community-based services, good-neighbour-scheme coordinators/volunteers, reablement/settlement workers, welfare-rights support workers, supported-shopping workers, and those providing domiciliary care. A cascade approach was taken to recruitment. An invitation was circulated via electronic mailing lists, bulletins and newsletters of various key local, regional, and national organisations in contact with older people or with a specific remit to work with BME groups. Other strategies included the use of social media sites and snowballing techniques, where respondents invited their contacts to take part.

Participants – interviews and stories

The primary focus of this study was on views and experiences of older women who self-identified as belonging to the following groups: Black Caribbean (and sub-groups), South East Asian (Chinese), South Asian (Bangladeshi Muslims) and Indian. These groups were targeted based on their comparatively large size, their ageing population structure and the similarities of their recent (post-war) large-scale entry to the UK (Black Caribbean and Indian), comparative levels of deprivation and social exclusion (Bangladeshi Muslims) and the great lack of available research evidence (Chinese). The criteria for inclusion were as follows:

- female

- 55 years of age or older
- self-identifying with one of the identified ethnic minority population groups by upbringing, birth or acculturation
- living in Wales.

Exclusion criteria were as follows:

- lacking mental capacity (as defined by the Mental Capacity Act 2005), such as through head injury, hypoxia or psychiatric history
- too unwell to participate.

The concept of saturation and standard estimates of samples for qualitative studies (above 15 and below 50) guided the sample size; 32 women were interviewed. The sample was generated by (i) purposive and snowball sampling, aided greatly by the research team's extensive network of contacts, and by contacts of advisory group members; and (ii) requests from the research team to BME and targeted 'mainstream' local, regional and national social service organisations, community groups and statutory departments, and to local and regional voluntary sector groups, for help in recruiting participants from their client lists. CRs were employed on a sessional basis and thus access to participants was also gained through the CRs' extensive contacts and social networks. The recruitment model used was one developed in a prior study (Saltus and Folkes, 2013). The study was led in North Wales by the North Wales Race Equality Network (NWREN), which managed all aspects of the data-collection process. This research partnership allowed for a level of access to, and trust from, potential participants and organisations known to the research partner.

Research ethics

Ethical approval to conduct this study was granted by the Ethics Committee of the Faculty of Health, Sport and Science, University of Glamorgan, in July 2011.

Data collection

Survey of service providers

Data were collected between March and June 2012. The Bristol Online Survey website was used to host the survey. A link to the survey site was emailed to organisations and relevant individuals (<https://www.survey.glam.ac.uk/dignitybme>). There was no requirement to log on to the site. Following the initial contact, two reminders were made at four-weekly intervals. A hard copy of the questionnaire was available, in case people preferred to complete it in hard copy or had limited access to a computer. Each copy was accompanied by a freepost envelope with return address. Also, an e-copy was attached to all invitations sent by email.

Interviews and story-capture with older women

The CRs were responsible for organising community workshops/focus groups, developing the data-collection tools, assisting in the purposive and progressive sampling schedule, interviewing, translating (where necessary), and validating transcripts. The study was promoted to cultural, religious, arts and equality organisations understood to be frequented by and of importance to the target groups. The outreach and engagement work conducted at the start of the study meant that recruitment of participants by the CRs did not prove difficult. Data collection took place between February and August 2012. The interviews took place in the homes of the research participants, local community centres and churches, and public areas such as cafes. The stories were audio-recorded with the participants' permission, and lasted between 18 and 100 minutes, with the average taking 48 minutes. All participants were given a token of appreciation, in the form of a £10 gift voucher.

The bulk of the digital and picture stories were produced between November 2012 and March 2013, and were captured by two community film companies, along with the CRs, after two or three meetings with the participants. We have collected seven digital stories to date and expect to collect 15 in total.

Data analysis

Survey of service providers

The quantitative analysis software package IBM SPSS version 19 was used to assist data analysis. Data collected online were imported directly and those collected via paper copies were entered manually. Descriptive statistics were used to describe frequencies and percentages of variables. Where similar questions related to the perceived views of older women from BME backgrounds and of older people in general, responses for the two groups were compared using Wilcoxon tests. Chi-square and Friedman tests were used to compare perceptions of those working in different sectors or different professional roles. Results were considered to be statistically significant at $p < 0.05$ (two-tailed). Some questions related to respondents' experiences of providing care or support to older women from BME backgrounds; all responses received were retained for the analysis, irrespective of the number of such experiences in the previous year, as respondents might have had experiences earlier or be generally aware of the culture they were asked to comment upon. Where respondents did not answer all questions, the remainder of their data was retained to maximize the sample size, with 12.3% of the required responses missing.

Interviews with older women

The interviews were anonymised, translated and transcribed verbatim. The CRs working in languages other than English kept journal entries of any words that did not easily or completely translate into English. A small number of the transcripts were back-translated and checked for consistent in phraseology, content and meaning. The data were analysed according to the methods of thematic analysis. The analysis started with reading the transcripts, and making notes regarding the salient points. In the initial (deductive) phase, the interview data were coded according to a number of a priori categories that corresponded to the core interview questions. The interview data were initially coded according to a number of a priori categories that corresponded to the core interview questions, with the aim being to explore if the categories were supported in the data. In

the subsequent inductive phases, data were coded, and, in so doing, compared with other passages to ensure that the coding was consistent, to explore the need for new codes, and to capture phenomena as they emerged. Themes were then identified. Original transcripts were constantly re-checked to ensure that the themes and thematic patterns accurately reflected the original data. Although one member led the analysis, two members of the research team were involved in testing the acceptability and credibility of the designated categories. The NVivo qualitative analysis software was used to assist in the coding, and in the subsequent thematic grouping process.

Findings

Survey of service providers

A total of 124 responses were received. The majority of the respondents were female from a white background. A large proportion of respondents (n=54) worked in the third sector, followed by the public sector and the private sector. The largest numbers of respondents were involved in providing support, followed by those managing services, supervising others and delivering hands-on care. Respondents from a minority ethnic background comprised 18.6% of the sample, and the majority of these people worked in the third sector.

- *Respondents were asked to list any words or phrases coming to mind when they heard the word 'dignity'. A word-frequency query found that 'respect' was most frequently mentioned, and was communicated or manifested itself through actions and behaviours. Dignity was closely associated with professional conduct, being underpinned by notions of equality, empathy, compassion, empowerment, kindness, politeness, non-judgement, confidentiality and professionalism.*
- *The majority of respondents perceived that older women from a BME background would think they were offered the opportunity and support to express their needs, but just under one quarter of the respondents (22%) thought they were seldom offered the opportunity, and 7.7% thought they were seldom offered support.*
- *Respondents perceived that older women from a BME background would think their physical needs were most often taken into account, whereas their cultural needs were least often taken into account.*
- *One quarter (25%) of the respondents perceived that older women from a BME background were seldom involved in decision-making about their own care, and 2.8% perceived that they were never involved.*

- *Close to one half of respondents (44.1%) perceived that older women from a BME background could seldom or never choose which language they wished to use to communicate, and 31.9% believed that members of this population group were seldom or never provided with information relevant to their ethnic or cultural background.*
- *The top five barriers that made it difficult to provide intercultural care with dignity were a lack of staff who can speak the relevant community language, a lack of interpretation services or limited access to interpreters, a lack of staff training, limited time, and not recognising the culturally specific needs of older people.*
- *The top two barriers or challenges to providing responsive services were failing to address the way local services were accessed, and not taking into account older people's culturally specific needs when designing services.*
- *With regard to key elements that might help respondents provide better care or support to older women from a BME background, staff training and recognition of, and information tailored, to older people's needs were most frequently reported.*
- *Over 50% of respondents with a supervisory or managerial role reported managers, care plans, internal policy and best-practice guidelines as sources of care information. Best-practice guidelines were seen as a source of care information for over 50% of respondents who worked in the third sector.*
- *Over half of all respondents indicated that they sourced external support and information from organisations that mainly work with older people. This was closely followed by organisations providing health and social care, and organisations mainly working with older people from a BME background, all of which were referred to by around half of all respondents. Equality organisations and cultural associations were referred to by around a third of respondents.*
- *Other sources of information and support were family members and friends of the person to whom respondents provided care or support (72.5%), the person to whom they provided care or support (67.5%), and their own experiences (55%).*
- *Most respondents thought that older people from a BME background and their family members were often unaware of services – especially mainstream ones – available to them. They also thought that a social support network was often not in place to facilitate access to relevant services on behalf of older people.*

- *Lack of funding was frequently seen as a key factor that had hindered the development and adaptation of support and care; this was even more of a pressing concern for those based in third-sector organisations.*
- *Some respondents stressed that staff members tended to be constrained from learning about and responding to culturally appropriate care, which often required more time and effort to plan and put into practice.*
- *Respondents reported that there were often few referrals of users from a BME background via social services or self-referrals. They felt unsure how and where to approach such users, and acknowledged difficulties in informing older people of newly developed programmes or services.*

Interviews with older women

The participants' ages ranged from 48 to 78 years. Two of the participants were aged 48, 12 were in their 50s, 12 were in their 60s, and five were in their 70s. The age of one of the participants was not known, although she was over fifty years old. The average (mean) age was 61.2 years. The majority of the women were either married or widowed, with few divorced, separated or never married. Interviews were conducted with six women of Indian heritage, seven women of Caribbean heritage, eight women of Bangladeshi heritage, and 11 women of Chinese heritage. All but two of the women had migrated to the UK and the sample consisted of a good mix of both long established residents and more recent settlers, with Two participants arriving in the UK within the last 10 years, six participants arriving in the UK within the last 20 years, 11 having been in the UK between 30 – 39 years, and nine participants having been resident in the UK for over 40 years (length of residency was unknown for one of the participants). At the time of arrival, three of the participants were aged over 50. In terms of health, the majority of participants rated their health as either 'good' or 'fair'. Five participants rated their health as 'bad' and one as 'very bad'. Four participants rated their health as 'very good'. The majority of the participants lived in South East Wales (n=24), the remainder lived in the North Wales region. Eight participants were living with their children and nine with their husbands. The majority of participants reported having some family living in close proximity and meeting with them regularly during the week.

- *All but two women were first-generation migrants; a common thread linking the women was the link between the experience of migration and its impact on their life trajectories.*
- *Migration shifted life trajectories in different ways, with varying levels of adaptation to life in the UK. The interviews revealed evidence of both disruption and reconstruction of roles, and of personal and collective identities, across the life course. It was evident that, for the participants, the process of acculturation was ongoing, varying and context-specific. For some, it was a clear and engaged choice that they embraced, while others described an ongoing struggle to adjust.*

- *The women's understanding of age and growing old was conceptualised within five overlapping dimensions: chronological age, biophysical age, psychological age, social age and significant life milestones. Despite consensus on the importance of biological status, the most shared perception of old age was psychological age. This involved the individuals' own attitudes towards their age and their own perceptions of how old they really were. Being old was perceived as a state of mind, rather than being determined solely by the physical state of the person. Old age was very much linked to (in)activity – both physical and mental (with old age being the result of losing their spark, or interest in life).*
- *A sense of dignity and respect was understood as something that can be learned from an early age through interactions with the family and close community (religious, cultural or ethnic). Some women also saw other platforms (such as work and their status as professionals) as being of importance. A sense of dignity in old age was linked to these elements, as well as to a sense of purpose fostered in their roles as wife, mother and grandmother, as well as those as mentor and guardian of cultural knowledge.*
- *Dignity was communicated, and manifested itself more commonly, through acceptable social conduct and appropriate levels of deference: displays of respect. Dignity in older age was rooted in both the status of being an older person and the importance of leading by example, based on experience and seniority.*
- *For some women, the sense of heightened vulnerability – because of advancing age, and the impact of accumulative negative encounters and racialised micro-aggressions – was real and pressing. What was also evident was the indignation that some participants felt at their experiences of loss of dignity, and the loss experienced by family and community members. What emerged was an understanding of dignity as both personal and social; with this came a sense of loss of both personal and collective dignity.*
- *Dignity and the loss of dignity were understood in many ways, not least as socially mediated, rooted in social processes that impacted on the positioning and recognition (or not) of individuals based on differences such as gender, ethnicity, nationality, age, and the intersecting of ageism, racism and sexism.*
- *Care was understood as encompassing both tangible and intangible dimensions. In the former, the emphasis was on the provision of practical and personal care and support, and in the latter the notion of care was expressed in terms of a psychological dimension of sustaining emotional connections with those who provided the care. Key to this intangible dimension of care was showing respect and positive regard towards the other person.*

- *For some of the participants, respect and dignity were considered to be closely linked to the provision of care within the family and between family members. Religion was important for well over half the women interviewed – and for some of the participants, care and giving care indicated their religious obligation and duty to their families. Despite references to religious obligation, care was understood by most of the participants as an expression of the respect, worth, honour and value of the older person. One participant described this as ‘love care’. Care in this sense was defined as respect: to provide care was a manifestation of worth and a display of respect, illustrating the value that many of the participants placed on this aspect.*
- *All the participants acknowledged they would need support and care at some point in the future, and the majority would prefer their family members to provide this – mainly due to the emotional connections already present and the protective environment this would provide in the context of increased levels of support and new levels of (varying) vulnerability.*
- *Most women realised their family might not be able to provide that care, and this was a major cause of concern. What was common among all women was the perception that providers of care, whoever they might be, must display an orientation or attitude to care provision that was dignity-enhancing, and must carry out the role with a high level of professional competence and compassion, engagement and intentionality. This meant that carers needed to express empathy and concern for those they were looking after, and show genuine caring on a psychological level rather than simply providing practical and personal assistance.*
- *Dignified care consisted both of a respect for the body and respect for the emotional and spiritual dimensions of the individual. Descriptions of care consisted both of a physical or practical, component, but also an emotional connection with the carer whether they were a family member or professional.*
- *Care with dignity was understood as a purposeful activity, undertaken with intent to acknowledge a person’s sense of worth and value. Care was understood to be that which acknowledged and showed respect to the individual, that was attentive to the increased potential of loss of dignity due to declining capabilities, and that was delivered with an understanding of the particularities of the individual and the specifics of their care or support needs, and also of the wider social context shaping the social care encounter.*
- *Most women wanted to receive personal/ intimate care that took account of their daily routine and personal hygiene rituals; have family members and friends and those from similar backgrounds to theirs involved if possible; receive care or support from those competent in acknowledging, assessing and acting on the requirements of people from a range of cultural, religious or ethnic backgrounds; be able to communicate effectively their care or support requirements; be provided with information in order to be able to make informed decisions regarding their care or support requirements and to play a role in how it was to be delivered; be able to retain their religious or*

culturally specific rituals and practices; and to receive care or support that was delivered as planned and expected.

Limitations of the study

Survey of service providers

As the main focus was on the perceived views of older women from BME backgrounds, the views of the older person were ‘once removed’. While the results also provided some evidence on the perceived views of the older population in general, the use of the terms ‘older people’ and ‘older people in general’ subsumes the great heterogeneity of the older population in Wales. We are equally aware of the great heterogeneity between and within BME groups.

The sample size is small. This limits the generalisation of the findings, and some significant associations observed might reflect an unrepresentative set of respondents. Male respondents (n = 13) were under-represented, which may reflect the demography of occupational groups involved in care settings. Respondents’ experiences of working with older people from BME backgrounds varied; this may have impacted on their perceptions. Also, as with research in general, there is potential selection bias. Those who participated might have a particular interest in, or concerns about, dignity. Some respondents did not answer all questions, resulting in missing data; this may have led to some imprecise results. However, the quantity of missing answers was low and is unlikely to have affected the overall conclusions of the study.

Finally, the questionnaire used for data collection was presented in English only. Some people requested this in another language, such as Chinese. Organisations providing services to a specific ethnic community often employ staff from their own community, who may not be proficient in English. As we were unable to provide the questionnaire in other languages, we omitted some of these people’s views.

Interviews with older women

There were also limitations to this aspect of the study, and key points to be made when considering the findings. One issue that arguably limits the power of the conclusions is the use of the term 'dignity'. The use of the term 'dignity' in the interview question of a study that is seeking to clarify the concept of dignity could be considered problematic. Moreover, the interviews were conducted in a number of different languages and in some cases the words used to convey what dignity meant differed, although sharing some semblance of the root meaning. In the interviews the term 'dignity' was used but no definition of the term was provided, with the onus being to invite the participant to share their views on the term, to offer alternative terms and views, and to arrive at a version of dignity that they were comfortable with. On a more general note, attention is drawn to possible validity issues because of the fact that we worked across a range of languages. To offset this, interviewers working in languages other than English were asked to keep a record of words and phrases that did not translate easily across linguistic boundaries or that had multiple meanings. In addition, a small number of the interviews were back-translated and also, in some cases the transcripts were returned to the participants for discussion and validation.

Second, although the research design meant that the study did include older people living outside the large Welsh cities in areas where the BME population is less than 2%, such as in North Wales, the majority of the participants were based in South East Wales. No women from Mid Wales were recruited to the study. We remain mindful of the specificity of experiences of women living in rural and semi-rural parts of Wales, and of the fact that much more work is needed to develop our knowledge of the experiences of older women from a range of locales. The sample was diverse in terms of age, mobility, membership of clubs and groups, and length of time living in Wales. We note that two women were born in Wales; the need to explore the perceptions of dignity and the care expectations of women from minority backgrounds who are not first- or second-generation migrants remains a research priority.

Third, attention is drawn to possible validity issues due to language in the interviews with Bangladeshi and Chinese women. Interviews were conducted in their own language and translated back into English by the interviewer. For this reason, specific words attributed to

the meaning of dignity by the participants might bear translator bias. To offset this, interviewers working in languages other than English were asked to keep a record of words and phrases that did not translate easily across linguistic boundaries or that had multiple meanings. In addition, a small number of the interviews were back-translated, and some transcripts were returned to the participants for discussion and validation.

Lastly, although this study was rooted in the lives of women, much more work is needed to explore the gender differences in how dignity is understood and how care with dignity is perceived. Questions were asked on perceptions of differences in understandings, and future work will explore this dimension in greater detail.

It is also important to note that in this report (and the accompanying reports), the research process and findings have been compartmentalised into the survey and interviews. This was a mixed-methods study, and the next important step will be to bring the two elements together and analyse them as one dataset. Despite these limitations, the study does add to empirical research evidence, and some recommendations can be drawn from the findings reported.

Preliminary recommendations

1. The quality of care depends on an awareness of – and responsiveness to – people’s needs and expectations. It is important to understand what terms such as ‘care’ and ‘dignity’ ‘look like and feel like’ across different population groups.
2. Dignity has a structural – as well as an interpersonal – dimension, both of which are constructed by the act of recognition. Thus, dignity – and care with dignity – can be seen to be understood both personally, and from the perspective of being part of a larger grouping. This may have implications for how perceptions of services are (re)produced and transmitted (negatively or positively) within and between particular groupings.
3. Much more work is needed to explore the role of cultural knowledge and values in shaping how dignity is understood and experienced, and how it can be enhanced or diminished in care encounters.
4. Learning from the views and perceptions of service providers remains key to the development of services for the UK’s increasingly diverse older population. However, the views of older women and men would be valuable as well. Since some respondents in this study perceived their own practice more positively, future research is needed to compare service providers’ perceptions of their practice with how older women experienced their care and support.
5. It is important to explore further the impact that racial inequality may have on the lives and well-being of older women from minority ethnic backgrounds. High-quality care that considers their socio-cultural backgrounds, psychological needs, religious beliefs and life history can support dignity and respect. Training in intercultural competence should be up-to-date, ongoing, and available to all staff members.
6. Service providers must be aware of good communication practices and how they can apply these to their own work. It is also important to understand barriers to service

delivery and to older women's involvement in their own care, so that various sources of support may be made available. Staff should be given the time to reflect on the impact of their own actions on older women for whom they provide care or support.

7. The people who migrated from the British colonies in the middle of the last century are now reaching later life. The meaning and quality of later life, the role of social networks, pathways to care and support, and the strategies used to maintain people's sense of worth and well-being all need to be better understood.
8. The study was about women, but much more work is needed to explore the gendered nature of ageing and associated social inequalities, as linked to the delivery of care and support to older women from minority ethnic backgrounds.
9. Research with a focus on minority ethnicities – as both a variable in itself, and as linked to a host of other intersecting variables such as age and class – remains necessary and pressing, as does the need to fully interrogate the meaning, relevancy and impact of these intersecting variables on people's lives.
10. Research on minority ethnicity and ageing has highlighted that older people, regardless of their ethnic and cultural backgrounds, have common expectations about the quality of services and the importance of dignified care; however, older people also have individual expectations, aspirations and desires based on their life experiences, and on their cultural, religious and ethnic backgrounds. There is a need to explore cultural values and orientations that shape how people make sense of concepts such as dignity and care.
11. The study has shown the importance of understanding care and dignity as personally as well as socially mediated, shaped by the wider social context and also by a person's life-course experiences. In building an evidence base on how dignity and care are conceptualised and experienced from a cross-cultural perspective, it is of equal importance to explore social dignity.

12. The notion of social dignity needs to be embedded into professional practice to a greater extent. Without attention being given to the wider societal context in which care and support are offered, delivered and experienced, a narrow focus on the person could limit the development of necessary cultural competences needed to engage and work in an intercultural context.

References

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Accompanying final reports

Dignity, care and support for older women from Black and Minority Ethnic (BME) backgrounds: Service providers' perceptions - Final Report (December 2012)

Dignity, care and support: The perceptions and expectations of older women from Black Caribbean, Chinese, Bangladeshi and Indian backgrounds - Final Report (April 2013)

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