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Caregiving for older adults with obesity in the United States.

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1 **Abstract:**

2

3 *Background/Objectives:* Older adults with obesity are a high-need and growing segment of the
4 population of the United States but little is known about disparities in caregiving. We assess
5 the difference in activities of daily living (ADL) assistance for obese compared to normal weight
6 older adults.

7 *Design/Setting:* Retrospective cohort study using the National Health & Aging Trends Study,
8 2011-2015.

9 *Participants:* 10,168 observations of 5,612 adults aged ≥ 65 years old in the United States with
10 disability in ADLs and body mass index (BMI) ≥ 18.5 kg/m².

11 *Measurements:* BMI was classified as normal weight (18.5-24.9 kg/m²), overweight (25-29.9
12 kg/m²), or obese (≥ 30 kg/m²). Primary outcome was self-reported receipt of help for specific
13 ADL disabilities. Models were adjusted for demographics (age, sex, race), degree of need (self-
14 reported general health, severity of disability), household resources (income, marriage, people
15 in household, number of children), and cognitive status (dementia, proxy respondent).

16 *Results:* Obese vs. normal weight older adults with disabilities had lower rates of assistance for
17 walking inside (OR 0.63, 95% CI 0.50-0.81), walking outside (OR 0.76, 95% CI 0.59-0.97),
18 toileting (OR 0.68, 95% CI 0.52-0.89), and getting in/out of bed (OR 0.67, 95% CI 0.50-0.87) after
19 adjustment for respondent demographics. Associations were partially explained by level of
20 need and cognitive status. In fully adjusted models, older adults with obesity still had
21 significantly lower odds of assistance in getting in and out of bed than normal weight adults (OR
22 0.69, 95% CI 0.49-0.98).

23 *Conclusion:* Older adults with obesity are less likely to receive assistance for ADL disabilities
24 than their normal weight counterparts—an important issue due to ongoing demographic
25 changes in the United States.

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28 KEY WORDS: Obesity, caregiving, disability, aging

29 **Background:**

30 In the coming decades, there are concerning medical, societal, and economic
31 implications in the increasing prevalence and absolute number of older adults with obesity. From 2000
32 to 2014, the prevalence of obesity in adults aged 60 and over in the United States rose from 30.5% to
33 37.7%.¹ At the same time, the projected growth in numbers of older adults in the United States, from 46
34 million in 2014 to 74 million in 2030, suggests that the number of older adults with obesity will continue
35 to grow significantly.² The costs of healthcare and caregiving for disabled older adults with obesity in the
36 baby boomer generation is estimated at 68 billion dollars for long term care alone.³ One of the many
37 challenges of these changing demographics is that older adults with obesity have higher rates of
38 disability than normal weight counterparts and the prevalence of disability in this population is
39 increasing over time.⁴⁻⁷ Yet, little is known about the particular barriers to caregiving and assistance for
40 disabilities faced by older adults with obesity and disability.

41 It is well known that obesity challenges caregivers by increasing the difficulty of providing
42 assistance with mobility, skin care, and personal hygiene for people with deficits in activities of daily
43 living.⁸ In the inpatient setting, morbidly obese patients require a mean of 4.5 individuals to assist them
44 with walking as opposed to 1.9 individuals for non-obese adults.⁹ Similar work has demonstrated higher
45 personnel needs for care of obese adults in nursing homes.¹⁰⁻¹³ Obesity has been linked to high rates of
46 musculoskeletal injuries in nurses and nursing assistants;¹⁴ these rates are already only surpassed by
47 those of firefighters, psychiatric aides, and waste collectors in the United States.¹⁵

48 The absence of appropriate levels of assistance is a possible explanation for the association
49 between obesity and lower quality of care at home for disabled adults. People with obesity are more
50 likely to be admitted to a nursing home¹⁶⁻¹⁹ and more likely to fall.²⁰ It is unclear if people with obesity in
51 all care settings receive the same amount of assistance for deficits in activities of daily living as normal
52 weight older adults. A single study demonstrated that obese adults of all ages with disability had lower
53 rates of paid help than non-obese adults but this association was explained by differences in the
54 younger age of disabled obese people and the analyses did not examine individual types of disability
55 deficits.²¹

56 We hypothesized that there may be several potential pathways leading older adults with obesity
57 to receive less assistance with disabled activities of daily living (ADLs) such as bathing, dressing, walking,
58 and toileting than normal weight adults (Figure 1). First, they may have barriers to receiving the
59 assistance they need. Obese, disabled individuals, who are generally younger than normal weight

60 disabled individuals, may have fewer nonworking family members and may be less likely to ask for
61 assistance. The difficulty of providing assistance, especially with physically demanding caregiving such as
62 mobility or personal care, may lead to less available, qualified, capable caregiving than a similar normal
63 weight individual.²² The presence of personal factors like poverty²³ or the absence of factors like
64 dementia²⁴ may make accessing assistance more difficult or less preferred. Stigma surrounding obesity
65 may serve as a barrier to requesting assistance and potential caregivers may have a bias against helping
66 obese adults needing assistance because they are seen as less frail and more capable to do self-care.²²

67 Alternatively, older disabled adults with obesity may have lower needs for assistance compared
68 to normal weight counterparts. The nature (either the type or the severity) of the disabilities
69 experienced by obese people may allow them to better compensate and so require less assistance.
70 Given the younger age of onset of disability for obese adults, they may be physically healthier with less
71 comorbid neurologic disease allowing them to manage mild disability with more independence.⁷ We
72 therefore aim to both assess the differences in receipt of assistance for impaired ADLs between normal
73 weight and older adults with obesity and explore the mediating pathways leading to this disparity in
74 assistance for older, disabled, obese adults.

76 **Methods:**

77 *Data:*

78 We used survey data from the annual survey waves of the National Health and Aging Trends
79 Study (NHATS), a nationally representative study of Americans age 65 and older, from 2011 to 2015.²⁵
80 NHATS relies on the Medicare enrollment database as its sampling frame, and in 2011 enrolled 8,245
81 adults, achieving response rates ranging from 71% in 2011 to 90% in 2014.²⁶ NHATS conducts annual in-
82 person surveys with proxy reporters if the participant is unable to respond. The cohort was refreshed in
83 2015 in order to maintain representativeness. All NHATS data used was de-identified and all
84 respondents provided informed consent under procedures approved by the Johns Hopkins Institutional
85 Review Board.

86 *Cohort:*

87 We included any observation where the respondent reported any difficulty, despite
88 accommodations (such as using devices like walkers and grab bars) in performing ADLs, which include
89 dressing, eating, bathing, toileting, walking inside, walking outside or getting in or out of bed. We

90 excluded observations missing covariate data. We additionally excluded those with underweight body
91 mass index (BMI), classified as $<18.5 \text{ kg/m}^2$, due to the potential reverse confounding as this population
92 has higher levels of underlying illness and mortality risk.²⁷

93 *Measures:*

94 NHATS assesses several measures of performance of ADLs to consider a spectrum of disability
95 and participation restriction.²⁸ Our primary dependent variable was participants' reported receipt of
96 assistance for an ADL that they have any level of difficulty performing, for example the rate of reporting
97 assistance with bathing for all those who reported difficulty bathing. The primary independent variable
98 was body mass index (BMI), classified as normal weight (BMI 18.5-24.9 kg/m^2), overweight (BMI 25-29.9
99 kg/m^2), or obese (BMI $\geq 30 \text{ kg/m}^2$) using World Health Organization classifications.

100 Covariates included proxy respondent status, age (in years), sex, race and ethnicity (non-Hispanic
101 white, non-Hispanic black, Hispanic, or other), self-reported general health (excellent, good, average,
102 below average, or poor),²⁹ self-reported cancer and dementia diagnoses, total household income,
103 marital status (married or not), number of people in the household, and number of living children. In
104 addition, the level of difficulty that respondents report in performing each ADL was included, on a three-
105 point scale (a little, some, or a lot of difficulty).

106 *Analysis:*

107 We described demographic characteristics and prevalence of medical comorbidities for those in
108 our cohort classified by BMI as normal weight, overweight and obese, and used χ^2 and t tests to
109 determine for significant differences between BMI groups. We then compared the prevalence of
110 specific ADL disabilities for all individuals in each BMI group.

111 We used multivariable logistic regression models to determine the association with BMI class
112 and odds of receiving assistance for a specific ADL for those reporting disability in that ADL and the
113 effect of potential mediating factors and confounders on the overall association. The initial model was
114 unadjusted. Further models sequentially added clusters of potential mediator covariates. Mediators
115 were determined from our hypothesized theory as well as prior evidence around the role of
116 demographics, stigma, household resources, and physical challenges to caregiving (Figure 1). The
117 second model adjusted for age, race, and sex. The third model added covariates assessing the severity
118 of need for assistance included general health and level of difficulty with performing the impaired ADL.
119 The fourth model added covariates assessing personal resources included total household income,

120 marital status, the number of people in the house, and number of children. The fifth model added, to all
121 the covariates previously mentioned, covariates assessing cognitive status and if the respondent was a
122 proxy. With each added cluster of variables, the odds ratio between obesity and receipt of assistance
123 was assessed for statistical significance and relative size compared to the prior model.

124 All models applied survey weights³⁰ and accounted for sampling strategy. Sensitivity analyses
125 included a hierarchical mixed-effects model to account for repeated measures for individuals as well as
126 modeling BMI as a fractional polynomial in order to allow it to be a continuous variable with flexibility of
127 shape in relation to receipt of assistance. In addition, some alternative approaches were used to
128 quantify the relative mediation effects of variable clusters. First, the coefficients were standardized
129 without survey weights applied, then the indirect effects were computed as the product of the
130 coefficients. Finally, bootstrapping was used to compute standard errors of the indirect effects of
131 covariates and direct effect of BMI class.³¹ This study was assessed and determined to be exempt from
132 review by the University of Michigan Institutional Review Board.

133 **Results:**

134 Between 2010 and 2015 there were 11,359 observations of NHATs respondents reporting
135 difficulty despite any accommodations in performing any ADLS, which include dressing, eating, bathing,
136 toileting, walking inside, walking outside or getting in or out of bed. We excluded 436 observations
137 (3.8%) missing BMI measurement for the individual during the current or prior survey wave, an
138 additional 375 observations (3.4%) with underweight BMI and an additional 13 observations with
139 missing covariates (1.0%). The final cohort was 10,535 observations of 5,639 individuals given that some
140 (2,440) individuals were followed for multiple survey waves.

141 Demographic and comorbidities vary between individuals in different BMI classes as
142 demonstrated in Table 1. Obese adults are younger, more likely to be women, more likely to be
143 Hispanic and non-Hispanic blacks, less likely to describe excellent and very good health, and less likely to
144 have a proxy respondent than normal weight individuals (all p values <0.05). Obese individuals have
145 different comorbidities than normal weight adults with lower rates of dementia but higher rates of heart
146 disease, hypertension and diabetes.

147 Figure 2 demonstrates the rates of specific ADL disabilities among adults age 65 and older with
148 BMI measurements collected by NHATs. In comparing obese and normal weight adults, older adults
149 with obesity reported higher rates of any ADL disability (39.7%) compared to overweight and normal

150 weight older adults (28.3% and 31.2% respectively). Rates of disability in eating and toileting were
151 similar but obese adults reported higher rates of difficulty getting in and out of bed (21.9% vs 15.30% of
152 normal weight older adults), walking inside (17.3% vs. 13.6%), dressing (17.3% vs. 13.0%), and walking
153 outside (15.5% vs. 10.8%).

154 In our initial unadjusted logistic regression model (Table 2), obese older adults with difficulty
155 walking inside had an odds ratio (OR) of 0.50 of receiving assistance (95% confidence interval (CI) 0.41 to
156 0.60) compared to those with normal weights. Obese older adults with disability had lower rates of
157 assistance in walking outside (OR 0.57, 95% CI 0.47-0.69), toileting (OR 0.58, 95% CI 0.46-0.73), getting
158 in/out of bed (OR 0.61, 95% CI 0.49-0.77), bathing (OR 0.61, 95% CI 0.48-0.77), and eating (OR 0.64, 95%
159 CI 0.47-0.86). There was no significant difference in assistance for those with difficulty dressing (OR
160 1.06, 95% CI 0.89-1.25).

161 We sequentially added clusters of covariates to the model in order to test the mediating role of
162 different factors described in our conceptual model (Table 2). Adjusting for demographic differences
163 between obese and normal weight individuals (age, race, sex) reduced the association of obesity with
164 assistance, although there were still significant differences in assistance for all ADLs other than bathing
165 and eating. Adding covariates for degree of need which included general health and severity of
166 disability reduced the association of obesity with assistance for walking outside (from OR 0.76 in prior
167 model to 0.85 when adjusting for degree of need). Adding covariates for home resources which
168 included total income, as well as, marriage, number of people in the household, and number of children,
169 did not change the association of obesity with assistance. Adding covariates for cognitive status
170 (dementia and proxy respondent) reduced the association of obesity with several ADLs to the degree
171 that they were no longer statistically significant: assistance for walking inside (OR 0.64 in prior model,
172 0.78 when adjusting for cognitive status), toileting (OR 0.64 in prior model, 0.76 when adjusting for
173 cognitive status). The association for getting in/out of bed remained statistically significant (OR 0.59 in
174 prior model, 0.69 when adjusting for cognitive status, 95% CI 0.49-0.98).

175 Additional attempts to assess for mediation in this logistic regression model found that BMI had
176 a significant direct effect on help walking inside as well as getting out of bed despite full adjustments,
177 and that the cognitive status and demographics had the greatest mediating effects on the association
178 (Appendix Table 1). In order to account for repeated observations, the full model was tested using a
179 hierarchical modeling approach, and results did not differ (results not shown). In order to account for
180 the range of BMIs as opposed to the standard categorization, BMI was modeled as a fractional

181 polynomial while adjusting for all covariates including age. In these models, there are decreasing rates of
182 assistance for walking inside, walking outside, and toileting as well as getting in/out of bed as BMI rises
183 beyond a normal range of 18.5-24.9 (Appendix Figure 1).

184 **Discussion:**

185 In a nationally representative cohort of older adults in the United States with ADL impairments,
186 we demonstrated that older adults with obesity have higher rates of ADL impairments and lower rates
187 of assistance compared to their normal weight counterparts. These gaps in assistance were largest for
188 assistance with mobility and transfers. This has significant policy and healthcare implications given the
189 predicted growing population of older adults with obesity. While part of the gap in assistance was
190 explained by severity of disability and cognitive status, even in our fully adjusted models obese
191 individuals reported significantly less assistance with walking indoors.

192 As we expected, the association of obesity with absent assistance with ADLs is particularly
193 strong for mobility-related ADLs where providing assistance is more physically demanding. Unlike prior
194 research,²¹ the finding persisted despite adjusting for demographics. We then explored potential
195 mediating factors to delineate if the lower assistance was due to barriers to assistance versus lower
196 need for assistance. Our analysis found partial mediation by degree of need, indicating that barriers to
197 assistance may play a role. However, we did not find that insufficient household resources in terms of
198 either assets or people to assist mediated the association as was hypothesized. Cognition appeared to
199 have the largest effect of the association, although still as a partial and not complete mediator. This
200 indicates that further research into the contributions of both stigma and the physical challenges of
201 obesity caregiving will be important next steps.

202 The factors that explained the greatest proportion of the difference in receipt of care between
203 obese and normal weight individuals was dementia and need for a proxy respondent, a related measure
204 of cognitive impairment. There are two hypotheses for this finding. One is that older adults without
205 cognitive impairment have increased ability to rally support from family or even gain access to nursing
206 home care. An alternative explanation is that the lower prevalence of cognitive impairment in older
207 adults with obesity enables them to cobble independent solutions at home alone despite disability and
208 avoid the complexity of entering into a care recipient role, which may not be preferred despite the
209 hardships of unmet needs. Therefore, dementia may indicate increased need for assistance, explaining

210 this gap. Further research with more in-depth surveying and interviews is needed to establish if this is
211 occurring and if it is a desired response to absent assistance by older adults with intact cognition.

212 This study has several limitations. This data was analyzed as a cross-sectional analysis, and
213 further longitudinal analysis will be important to understand causal relationships. Our study relies on
214 BMI as it is the most widely accepted and available measure of obesity, but we do not differentiate
215 obesity subtypes such as sarcopenic obesity.³² The reliability of responses from our proxy respondents
216 may be lower than non-proxies, especially regarding absent assistance and unmet needs in cases where
217 they are a primary caregiver, although there is some evidence this is not the case from other studies.³³
218 While we can capture the degree of difficulty that individuals report in performing an ADL as well as if
219 they have had to go without that ADL, we would ideally have more information as to the level of needs
220 that individuals have. Further, we have no measures of the implications of absent caregiving, both in
221 terms of physical effects (pressure ulcers, poor hygiene, infections) and psychological effects (social
222 isolation, perceiving weight bias, ADL-specific anxiety). Despite these limitations, the strength of our
223 study is that we capture a nationally-representative population, base our analysis on a conceptual
224 theory, and utilize data capturing both surveyed factors and measured BMI.

225 Research is needed to examine the implications of the lower rates of assistance received by the
226 growing population of older adults with obesity and disability. While the nursing challenges of assisting
227 obese individuals have been established,¹⁶ little is known about the patient and family experience. Even
228 obese individuals with available family members to assist them might require extra help with safe
229 transfers and mobility assistance. Given that Medicare and Medicaid generally do not reimburse for
230 additional home health aides for obese patients, research should assesses if enriched personal aid
231 funding for this population might offset high-cost nursing home care. Similarly, the possible
232 ramifications of inadequate nursing and custodial assistance for this population such as lower physical
233 function, higher rates of medical complications including depression, social isolation, infection, falls,
234 malnutrition, and pressure ulcers; and higher costs of care, hospitalizations and emergency department
235 visits are not well understood. Intervention and cost-effectiveness studies focusing on obese, disabled
236 individuals should consider assessing the impacts of enriched home-based personal aid and medical
237 equipment such as lifts, bariatric walkers and commodes, as well as no-lift policies in hospitals and
238 nursing homes to increase utilization of mechanical lifts.³⁴

239 This deficit in caregiving has policy implications given the cost of long term care and the high
240 healthcare utilization of obese, disabled, older adults. Further work needs to be done to understand the

241 evolving capacity of formal and informal long-term care to serve the needs of obese individuals.
242 Addressing these issues will only be more pressing as older adults increasingly find themselves struggling
243 with both obesity and disability.

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245 The authors have no potential conflicts of interest to disclose.

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doi:10.1615/JLongTermEffMedImplants.v15.i2.90.

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Figure 1. Hypotheses for association between obesity and lower rates of assistance.

Figure 2. Prevalence of specific activities of daily living disabilities in adults age 65 and older by body mass index (BMI).

Supplementary Materials:

Supplemental Figure S1: Partial residual plots of the association of BMI modeled as a fractional polynomial and activity of daily living assistance for disabled older adults.

Supplementary Table S1. Estimated indirect and direct effects of covariates with help with each ADL.

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Table 1. Baseline characteristics of adults age 65 with activities of daily living disability included in the cohort.

	Normal weight (n=1,919)	Overweight (n=1,948)	Obese (n=1,772)	p-value
Age, N (%):				
65-69	14.3%	21.2%	32.5%	<0.001
70-74	17.9%	20.7%	27.7%	
75-79	15.7%	22.3%	19.5%	
80-84	21.6%	17.0%	11.5%	
85-89	17.6%	12.4%	6.4%	
90+	13.0%	6.5%	2.4%	
Sex, N (%):				
Men	38.6%	47.9%	37.6%	<0.001
Women	61.4%	52.1%	62.4%	
Race, N (%):				
White, non-Hispanic	77.1%	78.2%	74.4%	<0.001
Black, non-Hispanic	7.7%	8.5%	11.9%	
Other	7.8%	5.5%	4.7%	
Hispanic	7.4%	7.8%	9.0%	
Self-reported health, N(%):				
Excellent	5.6%	7.1%	2.8%	<0.001
Very good	19.8%	21.4%	18.0%	
Good	33.0%	35.1%	35.3%	
Fair	27.9%	26.6%	30.9%	
Poor	13.7%	9.9%	13.1%	
Proxy responder (%):	13.7%	8.5%	4.8%	<0.001
Medical conditions, N (%):				
Dementia	12.5%	8.1%	4.5%	<0.001
Heart disease	23.3%	22.0%	25.6%	0.04
Hypertension	62.9%	71.7%	81.1%	<0.001
Diabetes	18.9%	29.2%	45.6%	<0.001
Osteoarthritis	31.4%	24.7%	22.3%	<0.001

Lung disease	19.4%	18.5%	24.2%	0.001
Cancer	21.4%	21.8%	20.8%	0.81

Group percentages weighted according to National Health and Aging Trends Study analytic weights.

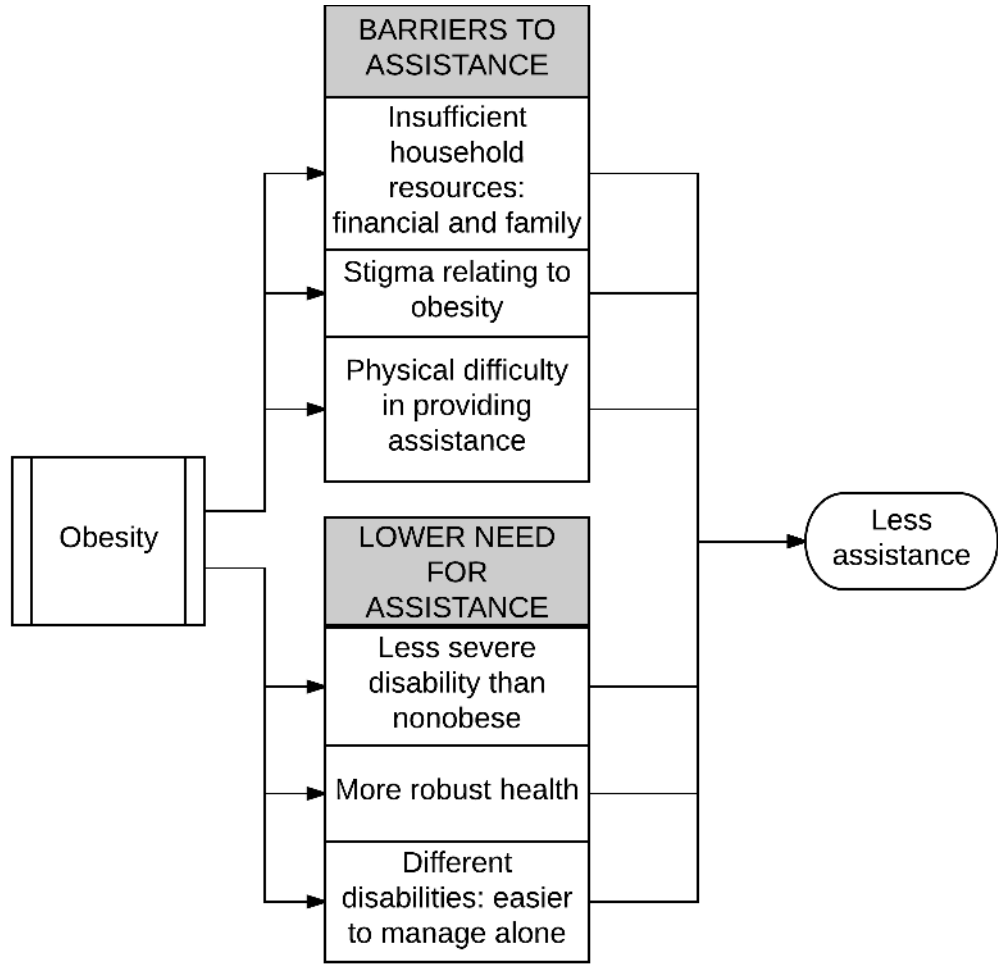
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Table 2. Odds of assistance for specific impaired activities of daily living by body mass index classification.			
	Normal weight	Overweight	Obese
<i>Model 1: Unadjusted.</i>			
Walking inside	1.00 (reference)	0.57 (0.48-0.68)	0.50 (0.41-0.60)
Walking outside	1.00 (reference)	0.74 (0.62-0.89)	0.57 (0.47-0.69)
Toileting	1.00 (reference)	0.79 (0.62-1.01)	0.58 (0.46-0.73)
Getting in/out of bed	1.00 (reference)	0.67 (0.55-0.81)	0.61 (0.49-0.77)
Bathing	1.00 (reference)	0.70 (0.57-0.84)	0.61 (0.48-0.77)
Eating	1.00 (reference)	0.72 (0.56-0.92)	0.64 (0.47-0.86)
Dressing	1.00 (reference)	0.84 (0.69-1.03)	1.06 (0.89-1.25)
<i>Model 2: Adjusting for age, race, and sex.</i>			
Walking inside	1.00 (reference)	0.63 (0.51-0.77)	0.63 (0.50-0.81)
Walking outside	1.00 (reference)	0.83 (0.68-1.01)	0.76 (0.59-0.97)
Toileting	1.00 (reference)	0.89 (0.65-1.21)	0.68 (0.52-0.89)
Getting in/out of bed	1.00 (reference)	0.71 (0.59-0.86)	0.67 (0.50-0.87)
Bathing	1.00 (reference)	0.85 (0.69-1.05)	0.91 (0.69-1.21)
Eating	1.00 (reference)	0.77 (0.59-1.00)	0.73 (0.52-1.03)
<i>Model 3: Adjusting for covariates from model above plus covariates for degree of need: general health and severity of disability.</i>			
Walking inside	1.00 (reference)	0.65 (0.51-0.82)	0.65 (0.50-0.85)
Walking outside	1.00 (reference)	0.87 (0.68-1.10)	0.85 (0.64-1.12)
Toileting	1.00 (reference)	0.90 (0.65-1.25)	0.64 (0.45-0.91)
Getting in/out of bed	1.00 (reference)	0.72 (0.56-0.93)	0.60 (0.43-0.83)
Bathing	1.00 (reference)	1.13 (0.84-1.52)	1.23 (0.88-1.72)
Eating	1.00 (reference)	0.91 (0.70-1.19)	0.92 (0.64-1.31)
<i>Model 4: Adjusting for covariates from models above plus covariates for home resources: total income, married, number of people in household, number of children</i>			
Walking inside	1.00 (reference)	0.65 (0.51-0.82)	0.64 (0.49-0.84)
Walking outside	1.00 (reference)	0.87 (0.69-1.11)	0.83 (0.63-1.09)
Toileting	1.00 (reference)	0.90 (0.65-1.25)	0.64 (0.45-0.90)
Getting in/out of bed	1.00 (reference)	0.71 (0.55-0.93)	0.59 (0.43-0.83)
Bathing	1.00 (reference)	1.13 (0.84-1.54)	1.22 (0.87-1.71)

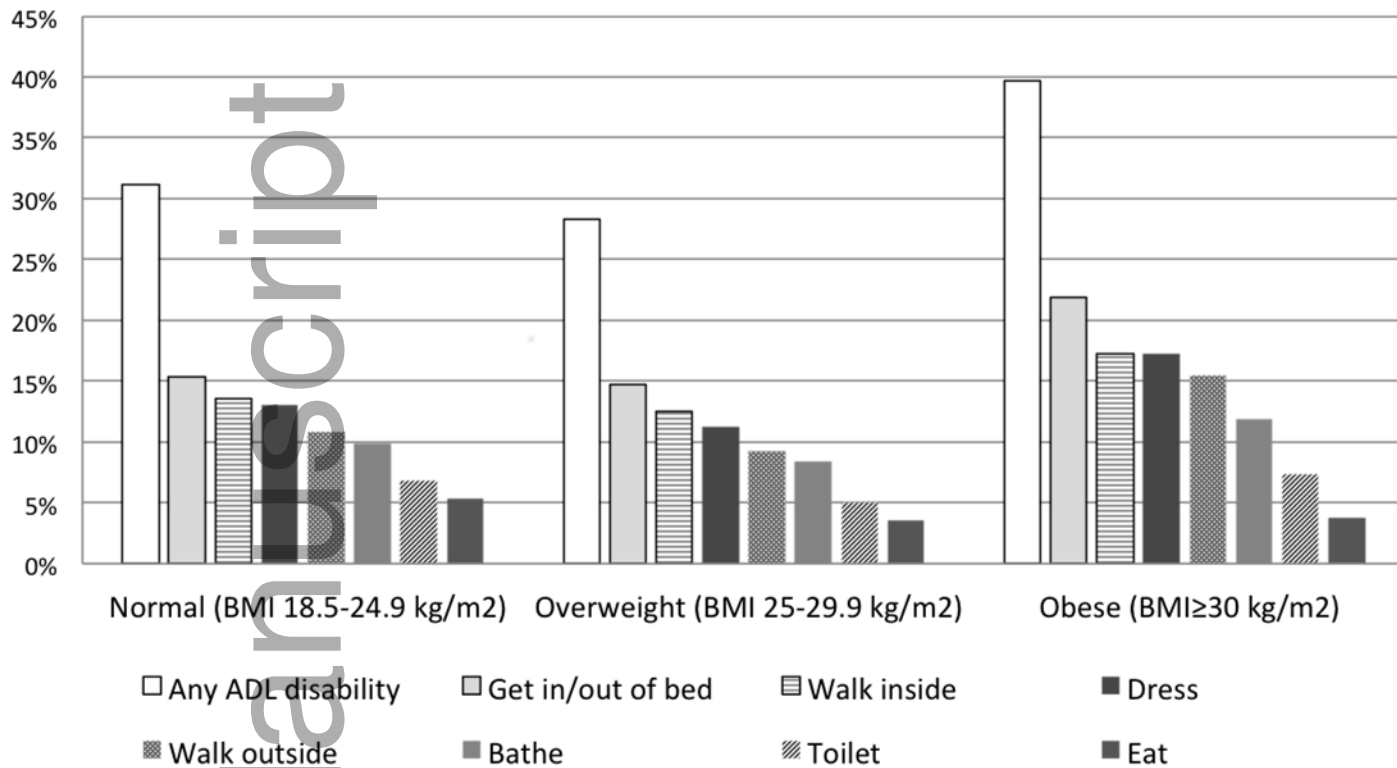
Eating	1.00 (reference)	0.88 (0.67-1.15)	0.87 (0.61-1.24)
<i>Model 5: Adjusting for covariates from models above plus covariates for cognitive status: dementia, proxy respondent</i>			
Walking inside	1.00 (reference)	0.73 (0.57-0.94)	0.78 (0.58-1.05)
Walking outside	1.00 (reference)	0.91 (0.70-1.17)	0.87 (0.65-1.17)
Toileting	1.00 (reference)	1.05 (0.76-1.45)	0.76 (0.53-1.08)
Getting in/out of bed	1.00 (reference)	0.82 (0.63-1.07)	0.69 (0.49-0.98)
Bathing	1.00 (reference)	1.20 (0.90-1.60)	1.39 (0.97-1.98)
Eating	1.00 (reference)	0.98 (0.69-1.39)	1.04 (0.72-1.52)

Hypothesis 1:
Association is mediated by barriers to care for obese individuals.

Hypothesis 2:
Association is mediated by lower need.



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