

Determinants of Trust and Mistrust in Physicians Identified by African American Family Caregivers

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Abstract

Objective: This qualitative study identified key determinants of trust/mistrust of physicians as perceived by African-American family caregivers of relatives diagnosed with stroke or dementia.

Design: A convenience sample of 21 African-American family caregivers participated in face-to-face, in-depth, and in-home interviews conducted by trained African American nurse interviewers.

Results: Qualitative analysis of interviews yielded four themes as contributing to caregivers' trust and mistrust of physicians - - physicians' medical knowledge base, physicians' having patients' best interests in mind, physicians' ability to communicate, and physicians' accessibility. Nested within these themes were elements that described cross-cultural and racially specific physician characteristics.

Conclusions: Trust/mistrust was not limited by a physician's ethnicity. Physician behaviors were the key determinants that engendered trust or mistrust in family caregivers.

Non-African-American physicians can promote trust if they demonstrate that they have the patients' best interests in mind and care about the patients.

Introduction

Trust is essential for effective communication and compliance with health care. A number of studies have provided evidence that trust and mistrust affect the health care choices of African-Americans (Bonner, Gorelick, Freels, Theis & Davis, 1999; Ayanian & Clearly, 1999; Ferguson, Weinberger & Westmoreland, 1998; Corbie-Smith, Thomas & Williams, 1999; Davidson & Deveney, 1991; Blackhall, Frank & Murphy, 1999; Reese, Ahern & Nair, 1999; Waters, 2001). For example, mistrust caused African-Americans to stipulate in living wills that every effort should be made to sustain life, regardless of illness status (Freimuth, Quinn, Thomas, Thomas, Cole, Zook & Duncan, 2001; Escarce, Epstein & Colby, 1993; O'Brien, Gusso & Maislin, 1995; Facione, 1999; Garrett, Harris, Norburn, Patrick & Davis, 1993). Mistrust was found to be a barrier for recruitment of African-Americans into clinical trials (Harris, Gorelick, Samuels & Bempong, 1996). Regarding AIDS, some African-Americans refused treatment because they believed AIDS was part of a genocidal conspiracy (Joseph, 1997). Others have not utilized AIDS-related social service agencies because they believed the services were designed to help other Americans, but not African-Americans (Stevenson, 1994).

Historical events have contributed to mistrust in the health care system for African-Americans. The roots of mistrust can be traced to the 19th century, in which African-American slaves were commonly used for medical experimentation (Savitt, 1982). Living African-Americans were used as specimens in medical schools for teaching medical, surgical, and pathological examination procedures. Medical records show that antebellum physicians used African-Americans for numerous medical and unanesthetized surgical procedures. Unanesthetized surgical experiments included surgery for oophorectomies and vesico-vaginal fistula repair. Virtually every organ system was used for experimentation, including pulmonary, hepatic, gastrointestinal, and genito-urinary systems (Gamble, 1993). Events generating mistrust are not limited to the antebellum period. For example, in the infamous Tuskegee Syphilis Study, African-Americans were allowed to develop the progressive effects of syphilis, even after effective treatment was developed (Jones, 1981; Thomas & Quinn, 1991). Since the study extended from 1934 to 1972, it was conducted well within the lifetime of the cohort of study subjects featured within this report. It seems reasonable that the wide publicity given to the Tuskegee Syphilis Study could engender mistrust regarding medical research and the healthcare system as a whole.

Clearly, given that trust is potentially a powerful variable affecting health care decisions, a better understanding is needed about the factors contributing to African-American family caregivers' trust and mistrust of the healthcare system. The purpose of this study was to understand the determinants of trust and mistrust in physicians as perceived by these caregivers.

Methods

Sample

The convenience sample consisted of African-American family caregivers (n = 21) of elderly relatives. Family caregivers were selected for this study because they had extensive experience negotiating the health care system as patients themselves and as the caregiver for others. The caregivers had primary responsibility for the health care decisions of their relative. The care recipients were African-American, age 55 or older, diagnosed with stroke or dementia.

Thirty potential participants were drawn from a list of caregivers who had participated in an earlier, completed study (Gorelick, Brody & Cohen, 1993). Participants were eligible for the current study based on their date of participation in the previous study, starting with the last to enter the study. Twenty-one participants were ultimately included in the study. The final number of participants was determined based on data saturation. Data saturation occurs when responses from the participants are repeated, and new information is not retrieved from the interviews. Nine caregivers refused to be interviewed, resulting in a 70% participation rate. Caregivers refusing reported they had participated in too many studies (n = 3); family members did not want them to participate (n = 2); or they were not interested (n = 4).

Almost all of the caregivers were older women (mean age = 74 years, SD = 9.2, range = 51-86 years); the majority (n=15) cared for their spouses or daughters. Care recipients also were older (mean age = 73.7 years, SD = 11, range = 50-92 years). There were slightly more women care recipients (n=13) than men care recipients (n=8). Diagnoses among care recipients were stroke without dementia (n=12), Alzheimer's disease (n=5) and stroke with dementia (n= 4).

Interview Content

The open-ended questions were developed to identify the content domain of elements contributing to trust/mistrust in physicians, based on the literature and the professional experience of the investigators. They also were designed to determine how caregivers conceptualized trust and mistrust. The interview questions were pilot tested with nine African-American family caregivers who understood the questions without difficulty.

Procedure

Interviews were conducted in the participant's home, rather than a medical setting in order to increase participants' comfort in revealing sensitive information. African-American registered nurses trained in interviewing African-Americans on sensitive topics conducted the interviews. All interviews were tape-recorded and lasted approximately one hour. The study was approved by the Institutional Review Board of the University of Illinois at Chicago. The researchers obtained both written and verbal informed consent from participants prior to participation in interviews.

Data Analysis

Data analyses were performed on the interview content using the inductive qualitative technique (Smith & Osborn, 2003). This technique is a coding process that organizes transcribed interviews or raw data. The researchers identified conceptual categories or themes from the raw data. The themes or conceptual categories were used to analyze the data. To ensure cultural sensitivity and valid interpretation of cultural expressions, three African-American health care professionals coded the transcribed interviews. First, the three coders analyzed the data independently to identify the elements. Second, the elements were discussed to clarify and refine their meaning. Whenever questions or disagreements were generated about the meaning of the elements, the transcribed interviews were re-reviewed by the three coders to determine exactly what the subject meant in the context of the interview. This iterative process continued until 100% agreement was reached. Third, throughout this iterative process, culturally specific language was transformed into terms that would be understood cross-culturally and yet retain the original meaning. This was accomplished in close collaboration with an expert in cross-cultural research. The expert studied quality of life issues in chronic diseases and developed culturally specific measures for African Americans. The final set of elements was clustered into four domains, which reflected the family caregivers' perceptions about trust and mistrust in physicians.

Results

Four themes emerged from the data as contributing to trust and mistrust: physician's medical knowledge base, physician having patient's best interest in mind, physician's ability to communicate with caregiver, and physician's accessibility to caregiver. The general similarity in the elements of trust and mistrust within each domain supported the idea that they were polar opposites of the same construct, rather than different constructs.

Physician's Medical Knowledge Base

Although the caregivers in this study were not qualified to judge medical competence, the respondents used sophisticated strategies to evaluate the physician's medical knowledge base. For example, caregivers reported that they would validate the answers given by physicians based on previous discussions with other physicians. Answers that matched promoted trust, and mismatched answers promoted distrust. They also talked with friends with similar medical problems to determine the concordance among answers from physicians. Comparison of care with other patients was used as a marker to determine physician competency and subsequent trust or mistrust.

Caregivers also judged medical competence in terms of providing "thorough care." For example, the physicians who were trusted showed that they understood the problems of the elderly; did everything they could to help the loved one progress; and kept the patient "under surveillance." "Under surveillance" meant that the physician was perceived as vigilant in following the patient over time. Another way in which medical competence was judged was whether the physician made referrals to a specialist. This was cited both in terms of engendering trust by making the referral and mistrust by failing to refer when appropriate.

Caregivers identified other behaviors that made them question the medical competence of the physician, which caused mistrust. An example was a physician prescribing treatment without first physically examining the patient. One caregiver reported, "When the doctor refuses to touch you, it makes you think they do not want the black to rub off on them." The most commonly reported element was making mistakes in medical care. Caregivers stated they thought medical mistakes were made when unusual and prolonged symptoms were experienced after treatment.

Physician Having Patient's Best Interest in Mind

The second domain consisted of elements that suggested that the physician had the patient's best interest in mind. Trust was engendered by physicians who conveyed the idea that patients were "worthy" human beings, meaning that they **were** worthy of their time and effort. This was conveyed by physicians who appeared genuinely concerned and interested in the patient's health care needs, rather than treating the patient as just another case. These were physicians who provided care that seemed personalized and tailored to the patients. In addition, caregivers stated trust was increased by physicians who invited them to participate in the health care decisions. They reported such doctors gave them options and allowed them to make suggestions regarding the care of their loved one.

Physicians who did more than was required of them were also seen as individuals who engendered high levels of trust. An example was physicians helping family caregivers and care recipients to obtain other services needed, such as home care and social services. Further, a caregiver reported the physician hospitalized a loved one diagnosed with end-stage Alzheimer's disease so an exhausted caregiver could get some rest.

Mistrust was engendered by physicians who appeared disinterested in treating older patients. Caregivers reported that physicians conveyed the idea that their time was being wasted. This

was communicated by physicians' such as "the patients were old and had lived their lives" and by questioning whether it was worth the effort to continue to care for the patient.

Mistrust also was engendered by physicians who were seen as lacking concern, through behaviors interpreted as arrogant, discourteous, and insensitive to patient and family needs. For example, one caregiver stated, "The doctor just ignores you. They look straight through you, as opposed to looking at you. It's like you are not there, like you do not exist."

Physician's Ability to Communicate with Caregivers

Good communication was identified as critically important for establishing a trusting relationship between physicians and family caregivers. Caregivers believed good communication centered on the physician's ability to create an unhurried atmosphere despite a full and busy schedule. This also was related to the idea of providing thorough care. One caregiver stated, "I trust a doctor who went through everything with me, even if he didn't talk much." Good communicators were also physicians who took the time to develop rapport with the caregivers, listened to their problems, educated them about medical conditions, and explained things to them in lay terms. All of these factors were reported to engender high levels of trust in the caregivers.

Physicians who were poor communicators promoted mistrust. Examples of poor communication behaviors exhibited by physicians included failures to educate the family or patient, to allow time for questions to be asked, and to share medical results. Caregivers spoke of the need for the physician to discuss their loved one's illness and state what they needed to do to provide appropriate care; suspicion was engendered by physicians who lacked these qualities. Another category of poor communicators who promoted mistrust were physicians who used medical jargon without explanations in lay terms, gave unclear and evasive answers to questions, and had strong foreign or difficult-to-understand accents. They were regarded with a high degree of skepticism.

Physician's Accessibility to Caregiver

The last domain that influenced a trusting relationship between physicians and the caregivers was accessibility. Physicians who were available when needed, spent appropriate time with patients, and were willing to talk to family members promoted the best trusting relationships. Caregivers further explained that "being available" included physicians who were accessible either through direct telephone contact or pagers, stayed in touch with them between extended appointments, and made house calls.

Conversely, physicians who were too busy and hurried were less likely to be accessible and more likely to be mistrusted. Physicians who turned the care over to assistants, such as residents and nurses, were also included as engendering mistrust. Respondents described physicians who were unavailable when needed as those who failed to give out a number where they could be contacted and failed to return calls at all or within an expeditious timeframe.

Physician's Race

Although physician's race was not a domain specified in the study, this topic warrants discussion because trust/mistrust in health care providers influenced decisions regarding racial choices for physicians. Caregiver's reported that African-American physicians were more likely to understand their health care needs, have greater compassion, and communicate with them better than colleagues from other racial groups. They also stated they identified with many of the physicians and felt comfortable having their relatives cared for by them. Such feelings engendered a great sense of trust in the African-American physicians and subsequently caregivers preferred them as health care providers. However, they also spoke of how some African-American physicians were arrogant, disrespectful and too busy to serve their needs. Therefore the caregivers concluded that the most important determinates for trust/mistrust in physicians were the domains cited above rather than physician race.

Discussion and Conclusions

This study identified the determinants of trust and mistrust in physicians as perceived by a group of urban African-American family caregivers. Findings indicate that the determinants of trust and mistrust in physicians were dependent upon the perceptions caregivers held about physician's behavior, specifically their medical knowledge base, having the patient's best interest in mind, ability to communicate, and accessibility to caregivers, all of which were more important than ethnic identity. African-American family caregivers were able to trust a non-African-American health care provider and identified examples of specific behaviors that had engendered this trust. Caregivers interpreted these behaviors as providing evidence that the physician was altruistic, egalitarian, and would have their best interests in mind. Foremost was the idea that the physician actually cared about the patients and their welfare. These findings are encouraging, suggesting that patient trust is not limited by a physician's ethnicity. More specifically, the findings indicate that trust was determined primarily by physician behavior rather than ethnicity, and this finding was strengthened by comments regarding attitudes towards African American physicians. Caregivers commented that all things being equal, they would prefer an African American doctor. However, they also made it clear that the behaviors that engendered trust and mistrust were more important than ethnicity; a Caucasian American physician they trusted would be preferred to an African American they did not trust.

Pervasive negative views of the health care system have been reported previously for African Americans (Hobson, 2001). The recent Institute of Medicine (IOM) report on health disparities and other reports in the literature document the magnitude of the problem with racism, discrimination, and mistrust in the delivery of health care (Bobo, 2001; Van Ryn, 2000; Morin, 2001; Lurie & Buntin, 2002). From these reports it is clear that mistrust forms a barrier to health care and interferes with the ability to make informed, appropriate health care decisions. This study's qualitative findings provide useful baseline data for future research on determinants of trust and mistrust in African-American family caregiver-physician patterns of interactions and communications. Study findings will be used by the investigators to develop a culturally sensitive instrument to measure trust and mistrust in physicians as perceived by African-American family caregivers of older African-Americans.

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References

- Ayanian, J. Z. & Clearly, P. D. (1999). The effect of patients' preferences on racial differences in access to renal transplantation. *New England Journal of Medicine*, 341, 1661-1669.
- Blackhall, L. J., Frank, G. & Murphy, S. T. (1999). Ethnicity and attitudes toward life sustaining technology. *Social Science Medicine*, 48, 1779-1789.
- Bonner, G., Gorelick, P., Prohaska, T., Freels, S., Theis, S. & Davis, L. (1999). Preferences for end-of-life treatment decisions made by African-American family caregivers. *Journal of Ethics, Laws, and Aging*, 5 (1)
- Bobo, L. D. (2001). Racial attitudes and relations at the close of the twentieth century. In
- Smelser, N. J., Wilson, W. J., and Mitchell, F. (Eds.) *America becoming: Racial trends and their consequences*, Washington, DC: National Academy Press.
- Corbie-Smith, G., Thomas, S. B. & Williams M. V. (1999). Attitudes and beliefs of African Americans toward participation in medical research. *Journal of General Internal Medicine*, 14, 537-546.
- Davidson, M. N. & Devney, P. (1991). Attitudinal barriers to organ donation among Black Americans. *Transplant Pro*, 23, 2531-2532.
- Escarce, J. J., Epstein, K.R. & Colby, D.C. (1993). Racial differences in the elderly's use of medical procedures and diagnostic tests. *American Journal of Public Health*, 83 (7), 948-954.
- Facione, N. (1999). Breast cancer screening in relation to access to health services. *Oncology Nursing Forum*, 26 (4), 689-696.
- Ferguson, J. A., Weinberger, M. & Westmoreland, G. R. (1998). Racial disparity in cardiac decision making. *Archives of Internal Medicine*, 158, 1450-1453.
- Freimuth, V. S., Quinn, S. C., Thomas, S. B., Thomas, S. B., Cole, G., Zook, E. & Duncan, T. (2001). African American's views on research and the Tuskegee syphilis study. *Social*

Science & Medicine, 52(5), 797-808.

Gamble, V. (1993). A legacy of distrust: African-Americans and medical research. . *American Journal of Preventive Medicine*, 9 (6), 35-38.

Garrett, J., Harris, R., Norburn, J., Patrick, D. & Davis, M., (1993). Life sustaining treatments during terminal illness: Who wants what? *Journal of General Internal Medicine*. 8, 361-368.

Gorelick, P.B., Brody, J. & Cohen, D. (1993). Risk factors for dementia associated with multiple cerebral infarctions: A case-control analysis in predominantly african-american hospital-based patients. *Arch. Neurol*, 50, 714-720.

Harris, Y., Gorelick, P., Samuels, P. & Bempong, I. (1996). Why African-Americans may not be participating in clinical trials. *Journal of the National Medical Association*, 88, 630-634.

Hobson, W. D. (2001). Racial discrimination in health care interview project – A special report. *Seattle: Seattle and King County Department of Public Health*.

Jones, J.H. (1981). *Bad Blood: The Tuskegee Syphilis Experiment*, New York: Free Press

Joseph, J. (1997). Woman battering: A comparative analysis of black and white women. In G.K. Kantor & J.L. Jasinski (Eds.) *Out of darkness: Contemporary perspectives on family violence*. Thousand Oaks, California: Sage Publications.

Kantor & J.L. Jasinski (Eds.) *Out of darkness: Contemporary perspectives on family violence*. Thousand Oaks, California: Sage Publications.

Lurie, N. & Buntin, M. B. (2002). Health disparities and the quality of ambulatory care. *New England Journal of Medicine*, 347(21), 1709-1710.

Morin R. (2001). Misperceptions cloud whites' view of blacks. *The Washington Post*, July11, 2001.

O'Brien, L., Gusso, J. & Maislin G., (1995). Nursing home residents' preferences for life-sustaining treatments. *Journal of American Medical Association*, 27, 1775-1779.

Reese, D. J., Ahern, R. E. & Nair, S. (1999). Hospice access and the use by African-Americans: Addressing cultural and institutional barriers through participatory action research. *Social Work*, 44, 549-559.

Savitt T. (1982). The use of blacks for medical experimentation and demonstration in the old south *Journal of Southern History*, XI VIII (3), 331-348.

- Smith, J. A. & Osborn, M. (2003). Interpretative phenomenological analysis. Smith, J. A. (Ed). (2003). *Qualitative psychology: A practical guide to research methods*. (pp. 51-80). Thousand Oaks, CA: Sage Publications.
- Stevenson, H. C. (1994). The psychology of sexual racism and AIDS: An ongoing saga of distrust and the sexual other. *Journal of Black Studies*, 3, 331-348.
- Thomas, S.B. & Quinn, S.C. (1991). The Tuskegee syphilis study, 1932 to 1972: Implications for HIV education and AIDS risk education programs in the black community. *American Journal of Public Health*, 81 (11), 1498-1505.
- Van Ryn M. (2000). Research on the provider contribution to race/ethnicity disparities in medical care. *Medical Care*, 40(1), I-140-I-151.
- Waters, C. M. (2001). Understanding and supporting African Americans' perspectives of end-of-life care planning and decision making. *Qualitative Health Research*, 11(3), 365-398.