

## Supplemental Data

### Sickle Cell Disease in Grenada: Quality of Life and Barriers to Care

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**Table S1.** Barriers to Care survey scores of adults with SCD analyzed by demographic variables

Variable	Mean (SD)					
	Total	Skills	Marginalization	Expectations	Knowledge	Pragmatics
<b>Age</b>						
18-34	69.7 (12.2)	71.4 (13.9)	68.8 (20.7)	65.8 (15.9)	74.5 (20.4)	69.9 (11.2)
35+	70.6 (10.5)	73.7 (7.4)	70.8 (14.2)	71.9 (17.4)	69.6 (18.9)	66.7 (9.6)
	p=0.87	p=0.69	p=0.82	p=0.44	p=0.62	p=0.53
<b>Sex</b>						
Male	78.6 (13.5)	81.25 (12.5)	81.8 (12.8)	75.7 (22.9)	77.5 (26.0)	75 (14.2)
Female	66.9 (9.1)	69.0 (10.0)	65.1 (18.1)	65.3 (13.2)	71.0 (17.4)	66.5 (8.4)
	<b>*p=0.04</b>	<b>*p=0.04</b>	p=0.08	p=0.23	p=0.54	p=0.12
<b>Education</b>						
Primary	83.6 (12.8)	80.5 (14.1)	88.6 (8.7)	88.4 (12.8)	87.5 (25)	73.6 (17.3)
Secondary	68.2 (6.1)	71.1 (10.4)	69.3 (12.8)	61.2 (10.7)	70.3 (18.2)	69.1 (9.0)
College+	64.2 (9.6)	68.7 (11.3)	58.8 (19.5)	64.3 (15.0)	67.0 (15.6)	65.5 (7.7)
	<b>*p=0.01</b>	p=0.28	<b>*p=0.02</b>	<b>*p=0.01</b>	p=0.22	p=0.49
<b>Employment</b>						
Less than full time	76.10 (10.7)	77.7 (11.0)	77.8 (16.5)	76.8 (16.2)	80.5 (17.5)	69.1 (12.5)
Full time	65.6 (9.9)	68.2 (11.0)	63.4 (17.5)	61.7 (13.7)	67.0 (19.6)	68.4 (9.5)
	<b>*p=0.04</b>	p=0.08	p=0.09	<b>*p=0.04</b>	p=0.14	p=0.90
<b>Age at Diagnosis</b>						
0-4	70.9 (14.1)	70.8 (13.6)	67.8 (24.1)	70.8 (16.0)	77.1 (19.6)	71.3 (16.0)
5-12	69.4 (9.4)	74.0 (11.0)	70.7 (16.6)	64.7 (16.8)	67.4 (19.5)	68.5 (4.8)
13-17	70.1 (14.1)	70.3 (13.1)	69.3 (16.0)	71.4 (18.7)	78.1 (21.3)	65.3 (12.1)
	p=0.97	p=0.84	p=0.96	p=0.72	p=0.55	p=0.70
<b>Children</b>						
No	70.6 (13.2)	71.0 (13.7)	70.7 (21.2)	68.5 (17.9)	71.0 (20.6)	71.5 (10.8)
Yes	69.3 (8.9)	73.8 (9.0)	67.9 (14.0)	67.4 (15.0)	75 (18.9)	64.9 (9.4)
	p=0.81	p=0.62	p=0.75	p=0.90	p=0.67	p=0.19

\*significance p&lt;0.05

**Table S2.** Barriers to Care survey scores of SCD caregiver participants analyzed by demographic variables

Variable	Mean (SD)					
	Total	Skills	Marginalization	Expectations	Knowledge	Pragmatics
Age						
18-34	68.8 (25.5)	79.0 (10.3)	77.9 (16.9)	79.2 (15.4)	83.0 (16.3)	62.1 (26.2)
35+	74.1 (13.9)	80.4 (16.5)	76.3 (22.1)	73.3 (21.1)	75 (20.6)	65.0 (20.0)
	p=0.50	p=0.80	p=0.85	p=0.44	p=0.30	p=0.75
Sex						
Male	82.4 (12.7)	84.4 (13.6)	88.6 (10.4)	79.8 (20.0)	81.3 (10.8)	75.0 (22.7)
Female	70.5 (19.9)	79.2 (14.2)	75.5 (20.3)	75.3 (19.1)	78.0 (19.9)	62.3 (22.4)
	p=0.33	p=0.56	p=0.29	p=0.71	p=0.79	p=0.36
Education						
Primary	77.7 (8.1)	80.7 (10.7)	81.8 (14.4)	81.5 (10.0)	74.0 (22.5)	67.6 (18.2)
Secondary	75.6 (14.8)	77.6 (17.0)	78.5 (21.2)	75.7 (23.1)	79.5 (22.0)	68.2 (18.4)
College+	63.4 (27.1)	81.9 (12.9)	72.0 (21.8)	72.2 (18.4)	79.9 (13.5)	55.8 (28.6)
	p=0.27	p=0.78	p=0.62	p=0.66	p=0.82	p=0.43
Employment						
Less than full time	68.2 (27.3)	78.1 (11.0)	76.6 (20.2)	81.1 (13.5)	81.9 (17.3)	63.5 (29.4)
Full time	74.1 (12.8)	80.9 (15.8)	77.3 (20.1)	72.5 (21.2)	76.2 (20.2)	63.9 (17.7)
	p=0.46	p=0.64	p=0.93	p=0.27	p=0.47	p=0.97
Children						
1-2	66.4 (23.8)	75.7 (15.4)	78.0 (20.3)	72.5 (22.4)	73.1 (20.3)	60.2 (24.8)
3+	77.3 (12.3)	83.9 (11.5)	76.0 (19.9)	79.1 (14.5)	83.7 (16.6)	67.3 (55.2)
	p=0.16	p=0.14	p=0.81	p=0.38	p=0.16	p=0.43
Children with SCD						
1	69.9 (19.9)	78.3 (13.8)	75.5 (20.1)	73.1 (19.0)	77.8 (19.0)	63.4 (22.9)
2	82.5 (13.5)	88.3 (13.6)	85.2 (17.6)	91.1 (6.8)	81.3 (21.7)	66.0 (22.0)
	p=0.24	p=0.19	p=0.38	p=0.08	p=0.75	p=0.83
Age of Child						
2-4	51.8 (33.2)	73.8 (4.7)	70.5 (30.4)	74.3 (19.1)	80.0 (16.8)	40.4 (33.9)
8-12	79.8 (10.7)	80.7 (15.8)	84.3 (10.4)	79.5 (12.9)	82.8 (15.1)	71.5 (13.0)
13-17	72.4 (10.8)	81.9 (15.1)	71.0 (21.5)	71.8 (25.5)	71.5 (24.2)	66.4 (17.6)
	<b>*p=0.02</b>	p=0.57	p=0.23	p=0.66	p=0.41	<b>*p=0.02</b>
Age at Diagnosis						
0-1	73.4 (13.4)	82.5 (10.6)	74.1 (20.9)	72.8 (15.2)	81.7 (15.8)	59.4 (18.8)
2-4	66.4 (30.0)	79.3 (16.9)	81.5 (20.2)	75.4 (26.5)	71.1 (23.4)	67.3 (30.5)
5-13	76.6 (11.8)	73.8 (17.9)	77.3 (18.7)	84.3 (13.0)	81.3 (19.8)	69.4 (17.6)
	p=0.63	p=0.50	p=0.72	p=0.53	p=0.45	p=0.62

\*significance p<0.05

**Table S3.** ASCQ-ME survey scores of individuals with SCD analyzed by demographic variables

Variable	Mean (SD)				
	Emotional	Social	Sleep	Stiffness	Pain
Age					
18-34	47.8 (4.0)	52.6 (6.2)	52.5 (4.7)	52.7 (8.2)	52.7 (5.9)
35+	47.3 (4.4)	44.2 (8.3)	52.1 (6.0)	49.7 (7.7)	48.9 (2.3)
	p=0.80	<b>*p=0.02</b>	p=0.89	p=0.44	p=0.13
Sex					
Male	49.0 (0.63)	50.7 (6.3)	52.2 (4.3)	49.4 (3.4)	49.1 (3.4)
Female	47.1 (4.6)	49.1 (8.7)	52.3 (5.4)	52.3 (9.0)	52.0 (5.6)
	p=0.40	p=0.7	p=0.95	p=0.49	p=0.28
Education					
Primary	47.5 (2.4)	47.4 (9.5)	50.3 (5.3)	47.5 (2.9)	47.8 (2.6)
Secondary	44.9 (3.5)	49.8 (5.9)	52.0 (4.2)	53.8 (8.2)	50.7 (5.7)
College+	50.7 (3.3)	50.4 (10.1)	53.9 (5.9)	51.4 (9.4)	53.8 (4.8)
	<b>*p=0.01</b>	p=0.84	p=0.54	p=0.45	p=0.17
Employment					
Less than full time	47.5 (4.2)	49.2 (10.8)	52.7 (5.9)	52.7 (6.7)	50.7 (5.9)
Full time	47.7 (4.1)	49.7 (5.8)	52.1 (4.6)	50.7 (8.9)	51.6 (4.9)
	p=0.91	p=0.89	p=0.79	p=0.60	p=0.72
Age at Diagnosis					
0-4	46.8 (3.6)	48.7 (8.9)	54.0 (4.6)	53.5 (6.1)	52.2 (6.8)
5-12	48.2 (4.5)	49.8 (9.4)	52.2 (5.4)	51.4 (7.1)	51.1 (5.3)
13-17	47.5 (4.4)	50.2 (3.5)	50.2 (5.4)	48.9 (12.7)	50.2 (2.3)
	p=0.83	p=0.96	p=0.54	p=0.70	p=0.84
Children					
No	48.3 (4.7)	50.1 (9.2)	53.3 (5.3)	51.6 (8.7)	51.3 (5.0)
Yes	46.7 (2.8)	48.7 (6.4)	51.1 (4.7)	51.5 (7.3)	51.3 (5.8)
	p=0.39	p=0.72	p=0.36	p=0.98	p=1.0

\*significance p&lt;0.05

**Table S4.** Correlations of SCD-related Caregiver Burden survey scores with demographic variables

Variable	Total	n (%)		p Value
		No Burden	Burden	
<b>Age</b>				
18-34	11 (42.3)	4 (28.6)	7 (58.3)	p=0.13
35+	15 (57.7)	10 (71.4)	5 (41.7)	
<b>Sex</b>				
Male	3 (11.5)	2 (14.3)	1 (8.3)	p=0.64
Female	23 (88.5)	12 (85.7)	11 (91.7)	
<b>Education</b>				
Primary	6 (23.1)	2 (14.3)	4 (33.3)	p=0.18
Secondary	11 (42.3)	5 (35.7)	6 (50.0)	
College+	9 (34.6)	7 (50.0)	2 (16.7)	
<b>Employment</b>				
Less than full time	10 (38.5)	4 (26.6)	6 (50.0)	p=0.26
Full time	16 (61.5)	10 (71.4)	6 (50.0)	
<b>Children</b>				
1-2	13 (50.0)	7 (50.0)	6 (50.0)	p=1.0
3+	13 (50.0)	7 (50.0)	6 (50.0)	
<b>Children with SCD</b>				
1	22 (84.6)	11 (78.6)	11 (91.7)	p=0.36
2	4 (15.4)	3 (21.4)	1 (8.3)	
<b>Age of Child</b>				
2-4	5 (19.2)	2 (14.3)	3 (25.0)	p=0.59
8-12	12 (46.2)	6 (42.9)	6 (50.0)	
13-17	9 (34.6)	6 (42.9)	3 (25.0)	
<b>Age at Diagnosis</b>				
0-1	13 (50.0)	5 (35.7)	8 (66.7)	p=0.07
2-4	8 (30.8)	7 (50.0)	1 (8.3)	
5-13	5 (19.2)	2 (14.3)	3 (25.0)	

**Table S5.** Correlations of Barriers to Care survey scores of adults with SCD with genetics of sickle cell disease knowledge questions

Question	Total	Skills	Mean (SD)			
			Marginalization	Expectations	Knowledge	Pragmatics
Sickle cell disease is a genetic condition.						
Correct	69.1 (11.9)	73.8 (11.9)	67.2 (18.4)	67.2 (16.9)	68.8 (18.5)	68.8 (10.0)
Incorrect	74.0 (6.0)	63.5 (6.5)	81.8 (12.7)	72.6 (14.4)	93.8 (6.3)	68.5 (15.8)
	p=0.42	p=0.17	p=0.21	p=0.61	<b>*p=0.04</b>	p=0.97
Children can catch sickle cell disease later in life.						
Correct	72.6 (11.2)	72.8 (13.0)	72.9 (13.6)	71.4 (16.8)	76.4 (18.2)	70.5 (11.8)
Incorrect	64.5 (10.3)	70.8 (9.2)	62.1 (25.4)	60.7 (13.6)	64.6 (21.2)	64.8 (6.0)
	p=0.16	p=0.74	p=0.24	p=0.19	p=0.23	p=0.28

\*significance p<0.05

**Table S6.** Genetics of sickle cell disease knowledge questions analyzed by demographic variables of caregiver participants

Variable	Sickle cell disease is a genetic condition.				Children can catch sickle cell disease later in life.			
	Total	Correct	Incorrect	p Value	Total	Correct	Incorrect	p Value
<b>Age</b>								
18-34	11 (42.3)	10 (45.5)	1 (25.0)	0.45	11 (42.3)	9 (50.0)	2 (25.0)	0.23
35+	15 (57.7)	12 (54.6)	3 (75.0)		15 (57.7)	9 (50.0)	6 (75.0)	
<b>Sex</b>								
Male	3 (11.5)	3 (13.6)	0 (0.0)	0.43	3 (11.5)	2 (11.1)	1 (12.5)	0.92
Female	23 (88.5)	19 (86.4)	4 (100.0)		23 (88.5)	16 (88.9)	7 (87.5)	
<b>Education</b>								
Primary	6 (23.1)	5 (22.7)	1 (25.0)	0.91	6 (23.1)	3 (16.7)	3 (37.5)	0.39
Secondary	11 (42.3)	9 (40.9)	2 (50.0)		11 (42.3)	9 (50.0)	2 (25.0)	
College+	9 (34.6)	8 (36.4)	1 (25.0)		9 (34.6)	6 (33.3)	3 (37.5)	
<b>Employment</b>								
Less than full time	10 (38.5)	8 (36.4)	2 (50.0)	0.61	10 (38.5)	7 (38.9)	3 (37.5)	0.95
Full time	16 (61.5)	14 (63.6)	2 (50.0)		16 (61.5)	11 (61.1)	5 (62.5)	
<b>Children</b>								
1-2	13 (50.0)	9 (40.9)	4 (100.0)	<b>*0.03</b>	13 (50.0)	7 (38.9)	6 (75.0)	0.09
3+	13 (50.0)	13 (59.1)	0 (0.0)		13 (50.0)	11 (61.1)	2 (25.0)	
<b>Children with SCD</b>								
1	22 (84.6)	18 (81.8)	4 (100.0)	0.35	22 (84.6)	15 (83.3)	7 (87.5)	0.79
2	4 (15.4)	4 (18.2)	0 (0.0)		4 (15.4)	3 (16.7)	1 (12.5)	
<b>Age of Child</b>								
2-4	5 (19.2)	5 (22.7)	0 (0.0)	0.39	5 (19.2)	4 (22.2)	1 (12.5)	0.85
5-12	12 (46.2)	9 (40.9)	3 (75.0)		12 (46.2)	8 (44.4)	4 (50.0)	
13-17	9 (34.6)	8 (36.4)	1 (25.0)		9 (34.6)	6 (33.3)	3 (37.5)	
<b>Age at Diagnosis</b>								
0-1	13 (50.0)	12 (54.6)	1 (25.0)	0.54	13 (50.0)	11 (61.1)	2 (25.0)	0.06
2-4	8 (30.8)	6 (27.3)	2 (50.0)		8 (30.8)	3 (16.7)	5 (62.5)	
5-12	5 (19.2)	4 (18.2)	1 (25.0)		5 (19.2)	4 (22.2)	1 (12.5)	

\*significance p<0.05

**Table S7.** Barriers to Care survey scores of caregiver participants analyzed by genetics of sickle cell disease knowledge

Question	Total	Skills	Mean (SD)			
			Marginalization	Expectations	Knowledge	Pragmatics
Sickle cell disease is a genetic condition.						
Correct	72.3 (21.1)	83.2 (11.4)	76.9 (21.3)	76.8 (20.3)	79.3 (19.4)	63.7 (24.2)
Incorrect	69.5 (2.7)	60.9 (12.6)	77.8 (8.8)	70.5 (3.4)	73.4 (18.0)	63.9 (6.8)
	p=0.80	<b>*p=0.002</b>	p=0.93	p=0.55	p=0.58	p=0.99
Children can catch sickle cell disease later in life.						
Correct	74.5 (14.1)	83.0 (11.8)	72.9 (21.4)	73.0 (20.0)	80.2 (18.8)	66.8 (19.6)
Incorrect	65.8 (28.2)	72.7 (16.7)	86.4 (11.5)	82.1 (15.0)	74.2 (19.9)	56.8 (27.7)
	p=0.30	p=0.08	p=0.11	p=0.26	p=0.47	p=0.30

\*significance p<0.05