Supplemental Data

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

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Contents

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

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

Table S3. ASCQ-ME survey scores analyzed by demographic variables

Table S4. Correlations of SCD-related caregiver burden survey scores with demographic variables

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

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

Table S7. Barriers to Care survey scores of caregiver participants analyzed by genetics of sickle cell disease knowledge
**Table S1.** Barriers to Care survey scores of adults with SCD analyzed by demographic variables

| Variable                  | Total     | Skills    | Marginalization | Expectations | Knowledge | Pragmatics |
|---------------------------|-----------|-----------|-----------------|--------------|-----------|------------|
| **Age**                   |           |           |                 |              |           |            |
| 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)| 67.5 (6.7) |
| p=0.87                    |           | p=0.66    | p=0.82         | p=0.44       | p=0.62    | p=0.53    |
| **Sex**                   |           |           |                 |              |           |            |
| 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)|
| *p=0.04                   |           | *p=0.04   | p=0.08         | p=0.23       | p=0.54    | p=0.12    |
| **Education**             |           |           |                 |              |           |            |
| 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)|
| *p=0.01                   |           | p=0.28    | *p=0.02        | *p=0.01      | p=0.22    | p=0.49    |
| **Employment**            |           |           |                 |              |           |            |
| 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)|
| *p=0.04                   |           | p=0.08    | p=0.09         | *p=0.04      | p=0.14    | p=0.90    |
| **Age at Diagnosis**      |           |           |                 |              |           |            |
| 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    |
| **Children**              |           |           |                 |              |           |            |
| 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    |

*p significance p<0.05
Table S2. Barriers to Care survey scores of SCD caregiver participants analyzed by demographic variables

| Variable                      | 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)  |
|                               | *p=0.02      | p=0.57        | p=0.23          | p=0.66       | p=0.41        | *p=0.02      |
| 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       |

*p significance p<0.05
### Table S3. ASCQ-ME survey scores of individuals with SCD analyzed by demographic variables

| Variable          | Emotional | Social | Mean (SD)  |
|-------------------|-----------|--------|------------|
|                   |           |        | 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    | *p=0.02| 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)|
|                   | *p=0.01   | 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     |

*p significance p<0.05*
| Variable                  | n (%)   | No Burden | Burden | p Value |
|---------------------------|---------|-----------|--------|---------|
| **Total**                 |         |           |        |         |
| Age                       |         |           |        |         |
| 18-34                     | 11 (42.3) | 4 (28.6) | 7 (58.3) | p=0.13  |
| 35+                       | 15 (57.7) | 10 (71.4) | 5 (41.7) |         |
| Sex                       |         |           |        |         |
| Male                      | 3 (11.5) | 2 (14.3) | 1 (8.3) | p=0.64  |
| Female                    | 23 (88.5) | 12 (85.7) | 11 (91.7) |         |
| Education                 |         |           |        |         |
| 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) |         |
| Employment                |         |           |        |         |
| 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) |         |
| Children                  |         |           |        |         |
| 1-2                       | 13 (50.0) | 7 (50.0) | 6 (50.0) | p=1.0   |
| 3+                        | 13 (50.0) | 7 (50.0) | 6 (50.0) |         |
| Children with SCD         |         |           |        |         |
| 1                         | 22 (84.6) | 11 (78.6) | 11 (91.7) | p=0.36  |
| 2                         | 4 (15.4) | 3 (21.4) | 1 (8.3) |         |
| Age of Child              |         |           |        |         |
| 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) |         |
| Age at Diagnosis          |         |           |        |         |
| 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 | 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          |              | *p=0.04   | 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 |
| Age                 |       |         |           |         |       |         |           |         |
| 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) |       |
| Sex                 |       |         |           |         |       |         |           |         |
| 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) |       |
| Education           |       |         |           |         |       |         |           |         |
| 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) |       |
| Employment          |       |         |           |         |       |         |           |         |
| 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) |       |
| Children            |       |         |           |         |       |         |           |         |
| 1-2                 | 13 (50.0) | 9 (40.9) | 4 (100.0) | *0.03 | 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) |       |
| Children with SCD   |       |         |           |         |       |         |           |         |
| 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) |       |
| Age of Child        |       |         |           |         |       |         |           |         |
| 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) |       |
| Age at Diagnosis    |       |         |           |         |       |         |           |         |
| 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     | 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    | *p=0.002   | 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