Disparities in Long-Term Care: Building Equity into Policy

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Abstract

Context: A growing body of evidence documents pervasive racial, ethnic, and class disparities in long-term care in the US. At the same time, major quality improvement initiatives are being implemented that rely on market-based incentives, many of which may have the unintended consequence of exacerbating disparities.

Methods: We review and summarize existing evidence on disparities in both the use and quality of long-term care services; analyze current market-based policy initiatives in terms of their potential to ameliorate or exacerbate these disparities; and suggest policies and policy modifications that may help decrease disparities and improve quality of long-term care.

Findings: Racial disparities in the use of formal long-term care, including use of nursing homes, home health care, and hospice care, have decreased over time, though blacks are still more likely to use informal care and less likely to use assisted living than whites. Disparities in quality of care are more consistently documented and appear to be related to racial and socioeconomic segregation of long-term care facilities, mirroring residential segregation, as opposed to within-provider discrimination. While current policies designed to improve quality of care may help ameliorate disparities, they may paradoxically exacerbate existing disparities in both use and quality of care. To mitigate this potential, we suggest a number of policy modifications aimed at improving the ability of consumers to access, understand, and use information and the ability of low-resource providers to undertake quality improvement efforts.

Conclusions: Market-based incentives are increasingly being employed in health care to improve choice, efficiency, and quality of care. These policies should explicitly incorporate the goal of mitigating the potential unintended consequence of increased disparities.

Introduction

Health care in the United States is uneven and often inadequate, particularly for racial and ethnic minorities and patients of low socioeconomic status--patients that have traditionally been underserved by the current health care system. Reducing disparities in quality and access to care is high on the national health policy agenda (Institute of Medicine 2002).

In long-term care (LTC), a growing body of evidence documents pervasive racial, ethnic, and class disparities in both use and quality of care. Despite this large body of evidence, the goal of reducing disparities has been overshadowed by efforts to improve overall quality and ensure access to LTC, important goals that have been challenging for decades due to fragmented financing and systems of care. Historically, these quality improvement (QI) efforts were implemented largely through regulation. More recent policy efforts, however, have relied to a much greater extent on individual decision-making and market-based incentives such as public reporting of quality (e.g., the Nursing Home Quality Initiative and the Home Health Quality Initiative) and pay-for-performance to spur QI.

Many of these policies hold great potential to improve overall quality of care, satisfaction with care, or access to care. However, some researchers, policymakers, and clinicians have expressed concern that these policies may have the unintended consequence of exacerbating disparities in care (Mor, Zinn et al. 2004; Casalino, Elster et al. 2007; Chien, Chin et al. 2007). This concern is rooted in the realization that consumers from different racial, ethnic, and socioeconomic groups may not have equal access to and benefit from quality information, and that health care providers may not be equally able to respond to QI incentives due to differences in available resources. If traditionally underserved groups are less likely to use quality information and/or are more likely to access providers with low resources and low quality,

disparities may worsen even as average access and quality increase. Concerns about this unintended consequence of QI initiatives have only recently been articulated and have not been adequately assessed or debated, particularly in the context of LTC where the prevalence of disparities is arguably higher. A timely and important opportunity exists to incorporate design changes or supplemental reforms into policy initiatives that would promote equity along with improving the access to and quality of LTC.

In this paper, we summarize the existing evidence on racial, ethnic, and socioeconomic disparities in use and quality of LTC services; analyze major market-based policy initiatives which may affect both access to and quality of long-term care in terms of their potential to affect disparities; identify and/or suggest design changes or supplemental interventions to current policy initiatives that may ameliorate the effects on disparities while still improving access and quality; and identify remaining research priorities in this area.

Conceptual Framework

The 2002 report by the Institute of Medicine (IOM) on racial and ethnic disparities in health care states that disparities are "racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention." (Institute of Medicine 2002) This definition implies that not all differences should be considered disparities, and that the reasons for the difference must be carefully considered. We generally adopt this approach in defining disparities, with several modifications. First, we consider differential access to be a potential disparity. Because some factors contributing to differential access to health care are well-known (e.g., insurance status), the IOM was charged with examining disparities beyond issues of access. However, in the case of long-term care, the

fragmented structure of financing and geographic differences in supply (Reed and Andes 2001; Mor, Zinn et al. 2004) make access an important element in any discussion of disparities. We therefore consider two types of disparities in this paper, *disparities in use* of LTC services and *disparities in quality* conditional on use; disparities in use may reflect differential access. Second, existing research on disparities in LTC generally does not make the distinction between differences and disparities, so we are in some cases limited in the extent to which we can separate the two. Consequently, we treat differences in these cases as reflecting potential inequity that researchers should strive to understand and policymakers should strive to reduce.

Without minimizing the potential importance of other types of disparities (e.g., gender disparities or urban/rural disparities), we focus in this paper on disparities by race, ethnicity, and socioeconomic status. The relationship among these factors is the subject of ongoing debate and research. Racial and ethnic identification and socioeconomic status may form partly overlapping risk pools for being underserved in the current health system, but they are not redundant in explaining health disparities (Farmer and Ferraro 2005) and they involve distinct pathways. Lower levels of education may act to constrain choices by making quality information more difficult to obtain or assimilate. On the other hand, minority status may act to constrain choices due to discrimination and residential segregation; even controlling for education, minority elders may disproportionately live in minority-dominant communities that are characterized by resource-poor institutions and health care providers (Wilson 1987; Massey and Denton 1993; Howard, Sloane et al. 2002; Smith, Feng et al. 2007). The IOM's approach, which includes as disparities those differences arising from socioeconomic factors that are correlated with race, has implications for how these factors should be studied. To be consistent with this approach, researchers interested in estimating overall disparities may not want to control for mediating

socioeconomic factors when assessing total disparities by race and ethnicity, as this controls for factors that contribute to the total disparity estimate. Given that the vast majority of research we review has not used this framework, we are limited in the extent to which we can be consistent with this approach. In addition, we are interested in disparities by socioeconomic status as well as by race and ethnicity. Therefore, we consider the paths of race and socioeconomic status separately to the extent possible.

We conceptualize LTC as distinct from settings of care. People with LTC needs generally have chronic conditions and associated functional and/or cognitive limitations that require assistance with activities of daily living (e.g., bathing, dressing, toileting, transferring, eating) or instrumental activities of daily living (e.g., housekeeping, using a telephone, preparing meals, money management). These types of needs can be served in a variety of settings. LTC can be provided in the home (formally or informally), in a nursing home, assisted living facility, hospice, or in an adult day care center, among others, with substantial (but not complete) overlap between settings in level of need and type of care provided. It is often financing—not level or type of need—that determines the setting of care. Coordination of care across settings is rare and, when it exists, often inadequate. Increasingly, experts in aging and LTC call for policies and practice to look beyond settings of care and to focus on care recipients and their needs and preferences more generally (Kane, Kane et al. 1998; Stone 2000). Therefore, while some of the evidence we consider is setting-specific and we discuss it as such, we take a broader, societal perspective where possible.

Current Evidence on Disparities in LTC

Our review and synthesis of the literature is based on a search of PubMed and Web of Sciences databases for peer-reviewed articles dated 1990 or later. Search terms included combinations of "long-term care", "disparities", "race", "ethnicity", "socioeconomic status", "Medicaid", and individual settings such as "nursing home". We included quantitative and qualitative analyses using any type of research design. Bibliographies of papers were searched to identify additional articles. Our search resulted in a total of 54 papers addressing disparities in use and/or disparities in quality of LTC.

Disparities in Use

Racial and ethnic disparities in the use of nursing home care and home health care have been the focus of research for several decades. Studies using data from the 1980s consistently found that blacks were less likely to use nursing home care and that they were more disabled than whites, on average, at the time of admission to a nursing home (Burr 1990; Coughlin, McBride et al. 1990; Salive, Collins et al. 1993; Mui and Burnette 1994; Clark 1997; Wallace, Levy-Storms et al. 1998). A rather large body of evidence tries to identify the main drivers of this difference and establish whether it reflects inequity or simply different preferences and social support networks. A subset of these studies examines potentially compensating differentials in use of other types of care, in particular home health and informal care. While several studies documented greater intent to use home health care among blacks (Webster, Curry et al. 2004) and Hispanics (Crist, Woo et al. 2007) and higher propensity to actually use formal home health care compared with whites—a positive indication in terms of access to home health care--the differential was not great enough to compensate for lower rates of nursing home use

(Wallace, Levy-Storms et al. 1998; Cagney and Agree 1999). Blacks also exhibited higher rates of informal care use and unmet needs, indicating that the difference in nursing home use likely reflects, at least in part, unequal access to formal care (Wallace, Levy-Storms et al. 1998).

Another subset of the studies on differential use of LTC services focuses more directly on the potential roles of attitudes, preferences, and cultural norms, generally using qualitative methods and analyses of survey data. In particular these studies have examined reasons underlying greater use of informal care by racial minorities. Dunlop and colleagues (2002) find that differences in economic access cannot explain differences in use of formal care between Hispanics and non-Hispanic whites and suggests that cultural explanations be explored. McCormick (2002) found that white Americans are more likely to express intent to use home health care in the case of permanent disability such as dementia, while – perhaps surprisingly – Japanese Americans are more likely to intend to use nursing home care, suggesting cultural factors may influence choices in long-term care. Headen (1992) posits that blacks provide more informal care because they face a lower opportunity cost of caregiving due to lower wages in formal labor markets. Generally, compared with whites, blacks express greater intent to use informal care and willingness to rely on informal networks of care (Bradley, McGraw et al. 2002; Bradley, Curry et al. 2004), and blacks are more likely to have friends as well as family in their informal care networks (Burton, Kasper et al. 1995). However, Burton and colleagues found that the total size of informal care networks did not differ by race, suggesting that greater access to informal care also could not explain lower rates of formal LTC use among blacks.

More recent evidence on disparities in nursing home use is mixed; while most agree that the gap has at least narrowed, there is some uncertainty as to whether it has disappeared or even reversed. Several studies that looked at race among other predictors using data from the 1990s

found little or no significant gap in use (Miller and Weissert 2000; Ness, Ahmed et al. 2004; Taylor, Osterman et al. 2005). Akamigbo and Wolinsky (2007) take issue with these conclusions; using 1993-2004 Survey of Asset and Health Dynamics Among the Oldest Old (AHEAD) data, they find that blacks were still 26% less likely than whites to use nursing home care over the 11-year period, controlling for level of need at baseline. However, Smith and colleagues (forthcoming), using combined MDS and census data from 2000, find that blacks' use of nursing homes was actually 14% higher than whites'. The main difference between these studies is perspective: The study by Akamigbo and Wolinsky essentially compares the probability of nursing home use for similar blacks and whites at baseline and finds that these probabilities are still different, while those studies that compute rates of use as a fraction of the population find no disparities in use (Ness, Ahmed et al. 2004; Smith, Feng et al. forthcoming). These conclusions can be reconciled if the underlying health status of black and white populations is different and/or if the level of need is changing at different rates.

All appear to agree on one important driver of the shifts in disparities over time: increased use of assisted living by whites. While the substitution of assisted living for nursing homes among whites increases the supply of nursing home beds available to blacks, it may also simply shift the disparity: Instead of blacks facing restricted access to nursing home care, whites receive care in assisted living while blacks receive care in the nursing home setting (Akamigbo and Wolinsky 2007).

Research on the use of hospice care reveals some similar trends; while some disparities seem to have diminished over time, some unexplained potential inequities remain. Han and colleagues (2006) use nationally representative data to find that rates of hospice use between blacks and whites equalized over the course of the 1990s, correcting a marked disparity in use

found in 1992-94. However, increasing use of hospice has not eliminated differences by race in place of death (Johnson, Kuchibhatala et al. 2005) and Asians and Pacific Islanders are still much less likely to enroll in hospice (Ngo-Metzger, Phillips et al. 2008). Furthermore, blacks are still less likely than whites to re-enroll in hospice after the initial discharge, making it more likely that they will die without the benefit of hospice services even though they were enrolled at one time (Kapo, MacMoran et al. 2005).

Evidence on disparities in use of LTC services by socioeconomic status depends largely on studies of access among Medicaid recipients compared with higher-income elderly, especially access to nursing homes. Issues of access surfaced in the 1980s when states commonly restricted the supply of nursing home beds, leading to high occupancy rates in nursing homes. Because Medicaid recipients are associated with low payment rates relative to private-pay residents, they faced restricted access to this constrained supply of nursing home beds, a situation that health economists called "excess demand" by Medicaid recipients (Scanlon 1980; Nyman 1985). By the late 1990s, however, as the growth of assisted living diverted many wealthier private-pay individuals out of nursing homes, the nursing home industry in most markets became much more competitive and occupancy rates fell, increasing access for Medicaid residents (Grabowski 2001; Grabowski, Ohsfeldt et al. 2003). This change in market structure is also consistent with increased access to nursing home care by blacks in recent years.

Across LTC, however, research shows that people of lower socioeconomic status still face substantial barriers to access to LTC services. Niefield and Kasper (2005) find that Medicare/Medicaid dual enrollees exhibit reduced and less appropriate utilization patterns than their Medicare counterparts and that the barriers to care—including outpatient medical care and a range of home- and community-based services such as adult day care, mobility devices, home

modifications, and transportation services--are organizational and geographic in nature. Jenkins (2001) finds that personal resources are a significant predictor of access to LTC services, especially nursing home care. While many additional studies explore access to care among Medicaid or dually eligible populations, most do not compare Medicaid recipients to other strata of the population and therefore are less directly relevant to the issue of disparities.

Disparities in Quality

The evidence on racial, ethnic, and socioeconomic disparities in quality of LTC (conditional on use) is dominated by studies in the nursing home setting. The evidence is markedly consistent, pointing to a high degree of segregation that largely mirrors residential segregation, with nursing homes that serve largely minority and Medicaid residents usually providing lower quality of care.

Numerous studies document that nursing homes are highly segregated. In a series of papers examining the supply of nursing homes in Chicago neighborhoods, Reed and Andes (2001) document that both blacks and (to a slightly lesser degree) Hispanics tend to reside in nursing homes in their own communities and that the supply of nursing homes – though not necessarily number of beds – is more restricted in black and poor neighborhoods. Other studies corroborate the high degree of segregation in nursing homes across several states (Fennell, Miller et al. 2000) and, more recently, nationwide (Smith, Feng et al. 2007), especially in terms of black-white segregation. Nursing homes are more segregated than other health care sectors and, often, more segregated than the neighborhoods in which they are located (Smith 1990). In addition, while blacks are less likely than whites to use assisted living overall, the same

segregation patterns tend to exist in assisted living as in nursing homes (Howard, Sloane et al. 2002).

Although segregation of nursing homes due to people's preference to stay in neighborhoods where they and their families live may not in itself result in disparities according to the IOM definition, the racial and socioeconomic composition of nursing home residents is highly correlated with quality. Each of the papers above also documented that facilities serving blacks were likely to have fewer resources and lower quality. In seminal work on disparities in nursing home quality, Mor and colleagues (2004) tie the segregation and quality pieces together to describe a health care delivery system with two tiers of nursing home care; the lower tier is characterized by a high proportion of residents on Medicaid and a low level of resources. These lower-tier facilities are more likely to serve black populations, have more health-related regulatory deficiencies, are more likely to be terminated from the Medicare and Medicaid programs, and tend to be located in the poorest counties. Several other studies provide corroborating evidence for these quality differences. Using nationally representative data, Grabowski (2004) found that blacks were disproportionately admitted to nursing homes with a higher number of deficiencies, controlling for individual, facility, and market-level characteristics. Angelelli and colleagues (2006) modeled within-market choice of nursing homes for post-acute care found that blacks and elderly without high school degrees were more likely to be admitted to low-quality facilities. Miller and colleagues (2006) used hierarchical modeling to show that the percent black at a facility level was a predictor of differences in care above and beyond individual characteristics. While that study produced some potential inconsistencies – use of anti-psychotic drugs was higher in facilities with more blacks but physical restraint use was lower – the results underscore the importance of site of care in determining quality.

There is little direct evidence, on the other hand, of within-facility disparities in nursing home care. Studies that find differences in process of care or outcomes of care by race or ethnicity tend to be clinical studies focusing on one aspect of care across nursing homes; the intent of these studies was to point out potential inequities across populations and not to identify whether the differences arise from within-home or across-home differences. Large studies of elderly individuals in nursing homes using administrative data, for example, found that black and Hispanic diabetic residents were significantly less likely to receive anti-diabetic medications than non-Hispanic whites (Spooner, Lapane et al. 2001; Allsworth, Toppa et al. 2005); that Asian/Pacific Islanders, blacks, and Hispanics at risk for secondary stroke received anti-coagulants less often than non-Hispanic white residents (Quilliam and Lapane 2001; Christian, Lapane et al. 2003); that black nursing home residents on antipsychotic drugs in Arkansas were less likely than their white counterparts to take a second-generation antipsychotic (Hudson, Cody et al. 2005); and that black residents of nursing homes in Ohio were less likely than white residents to be diagnosed with depression and less likely to receive treatment for depression conditional on diagnosis (Levin, Wei et al. 2007). A study using medical records from 59 nursing homes in Maryland found that black residents had higher rates of pressure sores (stage 2 and above) than whites and that several facility attributes (size, proprietary status, urban/rural location) did not mediate the effect (Baumgarten, Margolis et al. 2004). Because none of these studies controlled for site of care, it is not possible to determine whether they reveal within-home differences. Combined with the evidence on nursing home segregation and quality, it seems somewhat more likely that the documented differences in process of care arise from racial and ethnic minorities receiving care in lower-quality nursing homes. This conclusion would be consistent with current evidence that disparities by payer source arise mainly from across-facility

differences and not within-facility differential treatment of Medicaid and private-pay residents (Troyer 2004; Grabowski, Gruber et al. forthcoming).

One non-clinical study with a similar research design pointed to disparities in complaint investigations by state ombudsmen. Huber and colleagues (2001) examined data from six states to compare the filing and resolution of complaints about abuse or substandard care on behalf of white and minority residents. They concluded that more complaints were filed by or on behalf of minority residents but fewer were completely resolved. The main study limitation in terms of policy implications is similar to that in the clinical studies cited above, though disentangling the causal pathway is more complicated in this case because of the role of the ombudsmen: Are more complaints coming from minorities because they reside in low-quality facilities and is it simply more difficult to resolve complaints in these low-resource facilities? Or are ombudsmen discriminating among facilities or within facilities by race? Again, while the discrimination explanation cannot be ruled out, the results can be interpreted as consistent with the evidence on segregation and quality.

Evidence on disparities in quality from non-nursing home settings is more mixed and is based on only a few studies. In a study of end-of-life care across multiple settings, perceived quality of care, measured on a number of dimensions related to clinical care, family support, and communication with physicians, was found to be significantly lower among blacks than non-Hispanic whites (Welch, Teno et al. 2005). However, these differences may be due in part to the type of care used; a subsequent study looking only at the subset of people who used hospice care found diminished or no difference in perceived care quality measures by race (Rhodes, Teno et al. 2007). In the home health care setting, Brega and colleagues examined functional outcomes using a nationally representative sample from the Outcomes and Assessment Information Set

(OASIS) and found that blacks fare significantly worse than whites, controlling for functional status upon admission (Brega, Goodrich et al. 2005). That study controlled only for patient characteristics and not for provider characteristics; while the link to segregation and provider resources is less clear than in the case of nursing homes, there remains potential for omitted variables at the provider level that could bias results, and it is unclear whether the disparity is due to discrimination by providers or geographic/financial sorting of care recipients to high- and low-quality providers. Finally, a study of outcomes from twelve nationwide demonstration sites of the Program of All-Inclusive Care for the Elderly (PACE) found a slight "reverse" disparity in outcomes for black and white participants in that black mortality rates were lower, especially after participating in PACE for at least one year (Tan, Lui et al. 2003).

Study Designs and Statistical Methodology

The studies reviewed above are, without exception, observational studies. Because individuals cannot be randomized to race or socioeconomic status and conducting true experiments with issues such as neighborhood characteristics and segregation is extremely difficult, the topic lends itself to the use of secondary data and controlling for confounding factors through multivariate adjustment or quasi-experimental design. Most of the studies we reviewed relied on cross-sectional analysis with multivariate adjustment as opposed to more rigorous quasi-experimental designs, resulting in very little variation in quality of the research – the documented association were generally credible but did not lend themselves to causal inference. Cross-sectional analyses suffer from the important limitations of omitted variable bias, inadequate risk adjustment, and an inability to establish temporality, all of which preclude causal inference and can lead to widely different estimated magnitudes of effect. Nonetheless,

given these limitations, the evidence is surprisingly consistent; the limitations speak more to the difficulty of translating this evidence into appropriate policy.

To move from documenting disparities to analyzing and identifying potential policy and practice modifications, it would be useful for future studies—even those focused on specific processes or outcomes of care—to address whether disparities arise from within-provider or across-provider variation. In multivariate studies of nursing homes using large administrative databases such as Medicare/Medicaid claims or the Minimum Data Set (MDS), this can be accomplished quite easily – at least as a preliminary investigation – by including facility-level fixed effects. (This distinction cannot be gleaned from the facility-level clustering of standard errors alone.) If a disparity exists across the entire sample studied but diminishes in magnitude or disappears when site of care is controlled through the fixed effects, it is likely that the disparity arises from differences in quality from facility to facility (in conjunction with segregation) as opposed to within-facility discrimination. Clearly, the implied pathways and implications for action are quite different in these two cases, and distinguishing between the two is well worth the incremental effort of implementing the fixed effects model.

Instrumental variables methods offer an additional potential tool for advancing this literature, in particular in identifying causal effects from observational data. Because race and socioeconomic status are often correlated with unobservable health characteristics and because people are not randomly assigned to providers, between-group comparisons of utilization and outcomes may be confounded by selection bias. With valid instruments that are correlated with choice of provider and uncorrelated with utilization and health outcomes – for example, changes in state policy or local funding – it may be possible to control for selection bias within and across providers, improving the validity of comparisons.

Analysis of Market-Based Policies in Terms of Potential Effect on Disparities

LTC, like other types of health care, differs from other types of goods in that the lack of information on quality may reduce consumers' ability to choose high-quality services and, accordingly, reduce providers' incentive to compete on the basis of quality. In addition, the existence of third-party payment such as Medicaid, with associated rules about utilization designed to reign in costs, may distort individuals' decisions as to the most appropriate and cost-effective care. Each of the policy initiatives we consider in this paper is directed at increasing the accessibility and use of information and/or consumer control, in an attempt to make LTC markets function more like markets for other goods. Thus, we refer to them broadly as market-based incentives. These incentives may be aimed at providers, consumers, or both. Because changes in both disparities in use and quality may result from these policy initiatives, in the discussion that follows, we do not distinguish policies by their intended effect on access and quality; rather, we discuss each potential effect as applicable. We focus on market-based policies because they are increasingly popular while having significant potential for unintended consequences.

Over the past decade, major initiatives have been undertaken to address quality shortfalls in LTC. Early efforts were implemented through regulations. In nursing homes, for example, the Institute of Medicine (1986) issued a landmark report calling for major revisions in the way quality is monitored, prompting Congress to pass the 1987 Nursing Home Reform Act or OBRA. As a result of OBRA, each Medicare- and Medicaid-certified nursing home is inspected regularly and is required to submit regular comprehensive assessments of each resident. While OBRA led to some quality improvements, such as a drop in restraint use, psychotropic drug use, and

catheterization (Kane, Williams et al. 1993; Shorr, Fought et al. 1994; Castle, Fogel et al. 1996; Snowden and Roy-Byrne 1998), and slower rates of functional decline and hospitalization (Fries, Hawes et al. 1997; Mor, Intrator et al. 1997), significant problems with quality of care remained (Wunderlich and Kohler 2000). Home health care, while perhaps not beset with the same history of quality problems, has engendered similar increases in regulation and data collection for monitoring.

With regulation failing to fully reform long term care quality, the persistent problems of inadequate quality were attributed, at least in part, to the lack of information about quality with which to stimulate consumer choice of care and provider competition for high quality care. Thus, QI efforts have increasingly attempted to harness the power of individual decision-making by using market-based incentives and show promise in terms of improving the average levels of access and quality (Castle and Lowe 2005; Dale and Brown 2007; Kemper 2007; Mukamel, Spector et al. 2007).

Differential Consumer and Provider Response to Market-Based Incentives

The effect of market-based reforms aimed at improving quality of care on disparities is unclear. On one hand, these initiatives present an opportunity to improve access to and quality of LTC. As low-quality care may have the greatest potential for improvement, these policies may ameliorate disparities. However, concerns have emerged pointing to the potential for disparities to increase under these initiatives. There are numerous reasons consumers and providers might have differential responses to market-based incentives, and the effect on disparities (either worsening or ameliorating them) is unclear. We discuss the potential drivers

of differential response in general terms below, followed by a more detailed discussion of specific policy initiatives.

Accessing, Processing and Understanding Information

Consumer-driven changes in quality rely in large part on consumers' use of information about the quality of available care to make choices in care. These initiatives may increase disparities if the use and understanding of quality information is heterogeneous by resident characteristic, such as race or socioeconomic status. Information may be more accessible to residents who are educated or wealthy (Jewett and Hibbard 1996). If this is the case, we would expect the consumer response to quality information through increased choice of high-quality providers to be most pronounced among residents of high socioeconomic status, increasing disparities (Mor 2005). One study that modeled within-market choice of nursing homes for post-acute care found that blacks and elderly without high school degrees were more likely to be admitted to low-quality facilities (Angelelli, Grabowski et al. 2006).

A related point is that reliance on consumer use of quality information raises additional concerns about disparities in the use of the Internet and other electronic resources. Quality information is often disseminated though the Internet. There are numerous barriers to widespread use of information technology, and these barriers may differentially impact low-income health care consumers and racial and ethnic minorities who may have limited means to access or effectively use information technology to obtain health care information (Brodie, Flournoy et al. 2000; Baker, Wagner et al. 2003; Hsu, Huang et al. 2005; McNeill, Puleo et al. 2007; Lorence and Park 2008). In addition, although information technology use is largest among those age 50-64, its use drops substantially among older age groups, particularly above

the age of 75 (Brodie, Flournoy et al. 2000; Baker, Wagner et al. 2003; Hsu, Huang et al. 2005) and for elderly who are low-income or racial or ethnic minorities (Brodie, Flournoy et al. 2000). The use of the internet has increased dramatically over time among all sociodemographic groups (Pew Research Center), but there is mixed evidence on changes in disparities over time. One study found that racial differences in Internet use have abated, while an education gradient remains (Rice and Katz 2003). Other studies have found that disparities between race and income groups have increased (Hsu, Huang et al. 2005; Lorence and Park 2008).

Despite the discouraging news that disparities in use of information technology may be increasing, this technology nonetheless offers a powerful potential solution to disparities in health care. Strategies to reduce barriers to information technology might improve access to care particularly among low-income and racial and ethnic minorities, and thus may reduce disparities. These strategies include providing universal access to information technology, producing applications for the diversity of users who may access this information, ensuring the quality of available information, and conducting community outreach and training intermediaries to assist with information technology and disseminating information (Eng, Maxfield et al. 1998; Cashen, Dykes et al. 2004; Gibbons 2005; Gilmour 2007).

Supply

Another potential explanation for the disproportionate use of low-quality facilities by racial minorities is a lack of supply close to home. Fewer nursing homes are located in neighborhoods that are predominantly populated by racial minorities, and those that are located in minority neighborhoods tend to be of lower quality (Reed and Andes 2001; Reed, Andes et al. 2001; Mor, Zinn et al. 2004). One study that examined nursing home placement by race found

that the local supply of skilled nursing beds was an important factor in entering a nursing home for blacks but not for whites (Akamigbo and Wolinsky 2007). Market-based QI incentives rely in part on adequate supply and choice in health care providers; information about the quality of providers is not useful if access to high-quality providers close to home is restricted.

Provider Resources

Differences in provider resources may affect response to market-based incentives. If provider resources are greater among facilities that care for white or high-income residents, differential resources may play a role in increasing disparities between facilities. Researchers have documented that low-quality facilities tend to have worse financial performance in terms of profit margins and percent of private-pay residents (Weech-Maldonado, Neef et al. 2003; Weech-Maldonado, Neff et al. 2003; Smith, Feng et al. 2007) and that racial minorities and low-SES elderly tend to be in low-quality facilities (Grabowski 2004; Mor, Zinn et al. 2004; Angelelli, Grabowski et al. 2006; Smith, Feng et al. 2007). Because most QI efforts require significant financial investments, this raises the possibility that market-based incentives will induce improvements in facilities that are already well financed and of high quality, while low-quality facilities improve at a slower rate or remain stagnant due to lack of resources, thus increasing disparities. Furthermore, in the nursing home sector, potential exit of low-quality facilities from the market as a consequence of public reporting has been noted as a potential problem rather than a QI success. Although exit of low-quality facilities may be quality-improving, there may be a trade-off with access depending on the availability of alternatives, including other nursing homes or home- and community-based care options. Because underserved individuals are those most likely to be in low-quality facilities, exit of these

facilities could leave underserved elderly with even fewer options (Angelelli, Mor et al. 2003; Mor, Zinn et al. 2004; Angelelli, Grabowski et al. 2006).

Current Market-Based Policy Initiatives

In what follows, we discuss three major market-based policy initiatives designed to improve quality of LTC that may impact disparities by differentially changing both access to and quality of care by racial and ethnic and/or socioeconomic group: 1) public reporting of quality information; 2) pay for performance; and 3) consumer-directed care. All three are directly aimed at improving quality of care but may paradoxically exacerbate disparities in quality. Public reporting and pay for performance may also worsen access to care and thus affect disparities in use. Consumer-directed care, on the other hand, has the potential to improve access to LTC.

Public Reporting of Quality Information

Without publicly reported comparative information on health care quality, patients may choose health care providers based on more observable characteristics (such as cost) or by word-of-mouth or other informal referral practices not obviously related to their needs. By taking measurable information about health care quality and putting it in the public domain, public reporting may improve health care quality in two ways: First, public quality information may allow those seeking health care to preferentially select high quality providers. Second, public reporting may motivate providers to compete on quality and, by providing feedback and by identifying areas for QI, help providers to do so. Although the idea that patients will use public report cards to select the best clinical providers is plausible, the process depends on several conditions being satisfied: 1) patients (or their agents, such as discharge planners or adult

children) must know about the report cards and have access to them; 2) patients must be able to understand the quality rankings, believe them, and find them meaningful in terms of identifying the most important aspects of quality; and 3) patients must act on the report card information and not face overriding constraints to prevent action, such as a limited supply. For provider-driven quality improvement to occur, providers must similarly have access to the information, understand it, find it meaningful and important, and be able to act on the information.

Public reporting has been extensively adopted in long term care. Starting in the late 1990s, the federal government and some states began publicly rating nursing homes on the care they provided with regards to staffing ratios, patient outcomes such as rates of pressure sores and restraint use, and deficiencies. Then, in 2002, through the Nursing Home Quality Initiative, CMS released Nursing Home Compare, a guide detailing quality of chronic and post-acute care at all Medicare or Medicaid certified nursing homes (Centers for Medicare and Medicaid 2002). Shortly after the launch of the Nursing Home Quality Initiative, CMS followed with the Home Health Quality Initiative in 2004. Like Nursing Home Compare, Home Health Compare gives consumers information on the quality of care provided by home health agencies and thus selected aspects of quality are now measured and publicly reported for every Medicare-certified home health agency in the United States (CMS, 2003). Despite the substantial challenges, preliminary evidence suggests modest improvements in several measures of quality following the implementation of Nursing Home Compare (Zinn, Spector et al. 2005; Castle, Engberg et al. 2007).

While public reporting may increase quality of care on average, it has the potential to worsen racial disparities in access and quality. This may happen because underserved patients may have limited access to both quality information and high-quality providers, blunting

consumer-driven changes in quality with less selection of high-quality providers compared to patients who are more educated, wealthier, and live in areas with greater supply of high-quality providers. Additionally, if providers that predominantly serve poor and underserved individuals lack the resources necessary to invest in QI, then provider-driven QI will be smaller for these patients. It is also possible that market forces under public reporting will force low-quality providers that predominantly serve poor and underserved individuals to exit the market. If this further limits available choices for poor and underserved persons, this could exacerbate disparities in use of long-term care.

Pay-For-Performance

Pay-for-performance is an increasingly popular policy tool that uses financial incentives to motivate providers to improve quality of care. Under a traditional fee-for-service payment system, health care providers are paid based on volume or the intensity of services provided. In contrast, pay-for-performance places the emphasis on value rather than the intensity of care (Robinson 2001); bonuses are paid for achieving targeted thresholds of quality as represented by scores on selected quality measures. In some pay-for-performance schemes, bonuses are also paid based on improvement in scores over time. Thus, like public reporting, pay-for-performance creates an environment where health care providers are motivated to compete on quality, but the pay-for-performance incentives exist even in the absence of a consumer response. The financial incentives are also expected to help offset investments needed to support QI, such as investments in additional staff or training.

As such, numerous initiatives have been undertaken to implement pay-for-performance for physicians and physician groups (Centers for Medicare and Medicaid 2005), hospitals

(Centers for Medicare and Medicaid 2003). More recently, state Medicaid agencies have begun implementing pay-for-performance in nursing homes (Kane, Arling et al. 2007). In addition, the Centers for Medicare and Medicaid (CMS) plans to implement a nursing home pay-for-performance demonstration project in up to 5 states in 2008. A CMS two-year home health care pay-for-performance demonstration project is already underway in 7 states, though no results are available yet. The home health care demonstration incorporates bonus payments for top-performing home health agencies and those that improve the most based on 7 measures of quality, with the bonus payments to be drawn from savings in overall Medicare costs.

Pay-for-performance is predominantly used in conjunction with public reporting, and thus the effect of pay-for-performance may be similar to that of public reporting. In addition, because of the direct financial incentives of pay-for-performance, it may amplify the provider-driven increase in disparities observed under public reporting if payments reward providers that already have more resources (Rosenthal, Frank et al. 2005). Like public reporting, resource-poor facilities (that also serve racial and ethnic minorities and low-income people) may have smaller improvements in quality due to lack of resources to invest in QI, and thus be less likely to receive the direct financial incentives of pay-for-performance. This may further worsen their finances and potential for QI. In this way, pay-for-performance may widen the disparities between rich and poor facilities (Werner, Goldman et al. 2008).

Additionally, under public reporting and pay-for-performance, providers may avoid individuals of minority race or low socioeconomic status. Werner and colleagues (2005) found an increase in racial disparities in CABG use due to New York's CABG report card. These results suggest that surgeons responded to CABG report cards not just by improving quality, but also by "cream-skimming"--avoiding patients perceived to be at risk for bad outcomes, such as

blacks and Hispanics. Thus, disparities increased even as average mortality decreased, providing one example in which these concerns translated into increased disparities in practice. Studies of this issue in LTC settings have not yet been studied, but the same potential exists. In addition, the potential exists for LTC providers to "selectively discharge" to the hospital individuals who get sick. If nursing homes and home health agencies serving minorities and residents of low socioeconomic status are more likely to engage in selection, or if perceived risk of outcomes is correlated with race or socioeconomic status, disparities in access and hospitalization may increase.

Consumer-Directed Care

Consumer-directed care provides financial incentives for consumers to become involved in purchasing decisions regarding their health care, with the goal of simultaneously increasing choice and satisfaction and decreasing cost. In the health care system more broadly, the most typical manifestation of consumer-directed care involves high deductible health plans paired with health savings accounts. However, consumer-directed care is seen as particularly promising for people with chronic diseases and people with LTC needs and is therefore garnering increased attention among LTC stakeholders. Under consumer-directed care, consumers choose how to spend insurer contributions, and thus may be more sensitive to price and quality than they would be under typical insurance, creating efficiency and encouraging providers to compete to meet their health care needs. In addition, consumer-directed care expands choice of type of provider, potentially counterbalancing existing financial incentives that often determine care settings. In both ways, the quality of that health care would improve.

A number of policy changes have been made to facilitate a shift toward consumer-directed care, including the authorization of demonstration projects. In LTC, the grass-roots "culture change" movement incorporates the principles of consumer-directed care into its vision for nursing homes, and policy makers are increasingly looking for ways to support and promote the movement. Consumer-directed care has also been implemented by several state Medicaid programs, giving consumers a cash allowance with which to purchase needed LTC services. A Medicaid demonstration project, Cash and Counseling, was implemented in three states from 1999 to 2003 to evaluate how Medicaid beneficiaries fare in a system that allows them to direct their own personal and community-based services—including the paying of informal caregivers--with a defined contribution from their state's Medicaid program. Unlike many health care savings accounts, Cash and Counseling is accompanied by state consultants who help beneficiaries with their decision making. The design of the demonstration included randomization to treatment and control groups. Results showed that the consumer-directed program increased satisfaction with care and decreased unmet need, with a modest increase in cost and no significant change in clinical outcomes (Carlson, Foster et al. 2007). Cash and counseling has since been expanded to other states.

Numerous concerns have been raised, however, about the potential for consumer-directed care to exacerbate disparities in long term care. These concerns, which have not yet been studied empirically, relate in part to the unequal access to and use of quality information between racial/ethnic and income groups. If low-income groups are less able to navigate or access choices and search out appropriate caregivers, disparities may worsen. In addition, if low-income consumers are particularly cost-sensitive, they may be inappropriately directed toward lower levels of care than needed. On the other hand, consumer-directed care may also

ameliorate disparities in several ways. Consumer-directed initiatives such as Cash and Counseling may reduce disparities in use of long-term care by giving Medicaid recipients greater choice in care options. The availability of more funding for home- and community-based care could induce increased supply of these services in neighborhoods that previously had little and thereby reduce disparities in use of these services. In addition, because consumer-directed care often allows payment for informal caregivers, this may create paying jobs in low-income communities, where informal caregiving is prevalent and otherwise unpaid.

Potential Policy Modifications

Barring a grand social intervention that would eliminate discrimination and underlying inequities in education, income, and neighborhood infrastructure, there is no single intervention or even set of interventions that could counterbalance all potential pathways to increased disparities under market-based reforms. However, in what follows, we describe several policy approaches that could be used to mitigate disparities along at least one dimension in conjunction with market-based incentives, thereby encouraging improved quality and access for all social strata.

1. The concept of "medical homes" should be developed and encouraged for the elderly. These medical homes might act as agents in relaying and helping with information interpretation and informed decision making on LTC delivery options and quality, thus countering the fragmented LTC delivery and financing system to some extent. In primary care settings, "medical homes" emphasize the use of teams of people (including physicians and nurses, case managers, and social workers) to provide systematic, patient-centered, coordinated care management processes to improve access to and quality of care. In this setting, care is

facilitated by registries, information technology, health information exchange and other means to assure that patients' needs are met in a culturally and linguistically appropriate manner. Medical homes, often established through a primary care provider or a managed care organization, may be particularly beneficial to individuals with low-socioeconomic status who have traditionally had the most difficulty successfully navigating the health care system, but could be promoted flexibly depending on individual preferences and needs.

2. Researchers and policymakers should continue to develop ways of summarizing and presenting quality information to make it understandable, manageable, and useful in decision making. Making the wealth of available information more usable will increase the likelihood of achieving an equitable benefit from information.
3. Public reporting of quality information should be accompanied by informational and educational campaigns that target minorities and elderly of low socioeconomic status, including the availability of quality information in Spanish. Targeted recipients could also include hospital discharge planners and working-age adults who may be involved in care planning decisions of a patient or parent.
4. Pay-for-performance schemes should base rewards, in part, on improvement in quality as well as absolute levels of quality. While rewards based on quality thresholds give high-quality providers incentive to maintain high quality, improvement-based incentives give low-quality providers both the incentive to invest in QI even when a threshold-based reward is unattainable and, by rewarding improvements with financial incentives, improvement-based incentives give low-quality providers the necessary resources to further invest in QI to meet a high-threshold reward. By rewarding improvement as well as level, all providers face an incentive to improve quality and maintain high levels of quality and disparities in quality

may be reduced. The CMS home health care pay-for-performance demonstration may provide an empirical basis to further inform this point.

5. QI efforts of low-resource providers should be subsidized. The subsidy might be incorporated directly into a QI incentive, e.g. setting aside a greater proportion of pay-for-performance rewards for low-resource providers, or indirectly through other funds (from Civil Monetary Penalties imposed on nursing homes, for example, or through increased Medicaid rates tied to QI efforts). These subsidies may increase the likelihood that low-resource and low-quality facilities can achieve sustainable QI. Subsidies would have to be linked to quality improvement efforts to avoid creating additional incentives for segregation.
6. To promote choice of appropriate and efficient options among all social strata, Medicaid expansion into home- and community-based care should be encouraged and maintained, including the ability to pay informal caregivers. This is likely to work best in conjunction with a "medical home", case management, available guidance, or other way of ensuring effective communication of options, which could mitigate the potential adverse effects of this shift.

Research Priorities

While existing evidence on disparities in LTC is largely consistent, important gaps in the research base remain if policymakers and practitioners are to draw on this evidence to reduce disparities. We classify the resulting research priorities into four main categories:

1. *Research that explores the source or causal pathway of existing disparities*. The source of disparities has clear implications for policy and practice interventions, and moving from documenting disparities to designing interventions assumes some knowledge of the cause of

disparities. If disparities are rooted in differential treatment by the same providers, interventions might target the use of decision-making pathways or direct incentives to ensure equal treatment. If disparities are rooted in segregation and differential treatment due to choice of provider or site of care, then interventions might target neighborhood infrastructure and provider resources. As noted earlier, a first step in quantitative studies is to use readily available methodological tools such as fixed-effects models to separate within-provider discrimination from across-provider disparities. A complementary approach is to use qualitative and survey research to expand what we know about how consumers of different social strata use information on LTC quality, how they choose providers in this context, and how and why high-quality and low-quality providers respond (or do not respond) to market-based incentives.

2. *Research that tests the effect of QI initiatives on disparities*. While the discussion above reveals multiple strong reasons why disparities may increase under market-based reforms, the potential also exists for disparities to be ameliorated. There is little empirical evidence to back up concerns about increased disparities or to quantify the magnitude of effect of this unintended consequence. As data and preliminary conclusions on interventions such as Nursing Home Compare, Home Health Compare, and consumer-directed care begin to emerge, a second generation of studies should be undertaken that examines the results in terms of disparities. Future evaluations of QI initiatives should consider examining the effect on disparities in care as a key component of the initial evaluation.
3. Research that tests policy and practice modifications. If research does indeed reveal that increased disparities result from efforts to improve quality through market-based incentives, research is needed to assess whether specific policy and practice modifications, such as those

suggested above, are effective in mitigating this unintended consequence while maintaining the overall goals of improving quality. Policy changes should include, whenever possible, elements of an experimental design so that effectiveness can be evaluated.

4. Research on more racial and ethnic groups and on non-nursing-home settings. The research documenting disparities in LTC, especially disparities in quality, focuses mainly on black-white comparisons and on nursing homes. As Hispanics and other races/ethnicities make up an increasingly larger proportion of the US population, it will be important to identify the distinct disparities issues associated with each group. Likewise, as we strive to view LTC as increasingly home- and community-based, the proportion of research focusing on settings other than nursing homes needs to expand accordingly. The availability of large databases such as OASIS that include large sample sizes from multiple racial and ethnic groups should facilitate this shift.

The existence of disparities in access and quality in LTC is well documented, and reducing disparities in the US health care system is a national priority. While the research priorities described above may not be necessary to justify policy interventions and modifications to reduce disparities in LTC, it would help to identify the types of interventions that are most effective, and those that can work in harmony with the goal of improving overall quality and access. Adopting new interventions to decrease disparities and improve quality of care without a better understanding of what causes and changes these disparities would risk inadvertently worsening existing disparities.

The results of this analysis raise several issues with broad policy implications beyond our specific suggestions for policy and research. First, while the pathways are undoubtedly complex and the research base somewhat incomplete, it appears that residence may be more important

than race in explaining disparities in LTC. This is consistent with evidence from other health care sectors (Baicker, Chandra et al. 2004). The implications for policy are that efforts to reduce within-provider discrimination may have only a negligible effect on disparities; the remaining challenge to reduce disparities arising from residential and across-provider segregation is the more difficult one. Second, the analysis clearly points out that there may be trade-offs involved in the dual priorities of increasing the overall quality of and access to LTC and reducing disparities; an unanswered question is how much of a trade-off in one is worth improvement in the other. While this question may be unanswerable, to ignore the issue nonetheless results in a choice by default. As market-based incentives take on increased momentum in LTC, it seems explicit consideration of the issue of equity is long overdue.

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