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MAKING BETTER LONG-TERM CARE DECISIONS

Robert L. Kane, MD

WHAT IS THE PROBLEM

Older persons and their families often must make crucial decisions about long-term care (LTC) under very stressful and limiting circumstances; these decisions can affect the rest of their lives. A series of unfortunate factors may coincide to make these momentous decisions even more difficult. Most of the participants are ill informed and inexperienced on the topic.¹ The decisions are often made at the end of a hospitalization when there is great pressure to implement the discharge quickly.² In effect, the first train leaving the station is the best one to be on from the hospital’s perspective, regardless of the destination. There is likely disagreement among family members about the best course of action. Making these decisions may stir up serious underlying family conflicts. This is not the best time or place to act. It is often unrealistic to assume

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that a good decision can be made quickly. It is equally unrealistic to assume that enough time will be allowed to make the best decision.³

PREREQUISITES FOR A GOOD DECISION

In general, making a good decision requires several elements, which are applicable to the LTC situation:⁴

1. You need accurate information about risks, benefits, and costs associated with each option.⁵

2. But even before that, you need real options (that are actually accessible in a realistic time frame). Theoretical options may not help if there is a strong pressure to act. Options that take time to craft may have less valence than those that are immediately available. Thus, the pressure of time and circumstance may drastically limit real choices or at least appear to limit them.

3. It is essential to clarify just what goals take precedence. What are you trying to maximize? Before you can choose among goals, however, you need first to identify the contenders. These goals should be expressed in more general terms than modes of care; they should address outcomes that affect quality of life, rehabilitation, and safety concerns.⁶

4. Once the candidate outcomes have been identified, it is important to ascertain the level of consensus on each outcome among various decision makers. These include the older person herself, family members, and in some cases involved professionals (although some would argue that the professionals have no stake at this stage and instead should

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⁵ Id. at 474.
⁶ See generally, Mayo Clinic Staff, *supra* note 3.
be advisers and facilitators).\textsuperscript{7}

5. Making such complex decisions takes time. It takes time to comprehend the scope of the problem and more time to work through the conflicts that may surround it. It takes time to develop a satisfactory plan and assemble the requisite components.

6. It seems naïve to think about this kind of complex, emotional process as being a do-it-yourself proposition, especially by neophytes. Families need support and direction (including managing family conflicts). They need information but they may also need a referee and someone to keep them focused on the issues at hand.\textsuperscript{8} They may need help assembling solutions and warding off those who would pressure them to reach quick answers. They need an advocate who will stand up to those representing interest groups. Hospital discharge planners (and even welfare case workers) cannot be construed as family advocates; they work for other interests.\textsuperscript{9}

7. Making decisions this complex requires imposing a structure that leads the involved parties through a systematic process.\textsuperscript{10} For example, it is helpful to separate discussions about what type of care is sought from who should provide it.

\section*{Current Situation}

The way LTC decisions are generally made today stacks up poorly against the criteria just listed. LTC decisions are often made as part of hospital discharges.\textsuperscript{11} Because they are paid a
fixed amount for each stay, hospitals perceive themselves as under financial pressure to discharge patients quickly. They assign discharge planners whose marching orders are to get the patient out before "the end of the end." Naïve families may view the discharge planner as their ally, but in fact, these people are hospital employees with a clear mission based firmly on expediency. Requiring complex decisions, which often involve complicated arrangements requiring the coordination of several agencies and people, be made under the intense pressure of time seems doomed to fail.

The situation around LTC decisions from the community may be better only to the extent that the time pressure may be less, but these decisions too may be precipitated by a crisis. The older person gets worse or commits one additional act that breaks the back of the caregiving camel. Moving from a community situation may raise additional issues because it could be interpreted as caregiver failure (often by the caregiver). Hence, intermediate options that might ease the burden but permit continued living in the community (such as hiring home help) may be forgone. It is more often an all-or-nothing response.

Although good information is a prerequisite for informed decisions, it is scarce in LTC. Nursing Home Compare and Home Health Compare offer a little data about the quality of some settings, but they do not address the relative effectiveness of different settings for different types of clients, or their livability. Instead, most information comes from professionals,
who may have a bias.\textsuperscript{17} Hospital discharge planners may be inclined to recommend nursing homes because they come as a ready-made package of services.\textsuperscript{18} In many instances, they may never have actually seen the facilities they recommend. Family may rush to consider institutions because such a choice justifies the decision to take a major step, or they may simply be oblivious to other alternatives. One loud convincing voice can carry the day.

\textbf{LEVELS OF DECISIONS}

In theory, a good LTC decision would occur in two distinct steps.\textsuperscript{19} The first question to be addressed focuses on defining what modality of care is best.\textsuperscript{20} What type of care is most likely to result in maximizing the highest valued goals or outcomes? Once that question is resolved, the next issue involves determining which vendor of that type of care is best.\textsuperscript{21} Indeed, addressing each of these questions involves using different criteria. The first is largely a question of effectiveness, whereas the second encompasses elements of individual preferences about how one wants to live.\textsuperscript{22} Certainly, quality is a concern, but so is ambience.

In truth, however, the two decisions are more intertwined. Lifestyle preferences may influence both. In some cases, for example, the choice of a modality may depend on getting care from a highly rated vendor. The same type of care from a less prized source may be less desirable than another type of care from a good source. Likewise, availability and affordability play big roles. Getting on the waiting list for one's first choice does

\begin{flushleft}
\textsuperscript{17} Who Recommends, supra note 4, at 475, 480. \\
\textsuperscript{18} See id. at 475, 481. \\
\textsuperscript{19} Robert L. Kane et al., Helping People Make Better Long-Term Care Decisions, 47 The Gerontologist 244, 244 (2007) [hereinafter Helping People]; Who Recommends, supra note 4, at 474. \\
\textsuperscript{20} Helping People, supra note 19, at 244; Who Recommends, supra note 4, at 474. \\
\textsuperscript{21} Helping People, supra note 19, at 244; Who Recommends, supra note 4, at 474. \\
\textsuperscript{22} Helping People, supra note 19, at 244; Who Recommends, supra note 4, at 474. 
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little to alleviate the present crisis. For some older people, spending money, their own and even the government's, can be of great concern. Many may hope to preserve a financial legacy and postpone buying care. For example, some older people will defer spending money and “make do,” preferring to save it for the perennial “rainy day,” when they “really need it.” In some instances, this behavior presents a paradox. Government case managers are urging home care that the older person could never pay for on her own. The rationale is similar to that for preventive care. Presumably, the theory holds that such care will ultimately save money by delaying institutionalization, although some elderly and their families may disagree.

In general, decision-making should follow the two steps, dealing separately with what kind of care is best before dwelling too long on who should provide it. The priorities are different for each step. In the first phase, decisions about what care is best are predicated on what type of care will be most effective and least harmful. A central issue will be the role families are prepared to play. Often, home based options are feasible only if there are family members available and willing to play an active role in care; but this care may come at a high cost. Hence, honesty is essential, if politically difficult. Tolerance of risk is another issue that may require resolution within the family. There may be wide differences; the older person may be more

23. See generally What Older People Want, supra note 11, at 118 (discussing how hospital discharges require the need for quick action and available services).


25. See id. at 6.

26. See Who Recommends, supra note 4, at 474.

27. Helping People, supra note 19, at 244.

28. KAISER FAM. FOUND., supra note 2.

willing to take risks than is his or her family. Cost and coverage are also salient concerns. People paying privately will be anxious about the costs (in effect, making a crude cost-effectiveness calculation). Those covered by Medicaid will be limited by the program’s coverage policies. Obviously, access must also weigh heavily; availability of slots will bind the choices.

Preferences around specific vendors are likely to be based on issues around convenience and location. Older people want to be in situations where family members can visit them easily. Quality issues should be salient, but may be misunderstood. Although many people suffer under the misperception that bad places would not be allowed to operate, some are aware of the variations in quality and make use of publicly available information on quality inspections and surveys and data derived from mandated reporting systems. Many more would like information on quality of life, which is generally not available. The nursing home report card in Minnesota does provide data derived from actual interviews with nursing home residents about their quality of life. It is the most actively sought component of the report card.

For some residential options, other factors, like ambience or resident composition, religious orientation, activity options, or even a smoking policy, may be important. People may prefer to be with people similar to them. Obviously, cost is a major consideration as well.

30. What Older People Want, supra note 11, at 116-17.
31. Helping People, supra note 19, at 244.
32. Id.
33. Id.
35. See NH Compare, supra note 16; see also HH Compare, supra note 16.
36. A Quality-Based Payment Strategy, supra note 34, at 111.
37. See generally Jeremy Olson, Nursing Home Ratings Debut: Online System Aims to Equip Consumers with Key Information, PIONEER PRESS, Jan. 21, 2006, at 2B.
38. Helping People, supra note 19, at 244.
DEFINING GOALS

Setting goals for LTC is difficult. Most people do not think about expected courses in the context of LTC. \(^{39}\) Instead, they view it as an end game. However, different types and quality of care can make a real difference in changing the trajectory of care. \(^{40}\) While it is difficult to reverse the clinical trajectory and make people at this stage dramatically better, it is probably feasible to slow the rate of decline in both function and quality of life. The first step is to distinguish the need for post-acute care from LTC. The former refers to the short-term rehabilitation and recuperation associated with post-hospital care. \(^{41}\) It may indeed be associated with return to a functional active lifestyle. Among those with true LTC needs, the choices may differ depending on whether physical, functional, or cognitive needs predominate, although both can present together as well. \(^{42}\) Those who are cognitively intact may have stronger needs for a livable environment that permits them to enjoy as much freedom and control as possible. Depending on their level of impairment, those with cognitive difficulty may have different responses to their environment; concerns about wandering may dictate the design of the environment. \(^{43}\) For those at the very end of life, different criteria may apply, although there is a legitimate question about why the opportunities extended to this group in the form of hospice care (e.g., close attention to alleviating discomfort, flexible rules for

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39. What Older People Want, supra note 11, at 118.
40. See generally Mayo Clinic Staff, supra note 3 (discussing the levels of long-term care, the services each level provides, and methods for looking into long-term care facilities' quality).
visiting, concern over anxiety and depression) should not be available to many of those who still have considerable life expectancy.44

Families are usually unfamiliar with thinking in terms of trajectories and goals based on outcomes.45 They are more accustomed to addressing questions regarding the structure of care (e.g., how much and what kind of care is needed).46 They likely need guidance and direction in working towards consensus and closure around goals, especially when many of those goals involve some degree of risk-taking.47 Especially at the later stage of life, discussions about maximizing goals mean facing trade-offs. Families have to confront the task of weighing conflicting goals (e.g., safety versus autonomy; functional gain versus quality of life).48 They must deal with their own risk aversion.

**DETERMINING WHICH OPTION BEST FITS MOST IMPORTANT GOALS**

Once there is some consensus around the goals to be maximized, it is only logical to juxtapose the available models against the expected outcomes from each care modality to determine which approach(es) are most likely to achieve the desired results.49 In the absence of hard data on the likely

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45. See generally Helping People, supra note 19, at 244 (discussing how consumers frequently "act on the advice of professionals or friends who may offer only limited options based on their own predilections").
46. See, e.g., Mayo Clinic Staff, supra note 3 (discussing the "Types of long term care," "How to choose the right long term care facility," and "Paying for long term care").
47. See Barry, supra note 8, at 127 (discussing how health decision aids help facilitate shared decision-making); see also Helping People, supra note 19, at 247.
48. What Older People Want, supra note 11, at 116-17.
49. See Helping People, supra note 19, at 244, 246 ("Relevant items that affect the [long-term care] decision of care produces the best results. Behind that question is a clear specification of just what outcomes one hopes to maximize." The article also discusses a computer program that provides consumers with information about long-term health care providers that is relevant to their choice of modality and the
outcomes of care, we may need to fall back on expert opinion. But that opinion should be treated as suggestion, not dictate. The "expert" opinion should be examined in the light of family preferences.

**CHOOSING A VENDOR**

Choosing the agency that can best deliver the type of care selected requires exploring a new set of issues. The first step at this stage is to clarify what elements are most important, i.e., what issues around choosing a place to live or the care received are of greatest concern. The issues addressed will likely vary by type of vendor selected.

Because access issues are usually central (to facilitate family visiting and because a bird in the hand counts more than potential ones in the bush when action is needed quickly), the choices should be organized around that variable. For example, you can sort nursing home report card information around nursing home quality by zip codes. Other sources of information, including the comments of previous or current users (the equivalent of an Angie's List for LTC) could be available in some sort of chat room design.

This sort of information is useful in winnowing the options, but ultimately nothing will replace an actual visit to those sites that survive the screening. One has to experience firsthand what life would be like in such a setting. A good time to visit is

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50. Who Recommends, supra note 11, at 474-75.
51. See KAISER FAM. FOUND, supra note 2.
53. See id.
54. See generally, Helping People, supra note 19, at 244.
55. See Helping People, supra note 19, at 246.
at mealtimes. Not only are the staff stressed, it is important to get a sense of what kind and quality of food is available.

**STRUCTURING DECISIONS**

Making these LTC decisions is not easy. It is intellectually and emotionally complex. Some people view this activity as a do-it-yourself project. Simply give families a structural template and they can follow the instructions, but many others hold that the task is better accomplished when a talented case manager is involved.

The role of the case manager (or care facilitator) is multifaceted. He or she is a source of structure and information, an advocate, and at times the referee. The first task is to clarify the options. As neophytes to LTC, most families are not intimately familiar with the range of possibilities or their individual attributes. Many families enter the process already fixated on a specific option, usually the nursing home. The case manager's task is to make everyone aware of the full spectrum of options and to clarify what is involved in each, i.e., what are the benefits and liabilities of each type of care. At a minimum, the options would include assisted living, home care, home health, day care, adult foster care, and nursing homes. Moreover, the case manager needs to explain that the choice is not necessarily permanent. As conditions change, so too can the need for a certain mode of care change. Especially in the case of post-hospital care, the ultimate clinical course may be unclear at the

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57. *Id.*
58. *Id.*
59. *See Helping People, supra note 19, at 244.*
60. *Id. at 247.*
62. *See What Older People Want, supra note 11, at 118.*
outset. In an emotionally tumultuous situation, the case manager is responsible for keeping the discussion on course and not allowing too many tangential discussions, while at the same time allowing enough latent conflict to be aired to surface relevant issues. Needless to say, this is a hard balance to strike.

The case manager also has a major role in protecting the interests and the voice of the older person. All too often, the family members dominate the discussion and impose their beliefs on the older family member. Because these convictions are often quite conservative efforts to protect the older person, there is a real risk that the client's values will be minimized or dismissed as unrealistic. The case manager is fundamentally the advocate for the client and must assure that her values are given proper weight.

Case managers are also major sources of information. They should not impose suggestions about one type of care over another beyond offering a wide menu. Rather, they should know which types of care are likely to provide what sorts of outcomes for persons with the client's characteristics. Unfortunately, the empirical database around LTC is weak. There is little substantive information that can relate the effects of various types of care on selected outcomes for clients with varying attributes, in the absence of such information expert opinion must be substituted. One effort to collect such opinion surveyed a panel of national experts using a scenario technique to ask them to recommend what types of LTC would be most appropriate for clients with varying characteristics.

64. See What Older People Want, supra note 11, at 118.
65. See generally Brown, supra note 61, at 72.
66. See The Circumscribed Sometimes-Advocacy, supra note 63, at 72.
67. See id.
68. Id.
69. Id. at 71.
70. See Helping People, supra note 19, at 245.
71. Id.
72. Id.
ADDITIONAL STRUCTURE

The availability of computer programs that can be accessed over the internet can greatly enhance structured decision-making. Whether designed as a do-it-yourself project or a case manager guide, computer systems can provide an interactive basis for walking families through the complex maze of LTC decision making. They can customize the situation by asking questions about the client and providing information geared to those specifications. They can pose questions to families about their risk aversion and willingness to take on caregiving responsibilities. They can provide a structure that lets families sort out and prioritize their goals.

One attractive model for facilitating better decision making is the system developed at Dartmouth University called Shared Decision Making. This approach was designed to help patients make difficult medical choices between treatments when there was no clear best answer. It involves a combination of objective presentations of the pros and cons of alternative treatments with interviews of patients who have undergone the various treatment options and have had good and bad results. The underlying idea is to provide information in a format that allows repeated viewing until the patient comprehends and to provide that information in a form in which the patient can personally relate. It effectively takes the decision off-line, giving patients and families time to consider their options. It

73. See, e.g., id. at 244.
74. Id. at 244, 247.
75. Id. at 244, 246.
77. Id.
has been shown to substantially change the decisions patients ultimately make.\textsuperscript{80} It is not hard to see how this approach might be usefully adapted to LTC decision making.

\section*{Describing Options}

Consumer information has been widely criticized as not being useful to decision making in health care on the grounds that it is not seen as relevant to the person making the decisions.\textsuperscript{81} Several approaches can be used to address this concern. First, as noted earlier, it is feasible to prose choices based on expert opinion that correspond to the client's profile.\textsuperscript{82} Moreover, it is feasible to make the options more meaningful. Indeed, there are good models in the commercial world.

If real estate agents can show houses on-line using a combination of pictures and text, it should be feasible to give people a virtual tour of LTC options like nursing homes and assisted living facilities, complete with photos and detailed descriptions of amenities and services. This can be combined with videotaped interviews with clients and family members who have used each type of service and have had positive and negative experiences. The client interviews can be chosen from a matrix of clients with different problems (i.e., cognitive, physical, both) who received care in different settings. Families could choose to sample the experiences of those who were deemed most relevant in settings of greatest interest.

\section*{Role of Time and Timing}

By now, it should be clear that it takes time to work through issues involved in making such a complex and momentous decision. Simply convening all concerned members of the

\begin{footnotesize}
\begin{enumerate}
\item \textsuperscript{80} Id.
\item \textsuperscript{81} See James S. Lubalin & Lauren D. Harris-Kojetin, What Do Consumers Want and Need to Know in Making Health Care Choices?, 56 Supp. 1 Med. Care Res. and Rev. 67, 74 (1999).
\item \textsuperscript{82} Who Recommends, supra note 4, at 475.
\end{enumerate}
\end{footnotesize}
family may take time; they may come in from out of town. Evoking and resolving family conflicts that have long laid dormant or denied can be a lengthy process. Considering options and their consequences and then actually visiting potential sites takes time. Despite the need for time, there are active pressures to make a decision quickly. As already noted, hospitals have a strong incentive to discharge patients as soon as possible. Hospital discharge is already stressful and ironically can make it harder for people to focus clearly. The press for quick action gives great priority to available resources, even if these are not the most desired. The ease of finding pre-established packages (e.g., nursing homes) may influence choices. Discharge planners may be strongly motivated to push the options that can be implemented most rapidly.

The goal of giving family time to take in facts and make a thoughtful decision is in direct conflict with current hospital discharge planning. Clearly, some intermediate solution that would buy time at a lower rate than a day in the hospital costs must be found.

BARRIERS AND POTENTIAL SOLUTIONS

A number of barriers stand in the way of good LTC decision making, but there are potential solutions to each.

LACK OF SUPPLY OF SUFFICIENT TYPES OF CARE IN VARIOUS LOCATIONS

The ability to make meaningful LTC decisions will ultimately depend on having real choices. That will involve

83. Lieberman, supra note 56.
84. Id.
85. See id.
86. Id.
87. See What Older People Want, supra note 11, at 118-19.
88. Id. at 119.
89. Id. at 114.
90. See id. at 115.
stimulating the creation of options, hopefully with wide variations in attributes. The question is how much stimulation is needed. Will the market prevail or is some pump priming necessary? Can providers be expected to develop innovative approaches in order to attract new customers in a setting where decisions are made well, or is some external stimulation required through a grant mechanism?

**PRESSURES ON HOSPITALS TO PROVIDE ADEQUATE DISCHARGE PLANNING THAT CONSIDERS OPTIONS SYSTEMATICALLY**

Potential solutions include paying for discharge planning and added stay, bundling hospital and post-hospital care payments, and paying for transitional care to buy time to make better decisions.91 One simple, but expensive, approach would be to pay hospitals for the time and effort involved in discharge planning.92 Lengthening hospital stays would certainly add substantial cost, and there is no guarantee of substantially better results. A variant of this approach would be to create a bundled hospital payment that would cover the costs of all care from the time of admission through several months (physician care could be included or not).93 Hospitals would now have a financial and accountability incentive to facilitate better discharge decisions because they would be affected by the short-term consequences of bad decisions. Such a system would require new calculations of prospective payment rates, but this task is doable.94 There is also no guarantee that hospitals would give great weight to family preferences or issues like quality of life. A solution midway between these two is to shift the locus of decision making to some form of transitional care, outside the hospital. In effect, it would mean paying nursing homes or similar institutions a short-term fee to house patients for several days.

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91. See, e.g., id. at 123.
92. See id. at 123-24.
93. Id. at 124-25.
94. Id. at 125.
while the ultimate decision is being worked out. Obviously, provisions for ongoing care would need to prevail. This option would also entail added costs.

**SELECTIVE FUNDING OF LTC OPTIONS BY MEDICAID**

The choices for those with their own means are usually greater than for those who depend on public payment, typically through Medicaid. Although there are signs of improvement, Medicaid has long been biased in favor of nursing homes. Over the last decade, there has been a push to encourage Medicaid waiver programs that provide home and community based services, but the program is still tilted towards nursing homes. Part of the reason likely is that Medicaid eligibility in many states often comes from so-called medical necessity, spending more on medical care (including LTC) than is affordable; nursing home costs are more predictable (and usually higher) and hence it is easier to establish medical need for this type of care than for Home and Community Based Services (HCBS). One simple, if draconian, solution would be to change Medicaid coverage policy to address only services; room and board would need to be covered by other means. As a result, the playing field would be laid level; there would be no distinction between community and institutional care. Less extreme solutions would be to deliberately divert funds to HCBS through active efforts to divert clients from entering nursing homes and simply expanding HCBS. The latter would likely entail added costs by attracting new clientele.

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95. *Id.* at 123.
96. *Id.* at 115.
97. *Id.* at 118.
98. *Id.* at 121-22.
99. *Id.* at 122.
LACK OF STRUCTURED SUPPORT FOR DECISION-MAKING

There are several candidates for facilitating decision making. Efforts are already under way in most states to implement structured decision-making support systems. The emphasis to date has been on developing ease of access and referral, but it is not a big step to actually structuring the decision-making process. ADRCs (Aging and Disability Resource Centers) were created to develop such information support systems. Many have opted to create web-based support systems, although there is no evidence to date that such systems on their own can reshape the decision-making process. Some believe that the emerging generation of computer literate aging yuppies will make good use of such structured platform. Others envision the systems serving as an infrastructure to assist a new generation of case managers. But, these case managers will have to be trained to use them. Certainly a system designed to facilitate case management will differ from one designed to be used on its own.

LACK OF INFORMATION BASE ON LTC OPTIONS

The information available on various types of LTC is asymmetric. Most of the effort has gone into collecting data on nursing homes, and even that information lacks important components like quality of life. One step in the right direction would be to develop report cards for all types of LTC. Although collecting data on distributed care like HCBS might be


101. Id.

102. Id.


104. See A Quality-Based Improvement Strategy, supra note 34, at 110.
expensive, learning more about who is doing the job well (both in terms of specific providers and types of providers) would be very helpful. Moreover, discussions about generic LTC quality measures would require new dialogue about what information is most salient.\textsuperscript{105} A related step would stimulate more research on the relative effectiveness of various forms of LTC.

\textbf{FAILURE TO SUPPORT DECISION FACILITATORS}

An obvious first step would be to make such a service reimbursable under Medicare and/or Medicaid. This process would entail creating some standards for certifying providers of the decision facilitation and thus further work on defining the requisite skills involved. Simultaneously, one would need to educate consumers about the value of having their own advocate/facilitator rather than relying on a hospital employed discharge planner or a government caseworker, although it is likely that once the job is reimbursed some marketing by the facilitators will ensue.

\textsuperscript{105} Id. at 108.