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Supplementary Materials: Social Isolation Scale Adaptation

We adapted a social isolation scale from prior scales in the literature including Shankar et al. (2011), Shaw et al. (2017), and Cornwell & Waite (2009). Our goal was to measure different dimensions of social relationships that may be relevant to end of life social well-being, and to have an overall social isolation scale combining these different dimensions which may reflect particularly severe situations of social isolation among older adults. Below we describe our approach and rationale to adapting a scale to the end-of-life experience.

We began with the Shankar et al. (2011) scale which includes three dimensions of social connections: 1) marital status (0-1 point), 2) social network interaction (0-3 points), and 3) community engagement (0-1 point), with a total range of 0-5 points. We decided to expand each domain and re-assess cut-offs within each domain to be more directly relevant to our research question in palliative care (described below). All 15 items from the HRS Core interview or Leave-Behind-Questionnaire (LBQ) included in our adapted measure are listed below:
1. Core contacts
    a. 1 item (core) - Marital status
    b. 1 item (core) - Household size
    c. 1 item (core) – Number of Living children, Living within 10 miles from you.
2. Social Network Interaction
    f. 3 items (LBQ) – Frequency of speaking with Kids/Family/Friends
    g. 3 items (LBQ) – Frequency of e-mailing with Kids/Family/Friends
    h. 3 items (LBQ) – Frequency of meeting with Kids/Family/Friends
3. Community participation
    j. 1 item (Core) – Frequency of volunteer work
    k. 1 item (LBQ) – Attendance at community groups
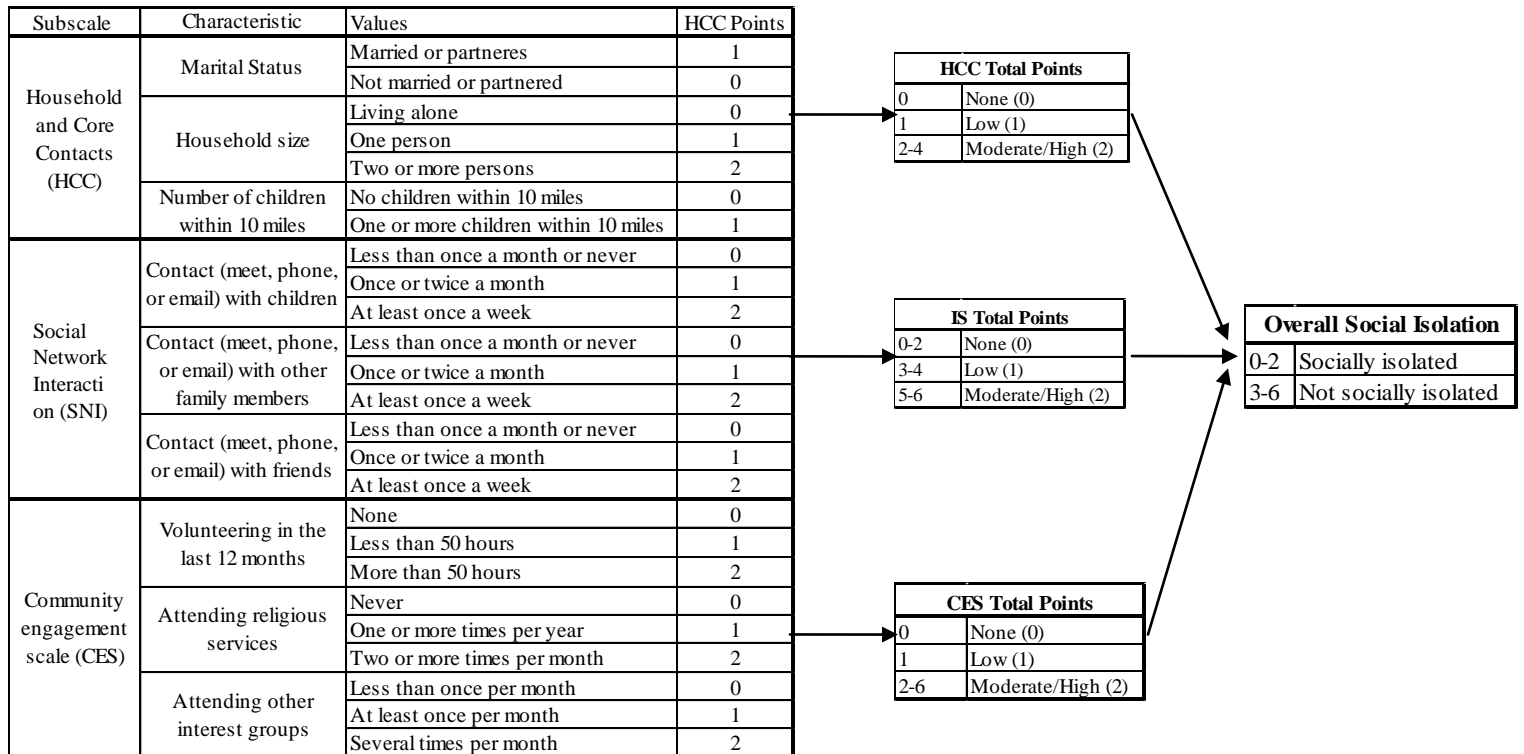   l. 1 item (Core) – Frequency of religious participation

We included a subscale for each of the three dimensions ranging 0-2 points, with a description of point values provided below:
1. *Household and core contacts (HCC) subscale.* Individuals approaching the end of life can have unique challenges when living alone at home. Individuals in the last days to months of life may be limited to their home due to the consequences of end-stages of chronic illness, acute illness, symptoms, or functional limitations. Consequently, local or in-home contacts may be essential for the provision of social support (caregiver and emotional support) and key medical support (e.g. home hospice eligibility, transportation to medical appointments, administering medications). Therefore we expanded marital status, which is used in several prior social isolation scales, to also include household size (excluding the spouse) and children living within 10 miles. This might better describe an individual's ability to find help with key medical needs at the end of life since nearly half our sample was widowed or unmarried. We categorize the subscale as: 1) None/Living alone (0 points), 2) 1 contact (1 point), or 3) 2+ contacts (2 points).
2. *Social Network Interaction Scale (SNI).* Social network interaction subscale is similar to the definition used in Shankar et al (2011) focusing on frequency of contact with children, family members, and friends through in-person, e-mail, or phone contact. This measure is distinct from household and core contacts in that it does not require relationships to be in the household or local area. Within each type of relationship (friends, family, or children) less than once a month was considered minimal interaction (0 points), which is similar to the Shankar et al. (2011) measure. In addition, we included categories for 1-2x/month as low interaction (1 point), and once per week as moderate interaction (2 points), yielding a range of 0-6 points. This was then re-scaled to the 0-2 point range as shown in the figure below.
3. *Community engagement Scale (CES)*. Engagement in the community is less critical to the provision of medical support as the social interaction and core contact measures, yet, it may be equally or more important to well-being and quality of life. It captures an individual's ability to participate in more complex social tasks, opportunities to help others, and a sense of belongingness in the community. Three items measure structured social participation including volunteering, participation in religious services, and participation in social/community clubs. We approximated Shankar et al. (2011)'s cut-off of minimal engagement with any activity (0 points), "some" engagement with any activity (1 point), and moderate engagement (2-6 points) using the thresholds shown in the figure below. This was then re-scaled to a 0-2 point range.

While the individual scales are useful in providing detail on end-of-life social experiences, it is important to determine how multiple features of isolation **combine** to create particularly severe situations of social isolation among older adults.

We therefore combined the three subscales - HCC, IS, and CES - to generate an overall social isolation scale ranging 0-6 points. We categorized individuals scoring 0-2 points as socially isolated which resembled the bottom quintile of our sample (similar to the strategy used in Shaw et al. 2017), which aligned well with clinically meaningful cut-offs within each subscale. Robustness checks were conducted at different cut-offs which yielded similar results. Further research is required on appropriate cut-offs among seriously ill populations.

Supplementary Figure 1. Social Isolation Scale

Subscale	Characteristic	Values	HCC Points
Household and Core Contacts (HCC)	Marital Status	Married or partneres	1
		Not married or partnered	0
	Household size	Living alone	0
		One person	1
		Two or more persons	2
	Number of children within 10 miles	No children within 10 miles	0
		One or more children within 10 miles	1
Social Network Interaction (SNI)	Contact (meet, phone, or email) with children	Less than once a month or never	0
		Once or twice a month	1
		At least once a week	2
	Contact (meet, phone, or email) with other family members	Less than once a month or never	0
		Once or twice a month	1
		At least once a week	2
	Contact (meet, phone, or email) with friends	Less than once a month or never	0
		Once or twice a month	1
		At least once a week	2
Community engagement scale (CES)	Volunteering in the last 12 months	None	0
		Less than 50 hours	1
		More than 50 hours	2
	Attending religious services	Never	0
		One or more times per year	1
		Two or more times per month	2
	Attending other interest groups	Less than once per month	0
		At least once per month	1
		Several times per month	2

HCC Total Points

0	None (0)
1	Low (1)
2-4	Moderate/High (2)

IS Total Points

0-2	None (0)
3-4	Low (1)
5-6	Moderate/High (2)

CES Total Points

0	None (0)
1	Low (1)
2-6	Moderate/High (2)

Overall Social Isolation

0-2	Socially isolated
3-6	Not socially isolated

Supplementary Table 1. Association of Social Isolation and Social Isolation Items with Frequent Loneliness in the Last Years of Life

Social Isolation Items		Frequent Loneliness	
		% (95% CI)	**p-value**
Overall Social Isolation	No	17 (15,20)	<0.001
	Yes	30 (24,37)	
Household/Core Contacts			
Marital Status	Married	12 (9,14)	<0.001
	Unmarried	26 (23,30)	
Household Size	1+ household members	16 (14,18)	<0.001
	Live Alone	27 (23,31)	
Nearby Children[1]	Nearby Children	18 (15,21)	0.03
	No nearby children	23 (20,26)	
Social Network Interaction[2]			
Interaction with Children	Moderate/High	18 (16,20)	<0.001
	Low	29 (23,34)	
Interaction with Family	Moderate/High	20 (17,22)	0.366
	Low	21 (17,25)	
Interaction with Friends	Moderate/High	17 (14,19)	<0.001
	Low	29 (24,34)	
Community Engagement			
Volunteer Activities[3]	Yes	12 (8,16)	<0.001
	No	22 (19,24)	
Religious Services[4]	Yes	17 (14,20)	<0.001
	No	24 (21,28)	
Community Groups[5]	Yes	15 (12,18)	<0.001
	No	22 (19,25)	

*All estimates adjusted for time of interview prior-to-death, age, sex, race/ethnicity, education, comorbidities, and number of ADL impairment

[1] Nearby children determined by asking about the presence of children <10 miles away

[2] Low interaction with children, family and friends was defined as on average less than monthly interaction with each relationship through in-person, e-mail, or phone

[3] No volunteer work defined as self-reports of no volunteering in the last 12 months

[4] No religious activities defined as never attending religious services in the last 12 months

[5] No community group engagement defined as less than monthly attendance at any community group

Supplementary Table 2. Prevalence of Social Isolation, Social Isolation Subscales, and Loneliness by Time Prior to Death

Characteristics	Predicted Prevalence of Social Isolation Subscales by Time Prior to Death % (95% CI)					P value
	4 years	2 years	1 year	6 months	3 months	
Social Isolation	18 (14-21)	22 (20-24)	24 (20-29)	26 (20-31)	27 (20-34)	0.05
Low Social Network Interaction[1]	57 (54-61)	63 (61-64)	65 (62-68)	66 (63-70)	67 (63-71)	0.003
Low Community Engagement[2]	42 (38-46)	47 (45-50)	50 (46-53)	51 (47-55)	52 (47-56)	0.01
Few Household contacts[3]	45 (40-50)	46 (43-48)	46 (43-49)	46 (42-50)	46 (42-51)	0.64
Frequent Loneliness[4]	18 (14-21)	29 (18-23)	22 (19-25)	23 (18-26)	23 (18-27)	0.13
Any Loneliness[5]	66 (62-70)	69 (68-72)	71 (68-73)	71 (68-75)	72 (68-76)	0.09

[1]The Social network interaction subscale assessed the frequency of at least monthly meetings with children, family, or friends through in-person, e-mail, or phone interactions. [2]Community engagement subscale included the frequency of participation in religious services, or other community groups and community volunteering. [3]Household and core contacts subscale included marital status, household size, and having nearby children. [4]Frequent Loneliness was defined as 4+ points on the UCLA loneliness scale (Range 0-6 points). [5]Any loneliness was defined as 1+ point on the UCLA Loneliness Scale (Range: 0-6 points). All prevalence estimates are derived from separate logistic regression models adjusting for the following covariates: time before death, age at death, sex, race/ethnicity, and education.

Supplementary Table 3. Adjusted Prevalence of Loneliness and Social Isolation During the Last 4 Years of Life Across Subgroups

Characteristics		Loneliness % (95% CI)	Loneliness p-value	Social Isolation % (95% CI)	Social Isolation p-value
Age at death	<=75	23 (19,27)	0.09	20 (17,24)	0.25
	>75	19 (17,22)		23 (20,25)	
Gender	Male	17 (14,20)	0.004	23 (20,25)	0.33
	Female	23 (20,26)		21 (18,24)	
Marital Status	Not Married/Partnered	26 (23,30)	<0.001	-	-
	Married/Partnered	12 (9,14)		-	
Race/Ethnicity	White	21 (19,24)	Ref	23 (20,26)	Ref
	AA	14 (8,20)	0.04	18 (11,24)	0.15
	Latino	24 (18,30)	0.36	21 (12,30)	0.68
	Other	22 (5,39)	0.90	9 (1,17)	0.02
Education	>=HS	19 (16,22)	0.16	19 (17,21)	0.003
	<HS	23 (18,27)		27 (22,32)	
Net Worth	<6,000	29 (23,36)	<0.001	34 (27,40)	<0.001
	6,000-<81,000	21 (17,25)		20 (15,26)	
	81,000-<239,000	17 (13,22)		20 (15,24)	
	>=239,000	13 (10,16)		14 (11,18)	
Cancer	No	22 (19,25)	0.04	24 (21,26)	0.01
	Yes	16 (12,19)		17 (13,21)	
Diabetes	No	19 (17,22)	0.23	22 (19,25)	0.89
	Yes	22 (18,27)		22 (17,26)	
Lung disease	No	20 (18,23)	0.94	20 (18,23)	0.03
	Yes	20 (15,25)		27 (22,33)	
Stroke	No	19 (17,22)	0.13	21 (19,24)	0.47
	Yes	23 (18,28)		24 (17,30)	
Heart disease	No	20 (15,24)	0.83	22 (18,26)	0.99
	Yes	21 (16,25)		22 (18,25)	
Any ADL Dependence	No	19 (16,22)	0.22	20 (16,23)	0.06
	Yes	23 (18,28)		26 (21,31)	
Telephone Difficulty	No	19 (16,22)	0.12	21 (18,24)	0.43
	Yes	24 (18,30)		25 (17,33)	

Managing Money Difficulty	No	17 (15,20)	0.002	20 (17,22)	0.04
	Yes	25 (21,30)		25 (20,30)	
Medications Difficulty	No	20 (17,23)	0.48	21 (19,24)	0.67
	Yes	23 (16,29)		24 (14,33)	
Shopping Difficulty	No	17 (14,20)	0.007	18 (15,22)	0.008
	Yes	24 (20,28)		26 (22,30)	
Preparing Meals Difficulty	No	15 (13,17)	<0.001	19 (16,21)	0.003
	Yes	29 (25,34)		27 (22,31)	
Walking a block difficulty	No	15 (13,17)	<0.001	19 (15,23)	0.04
	Yes	26 (22,29)		25 (21,28)	
Cognition	Normal	16 (14,18)	0.01	19 (16,21)	0.07
	CIND	21 (17,24)		22 (18,26)	
	Dementia	25 (19,31)		25 (19,31)	
Vision impairment	No	17 (14,20)	0.006	20 (16,23)	0.06
	Yes	24 (20,28)		25 (21,28)	
Hearing impairment	No	17 (14,19)	<0.001	20 (16,23)	0.02
	Yes	26 (22,30)		26 (22,29)	
Current Pain	No	18 (16,21)	0.02	21 (19,24)	0.69
	Yes	24 (20,28)		22 (18,27)	
Incontinence	No	16 (14,18)	<0.001	22 (18,25)	0.80
	Yes	27 (23,31)		22 (18,26)	
Hospitalization in last 2 years	No	19 (16,21)	0.07	24 (20,28)	0.10
	Yes	22 (19,25)		20 (17,23)	

Each regression model adjusts for time before death, age, sex, race/ethnicity, education, comorbidities, and number of ADL impairment

Abbreviations: AA – African American, HS – High School, CIND – Cognitive Impairment Not Dementia;

[1]Marital Status was not included in the social isolation regression model as it was part of the definition of social isolation; [2] Net Worth was calculated as sum of all assets minus the sum of all debts. [3]Cognitive Impairment was defined using the Langa-Weir methods; [4]Frequent loneliness was defined using the UCLA 3-item Loneliness Scale with cut-off of 4-6 points; [5]Social Isolation was defined by combining the Household, Social Network Interaction, and Community Engagement subscales to create a 0-6 point scale with 0-2 points categorized as socially isolated.