

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

CONTENTS OF SAS DATASET: R67.SD2
DATA FROM CSSCD FORM 67 - PSYCHOSOCIAL QUESTIONNAIRE
for PARENTS OF SCD PATIENTS 8-13 YEARS OF AGE
VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION
IN THE SAS DATASET AND ON FORM 67
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Data Set Name	OUT1.R67	Observations	89
Member Type	DATA	Variables	171
Engine	V9	Indexes	0
Created	15:23 Monday, November 6, 2006	Observation Length	1368
Last Modified	15:23 Monday, November 6, 2006	Deleted Observations	0
Protection		Compressed	NO
Data Set Type		Sorted	NO
Label			
Data Representation	WINDOWS		
Encoding	wlatin1 Western (Windows)		

Engine/Host Dependent Information

Data Set Page Size	16384
Number of Data Set Pages	10
First Data Page	2
Max Obs per Page	11
Obs in First Data Page	8
Number of Data Set Repairs	0
File Name	r67.sas7bdat
Release Created	9.0000M0
Host Created	XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
69	F67ASSIT	Num	8	IF NO ONE, CHECK
105	F67ATGRD	Num	8	IF DROPPED OUT, AT WHICH GRADE
3	F67BDATE	Num	8	PATIENTS BIRTHDATE RECODE AGE AT VISIT
8	F67BROTH	Num	8	NUMBER OF BROTHERS
170	F67CHRON	Num	8	OTHER CHRONIC ILLNESS
81	F67CHUR	Num	8	CHURCH
90	F67CIVIL	Num	8	CIVIL SERVICE
6	F67COHAB	Num	8	NUMBER LIVING IN HOUSEHOLD
74	F67COMM	Num	8	COMMUNITY HEALTH WORKER
78	F67COUN	Num	8	COUNSELOR
2	F67CYCLE	Num	8	RECORD 67 CYCLE
11	F67DEM1	Num	8	STAND UP FOR RIGHTS
12	F67DEM2	Num	8	KNOW CITY
13	F67DEM3	Num	8	PLAY OUTSIDE WHEN NOISY
14	F67DEM4	Num	8	WILLING TO TRY NEW THINGS
15	F67DEM5	Num	8	BE ACTIVE
16	F67DEM6	Num	8	SHOW PRIDE
17	F67DEM7	Num	8	TAKE PART IN PARENT'S INTERESTS

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18	F67DEM8	Num	8	TRY HARD
19	F67DEM9	Num	8	EAT ALONE
20	F67DEM10	Num	8	LEAD
21	F67DEM11	Num	8	MAKE FRIENDS
22	F67DEM12	Num	8	HANG UP CLOTHES
23	F67DEM13	Num	8	DO WELL IN SCHOOL
24	F67DEM14	Num	8	UNDRESS AND GO TO BED
25	F67DEM15	Num	8	HAVE INTERESTS

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#	Variable	Type	Len	Label
26	F67DEM16	Num	8	EARN SOME MONEY
27	F67DEM17	Num	8	DO SOME TASKS
28	F67DEM18	Num	8	STAY HOME ALONE
29	F67DEM19	Num	8	MAKE DECISIONS
30	F67DEM20	Num	8	COMPETE WELL
44	F67DEM21	Num	8	NOT TO FIGHT
45	F67DEM22	Num	8	NOT TO PLAY
46	F67DEM23	Num	8	NOT TO BE NOISY
47	F67DEM24	Num	8	TO BE CAUTIOUS
48	F67DEM25	Num	8	NOT TO RUN AND JUMP
49	F67DEM26	Num	8	NOT TO BE CENTER OF ATTENTION
50	F67DEM27	Num	8	TO BE RESPECTFUL
51	F67DEM28	Num	8	TRY NOT TO DO THINGS HIMSELF
52	F67DEM29	Num	8	NOT TO BE SLOPPY
53	F67DEM30	Num	8	NOT TO BOSS OTHER CHILDREN
54	F67DEM31	Num	8	NOT TO PLAY WITH CHILDREN
55	F67DEM32	Num	8	NOT TO LEAVE CLOTHES LYING
56	F67DEM33	Num	8	NOT TO FAIL AT SCHOOL WORK
57	F67DEM34	Num	8	NOT TO STAY OUT AFTER DARK
58	F67DEM35	Num	8	NOT TO DEPEND ON PARENTS
59	F67DEM36	Num	8	NOT TO EARN MONEY
60	F67DEM37	Num	8	NOT TO WHINE OR CRY
61	F67DEM38	Num	8	NOT DO HOUSEHOLD TASKS
62	F67DEM39	Num	8	NOT TO MAKE IMPORTANT DECISIONS
63	F67DEM40	Num	8	NOT TO TRY TO BEAT IN PLAY
84	F67DEPT	Num	8	DEPT. OF VOCATIONAL REHAB
70	F67DOCT	Num	8	DOCTOR
110	F67DYMIS	Num	8	DAYS MISSED FROM SCHOOL
108	F67EDUC	Num	8	REQUIRED SPECIAL EDUCATON
116	F67EFFCT	Num	8	WHAT KIND OF EFFECT
92	F67EMOT	Num	8	AFFECT YOU EMOTIONALLY
112	F67FAIL	Num	8	FAILED OR REPEATED A GRADE
85	F67FAMS	Num	8	FAMILY SERVICES
118	F67FEL1	Num	8	SADNESS
119	F67FEL2	Num	8	THINGS WORKING OUT
120	F67FEL3	Num	8	DOING THINGS
121	F67FEL4	Num	8	HAVING FUN
122	F67FEL5	Num	8	ACTING BAD
123	F67FEL6	Num	8	THINKING BAD
124	F67FEL7	Num	8	HATRED
125	F67FEL8	Num	8	FAULT OF BAD THINGS
126	F67FEL9	Num	8	SUICIDE
127	F67FEL10	Num	8	CRYING
128	F67FEL11	Num	8	THINGS THAT BOTHER
129	F67FEL12	Num	8	BEING WITH PEOPLE
130	F67FEL13	Num	8	DECIDING
131	F67FEL14	Num	8	SELF-APPEARANCE
132	F67FEL15	Num	8	SCHOOLWORK

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133	F67FEL16	Num	8	SLEEPING
134	F67FEL17	Num	8	TIREDNESS
135	F67FEL18	Num	8	EATING
136	F67FEL19	Num	8	ACHES

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#	Variable	Type	Len	Label
137	F67FEL20	Num	8	FEELING ALONE
138	F67FEL21	Num	8	FUN AT SCHOOL
139	F67FEL22	Num	8	FRIENDS
140	F67FEL23	Num	8	SCHOOLWORK
141	F67FEL24	Num	8	CAN BE AS GOOD
142	F67FEL25	Num	8	FEELING LOVED
143	F67FEL26	Num	8	OBEDIENCE
144	F67FEL27	Num	8	GETTING ALONG
113	F67FGRD	Num	8	FAILED OR REPEATED WHICH GRADE
76	F67FRIEN	Num	8	FRIENDS
73	F67GENE	Num	8	GENETIC COUNSELOR
158	F67GOSHL	Num	8	HOW FAR WILL YOUR CHILD GO IN SCHOOL
101	F67GRADE	Num	8	GRADE 1 THRU COLLEGE
106	F67GRDS	Num	8	CHILD'S GRADES
168	F67HAVSC	Num	8	DO YOU HAVE SCD
169	F67HAVST	Num	8	DO YOU HAVE SICKLE CELL TRAIT
109	F67HOMBD	Num	8	REQUIRED HOMEBOUND INSTRUCTION
117	F67HOWFR	Num	8	HOW FAR TO GO IN SCHOOL
161	F67IDEA1	Num	8	SCD CAN BE CURED
162	F67IDEA2	Num	8	SCD CAN BE CAUGHT
163	F67IDEA3	Num	8	ALL WHO HAVE SCD HAVE SEVERE ILLNESS
164	F67IDEA4	Num	8	MOST PERSONS ARE DEPENDENT
165	F67IDEA5	Num	8	MOST LEAD USEFUL LIVES
166	F67IDEA6	Num	8	MOST CANNOT LEARN WELL
100	F67ILL	Num	8	HOW ILL IS CHILD
64	F67MMPI1	Num	8	WHAT IS GOING TO HAPPEN
65	F67MMPI2	Num	8	WHAT HAPPENS TO ME
66	F67MMPI3	Num	8	MAKING PLANS
67	F67MMPI4	Num	8	GETTING WHAT I WANT
68	F67MMPI5	Num	8	I HAVE LITTLE INFLUENCE
5	F67MSTAT	Num	8	PARENT'S MARITAL STATUS
115	F67MYREL	Num	8	COMPARE YOUR RELATIONSHIP
104	F67NTSCH	Num	8	NOT IN SCHOOL, GRADUATED OR DROPPED OUT
71	F67NURS	Num	8	NURSE
152	F67OLDR1	Num	8	PERSONALITY
153	F67OLDR2	Num	8	FINANCIAL STATUS
154	F67OLDR3	Num	8	SICKLE CELL DISEASE
155	F67OLDR4	Num	8	EDUCATION
156	F67OLDR5	Num	8	RACE
157	F67OLDR6	Num	8	SEX
91	F67OTER	Num	8	OTHER
10	F67OTH	Num	8	NUMBER OF OTHER PEOPLE IN HH
79	F67OTHR	Num	8	OTHER
159	F67PAIN	Num	8	PAIN IS CAUSED BY
96	F67PHSY	Num	8	AFFECT PHYSICAL ACTIVITY
99	F67PLAN	Num	8	AFFECT PLANS FOR CHILDREN
77	F67PRIE	Num	8	PRIEST
4	F67PSEX	Num	8	SEX OF PARENT

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86	F67PUBC	Num	8	PUBLIC ASSISTANCE
31	F67REA1	Num	8	KISS OR HUG
32	F67REA2	Num	8	TELL HOW GOOD
33	F67REA3	Num	8	PRAISE HIM

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#	Variable	Type	Len	Label
34	F67REA4	Num	8	GIVE TREAT
35	F67REA5	Num	8	DO NOTHING
36	F67REA6	Num	8	SHOW EXPECTATIONS
37	F67REA7	Num	8	COULD HAVE DONE BETTER
38	F67REA8	Num	8	SCOLD OR SPANK
39	F67REA9	Num	8	SHOW DISAPPOINTMENT
40	F67REA10	Num	8	DEPRIVE YOUR CHILD
41	F67REA11	Num	8	DON'T SHOW FEELINGS
42	F67REA12	Num	8	POINT OUT
43	F67REA13	Num	8	JUST WAIT
111	F67REAS	Num	8	MOST COMMON REASON FOR ABSENCES
114	F67REASN	Num	8	REASON FOR FAILURE
7	F67RELAT	Num	8	RELATIONSHIP TO CHILD
98	F67RELBR	Num	8	AFFECT RELATIONSHIP WITH SIBS
94	F67RELS	Num	8	RELATIONSHIP WITH SPOUSE
93	F67RELT	Num	8	AFFECT YOUR RELATIONSHIP
167	F67RELTN	Num	8	WHAT IS YOUR RELATIONSHIP TO PATIENT
75	F67RELTV	Num	8	RELATIVES
82	F67SCHL	Num	8	SCHOOL
97	F67SCLW	Num	8	AFFECT SCHOOL WORK
160	F67SICKL	Num	8	SICKLE CELL DISEASE MAY CAUSE
87	F67SIKLC	Num	8	SICKLE CELL PROGRAMS
9	F67SIST	Num	8	NUMBER OF SISTERS
95	F67SOCIA	Num	8	AFFECT FAMILY'S ACTIVITIES
83	F67SOCSC	Num	8	SOCIAL SECURITY
72	F67SOCW	Num	8	SOCIAL WORKER
103	F67SPED	Num	8	SPECIAL ED.,CHECKED YES OR NO
80	F67SUPP	Num	8	IF NONE, CHECK
102	F67TRADE	Num	8	TRADE SCHOOL,CHECKED YES OR NO
145	F67TRUE1	Num	8	MAKES ME AFRAID
146	F67TRUE2	Num	8	MAY DIE YOUNG
147	F67TRUE3	Num	8	MAKES A SCHOOL DIFFERENCE
148	F67TRUE4	Num	8	MAKES A CAREER DIFFERENCE
149	F67TRUE5	Num	8	MAKES PLANNING DIFFICULT
150	F67TRUE6	Num	8	MARRIAGE PLANS
151	F67TRUE7	Num	8	HAVING CHILDREN
107	F67TUTOR	Num	8	REQUIRED TUTORING
89	F67UNB	Num	8	UNION BENEFITS
88	F67VA	Num	8	V.A. BENEFITS
171	JF67DATE	Num	8	DATE OF VISIT - RECODE DAYS SINCE DOE

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* R67.FMT contains value labels for numerical codes assigned to
categorical *
* variables in the SAS dataset R67.SD2
*

*****;

* SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 12/25/99 09:41:47;

PROC FORMAT PRINT;

VALUE F67PSEX

1	= 'MALE'
2	= 'FEMALE';

VALUE F67MSTAT

1	= 'SINGL NEV MAR,SINGL DIVR,WIDOW,SEPARAT,LIV TOGE'
3	= 'MARRIED OR REMARRIED';

VALUE F67RELAT

1	= 'MOTHER'
2	= 'FATHER'
4	= 'STEP-MOTHER'
8	= 'STEP-FATHER'
16	= 'BROTHER'
32	= 'SISTER'
64	= 'GRANDMOTHER'
128	= 'GRANDFATHER'
256	= 'OTHER'
512	= 'NONE';

* FORMAT STRESS IS DEFINED FOR VARIABLES: F67DEM1-F67DEM20 F67DEM21-F67DEM40;

VALUE STRESS

1	= 'DIDN'T STRESS'
2	= 'STRESSED SELDOM'
3	= 'STRESSED SOMETIME'
4	= 'STRESSED OFTEN'
5	= 'STRESSED ALL THE TIME';

* FORMAT OCCUR IS DEFINED FOR VARIABLES: F67REA1-F67REA13;

VALUE OCCUR

1	= 'DIDNT OCCUR'
2	= 'OCCURRED SELDOM'
3	= 'OCCURRED SOMETIME'
4	= 'OCCURRED OFTEN'
5	= 'ALWAYS OCCURRED';

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* FORMAT CHOICE IS DEFINED FOR VARIABLES: F67MMPI1-F67MMPI5;

VALUE CHOICE

1 = 'CHOICE A'
2 = 'CHOICE B';

VALUE F67ASSIT

1 = 'NO ONE';

* FORMAT HELPFUL IS DEFINED FOR VARIABLES: F67DOCT F67NURS F67SOCW
F67GENE

F67COMM F67RELTV F67FRIEN

F67PRIE

F67COUN F67CHUR F67SCHL

F67SOCSC

F67DEPT F67FAMS F67PUBC

F67SIKLC

F67VA F67UNB F67CIVIL;

VALUE HELPFUL

1 = 'NOT USED'
2 = 'VERY HELPFUL'
3 = 'SOMEWHAT HELPFUL'
4 = 'NOT HELPFUL';

* FORMAT OTHER IS DEFINED FOR VARIABLES: F67OTHR F67OTER;

VALUE OTHER

1 = 'NOT USED'
2 = 'VERY HELPFUL'
4 = 'SOMEWHAT HELPFUL'
8 = 'NOT HELPFUL'
16 = 'WRITE-IN';

VALUE F67SUPP

1 = 'NONE';

VALUE F67EMOT

1 = 'LESS SUSPICIOUS'
2 = 'MORE SUSPICIOUS'
4 = 'LESS WORRIED'
8 = 'MORE WORRIED'
16 = 'LESS ANGRY'
32 = 'MORE ANGRY'
64 = 'NONE ABOVE';

VALUE F67RELT

1 = 'LESS CARING'

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2	=	'MORE CARING'
4	=	'NOT AS CLOSE'
8	=	'I AM CLOSER'
16	=	'LESS PROTECTIVE'
32	=	'MORE PROTECTIVE'
64	=	'NONE';

VALUE F67RELSA

1	=	'NEVER MARRIED'
2	=	'NO'
4	=	'LESS CARING'
8	=	'MORE CARING'
16	=	'NOT AS CLOSE'
32	=	'CLOSER'
64	=	'LESS TIME'
128	=	'MORE TIME';

VALUE F67SOCIA

1	=	'ACTIVITY DECREASED'
2	=	'ACTIVITY INCREASED'
3	=	'NOT AFFECTED';

VALUE F67PHSY

1	=	'ACTIVITY DECREASED'
2	=	'ACTIVITY INCREASED'
3	=	'ACTIVITY STAYED THE SAME';

VALUE F67SCLW

1	=	'FAVORABLY AFFECTED'
2	=	'UNFAVORABLY AFFECTED'
3	=	'NOT AFFECTED';

VALUE F67RELBR

1	=	'NO SIBLINGS'
2	=	'GET ALONG BETTER'
4	=	'GET ALONG WORSE'
8	=	'ARE CLOSER'
16	=	'NOT AS CLOSE'
32	=	'SPEND MORE TIME'
64	=	'SPEND LESS TIME'
128	=	'DOES NOT AFFECT';

VALUE F67PLAN

1	=	'CHOICE A'
2	=	'CHOICE B'
3	=	'CHOICE C'
4	=	'UNDECIDED';

VALUE F67ILL

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1 = 'SEVERLY ILL'
2 = 'MODERATELY ILL'
3 = 'MILDLY ILL'
4 = 'NOT ILL';

VALUE F67GRADE

1 = 'IN 1ST GRADE'
2 = 'IN 2D GRADE'
3 = 'IN 3D GRADE'
4 = 'IN 4TH GRADE'
5 = 'IN 5TH GRADE'
6 = 'IN 6TH GRADE'
7 = 'IN 7TH GRADE'
8 = 'IN 8TH GRADE'
9 = 'IN 9TH GRADE'
10 = 'IN 10TH GRADE'
11 = 'IN 11TH GRADE'
12 = 'IN 12TH GRADE'
13 = '1ST YEAR COLLEGE'
14 = '2D YEAR COLLEGE'
15 = '3D YEAR COLLEGE'
16 = '4TH YEAR COLLEGE';

* FORMAT CHECK IS DEFINED FOR VARIABLES: F67TRADE F67SPED;

VALUE CHECK

1 = 'NO, NOT CHECKED'
2 = 'YES, CHECKED';

VALUE F67NTSCH

1 = 'GRADUATED, NOT IN SCHOOL'
2 = 'DROPPED OUT, NOT IN SCHOOL';

VALUE F67ATGRD

1 = 'DROPPED OUT OF 1ST GRADE'
2 = 'DROPPED OUT OF 2D GRADE'
3 = 'DROPPED OUT OF 3D GRADE'
4 = 'DROPPED OUT OF 4TH GRADE'
5 = 'DROPPED OUT OF 5TH GRADE'
6 = 'DROPPED OUT OF 6TH GRADE'
7 = 'DROPPED OUT OF 7TH GRADE'
8 = 'DROPPED OUT OF 8TH GRADE'
9 = 'DROPPED OUT OF 9TH GRADE'
10 = 'DROPPED OUT OF 10TH GRADE'
11 = 'DROPPED OUT OF 11TH GRADE'
12 = 'DROPPED OUT OF 12TH GRADE'
13 = 'DROPPED OUT OF 1ST YR. COLL.'
14 = 'DROPPED OUT OF 2D YR. COLL.'
15 = 'DROPPED OUT OF 3D YR. COLL.'
16 = 'DROPPED OUT OF 4TH YR. COLL.';

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VALUE F67GRDS

1	= 'EXCELLENT'
2	= 'ABOVE AVERAGE'
3	= 'AVERAGE'
4	= 'BELOW AVERAGE';

* FORMAT NO_YES IS DEFINED FOR VARIABLES: F67TUTOR F67EDUC F67HOMBD
F67FAIL;

VALUE NO_YES

1	= 'NO'
2	= 'YES';

VALUE F67DYMIS

1	= 'NONE'
2	= '1-5 DAYS'
3	= '6-10'
4	= '11-15'
5	= '16-20'
6	= '21-30'
7	= 'OVER 30 DAYS';

VALUE F67REAS

1	= 'RELATED TO SCD'
2	= 'NOT RELATED TO SCD'
3	= 'FAMILY EVENT'
4	= 'LACK OF TRANSPORT'
5	= 'WEATHER'
6	= 'FINANCIAL'
7	= 'OTHER';

VALUE F67FGRD

1	= '1ST GRADE'
2	= '2D GRADE'
3	= '3D GRADE'
4	= '4TH GRADE'
5	= '5TH GRADE'
6	= '6TH GRADE'
7	= '7TH GRADE'
8	= '8TH GRADE'
9	= '9TH GRADE'
10	= '10TH GRADE'
11	= '11TH GRADE'
12	= '12TH GRADE'
13	= '1ST YR. COLL.'
14	= '2D YR. COLL.'
15	= '3D YR. COLL.'
16	= '4TH YR. COLL.';

VALUE F67REASN

1	= 'TOO ADVANCED'
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2 = 'REPEATED ABSENCES'
4 = 'UNINTERESTED'
8 = 'DISLIKED CHILD'
16 = 'PREJUDICIAL'
32 = 'SCD ILLNESS'
64 = 'OTHER'
128 = 'NONE';

VALUE F67MYREL

1 = 'CLOSER'
2 = 'MORE PROTECTIVE'
4 = 'MORE CARING'
8 = 'LESS CLOSE'
16 = 'LESS PROTECTIVE'
32 = 'LESS CARING'
64 = 'NO OTHER CHILDREN'
128 = 'ALL HAVE SCD';

VALUE F67EFFCT

1 = 'DECREASE LIFESPAN'
2 = 'INCREASE LIFESPAN'
3 = 'NO EFFECT'
4 = 'DONT KNOW';

VALUE F67HOWFR

1 = 'STOP NOW'
2 = 'HIGH SCHOOL'
3 = 'TRAINING PROGRAM'
4 = 'JUNIOR COLLEGE'
5 = 'COLLEGE'
6 = 'GRADUATE SCHOOL';

* FORMAT FEL1X IS DEFINED FOR VARIABLE F67FEL1;

VALUE FEL1X

1 = 'SOMETIMES'
2 = 'OFTEN'
3 = 'ALL THE TIME';

* FORMAT FEL2X IS DEFINED FOR VARIABLE F67FEL2;

VALUE FEL2X

1 = 'NEVER'
2 = 'NOT SURE'
3 = 'SURE';

* FORMAT FEL3X IS DEFINED FOR VARIABLE F67FEL3;

VALUE FEL3X

1 = 'MOST OK'

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2 = 'MANY WRONG'
3 = 'ALL WRONG';

* FORMAT FEL4X IS DEFINED FOR VARIABLE F67FEL4;

VALUE FEL4X

1 = 'MANY THINGS'
2 = 'SOME THINGS'
3 = 'NOTHING';

* FORMAT FEL5X IS DEFINED FOR VARIABLE F67FEL5;

VALUE FEL5X

1 = 'ALL THE TIME'
2 = 'OFTEN'
3 = 'SELDOM';

* FORMAT FEL6X IS DEFINED FOR VARIABLE F67FEL6;

VALUE FEL6X

1 = 'SELDOM'
2 = 'OFTEN'
3 = 'ALL THE TIME';

* FORMAT FEL7X IS DEFINED FOR VARIABLE F67FEL7;

VALUE FEL7X

1 = 'HATES'
2 = 'DOES NOT LIKE'
3 = 'LIKES';

* FORMAT FEL8X IS DEFINED FOR VARIABLE F67FEL8;

VALUE FEL8X

1 = 'ALL ARE'
2 = 'MANY ARE'
3 = 'SOME ARE';

* FORMAT FEL9X IS DEFINED FOR VARIABLE F67FEL9;

VALUE FEL9X

1 = 'DOES NOT'
2 = 'THINKS BUT WONT'
3 = 'DOES';

* FORMAT FEL10X IS DEFINED FOR VARIABLE F67FEL10;

VALUE FEL10X

1 = 'EVERY DAY'

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2 = 'MANY DAYS'
3 = 'SELDOM';

* FORMAT FEL11X IS DEFINED FOR VARIABLE F67FEL11;

VALUE FEL11X

1 = 'ALL THE TIME'
2 = 'MANY TIMES'
3 = 'SELDOM';

* FORMAT FEL12X IS DEFINED FOR VARIABLE F67FEL12;

VALUE FEL12X

1 = 'LIKES'
2 = 'OFTEN DISLIKES'
3 = 'ALWAYS DISLIKES';

* FORMAT FEL13X IS DEFINED FOR VARIABLE F67FEL13;

VALUE FEL13X

1 = 'CANNOT'
2 = 'HAS TROUBLE'
3 = 'EASY';

* FORMAT FEL14X IS DEFINED FOR VARIABLE F67FEL14;

VALUE FEL14X

1 = 'OK'
2 = 'SOME BAD'
3 = 'UGLY';

* FORMAT FEL15X IS DEFINED FOR VARIABLE F67FEL15;

VALUE FEL15X

1 = 'CONSTANT PUSH'
2 = 'OFTEN PUSH'
3 = 'NO BIG PROBLEM';

* FORMAT FEL16X IS DEFINED FOR VARIABLE F67FEL16;

VALUE FEL16X

1 = 'TROUBLE EVERY NIGHT'
2 = 'TROUBLE MANY NIGHTS'
3 = 'PRETTY WELL';

* FORMAT FEL17X IS DEFINED FOR VARIABLE F67FEL17;

VALUE FEL17X

1 = 'SELDOM'

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2 = 'OFTEN'
3 = 'ALWAYS' ;

* FORMAT FEL18X IS DEFINED FOR VARIABLE F67FEL18 ;

VALUE FEL18X
1 = 'NO, MOST TIMES'
2 = 'NO, OFTEN'
3 = 'GOOD APPETITE' ;

* FORMAT FEL19X IS DEFINED FOR VARIABLE F67FEL19 ;

VALUE FEL19X
1 = 'NO WORRY'
2 = 'WORRY SOMETIMES'
3 = 'WORRIES' ;

* FORMAT FEL20X IS DEFINED FOR VARIABLE F67FEL20 ;

VALUE FEL20X
1 = 'DOES NOT'
2 = 'OFTEN'
3 = 'ALWAYS' ;

* FORMAT FEL21X IS DEFINED FOR VARIABLE F67FEL21 ;

VALUE FEL21X
1 = 'NEVER'
2 = 'SELDOM'
3 = 'MOST' ;

* FORMAT FEL22X IS DEFINED FOR VARIABLE F67FEL22 ;

VALUE FEL22X
1 = 'PLENTY'
2 = 'SOME'
3 = 'NONE'
4 = 'SATISFIED' ;

* FORMAT FEL23X IS DEFINED FOR VARIABLE F67FEL23 ;

VALUE FEL23X
1 = 'ALL RIGHT'
2 = 'NOT AS GOOD'
3 = 'VERY BADLY' ;

* FORMAT FEL24X IS DEFINED FOR VARIABLE F67FEL24 ;

VALUE FEL24X

CODEBOOK FOR CSSCD PERSONAL DIARY
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1 = 'NEVER'
2 = 'PERHAPS'
3 = 'JUST AS';

* FORMAT FEL25X IS DEFINED FOR VARIABLE F67FEL25;

VALUE FEL25X

1 = 'NOBODY DOES'
2 = 'NOT SURE'
3 = 'SOMEBODY DOES';

* FORMAT FEL26X IS DEFINED FOR VARIABLE F67FEL26;

VALUE FEL26X

1 = 'USUALLY'
2 = 'NOT USUALLY'
3 = 'NEVER';

* FORMAT FEL27X IS DEFINED FOR VARIABLE F67FEL27;

VALUE FEL27X

1 = 'OFTEN'
2 = 'FIGHTS OFTEN'
3 = 'ALWAYS FIGHTS';

* FORMAT TRUTH IS DEFINED FOR VARIABLES: F67TRUE1-F67TRUE7;

VALUE TRUTH

1 = 'VERY TRUE'
2 = 'SOMEWHAT TRUE'
3 = 'SOMEWHAT UNTRUE'
4 = 'VERY UNTRUE';

* FORMAT EFFECT IS DEFINED FOR VARIABLES: F67OLDR1-F67OLDR6;

VALUE EFFECT

1 = 'NO EFFECT'
2 = 'LITTLE'
3 = 'MODERATE'
4 = 'MUCH'
5 = 'VERY MUCH';

VALUE F67GOSHL

1 = 'STOP NOW'
2 = 'HIGH SCHOOL'
3 = 'TRAINING PROGRAM'
4 = 'JUNIOR COLLEGE'
5 = '4 YEARS COLLEGE'
6 = 'GRAD SCHOOL'
7 = 'DONT KNOW';

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VALUE F67PAIN

1 = 'LACK OF IRON'
2 = 'BLOCKAGE OF VESSELS'
3 = 'ARTHRITIS'
4 = 'ALL OF THE ABOVE'
5 = 'NOT SURE';

VALUE F67SICKL

1 = 'SCALY SKIN'
2 = 'OBESITY'
4 = 'PERIODS OF PAIN'
8 = 'LOSS OF HAIR'
16 = 'ALL OF THE ABOVE'
32 = 'NOT SURE';

* FORMAT T_F IS DEFINED FOR VARIABLES: F67IDEA1-F67IDEA6;

VALUE T_F

1 = 'TRUE'
2 = 'FALSE'
3 = 'NOT SURE';

VALUE F67RELTN

1 = 'MOTHER'
2 = 'FATHER'
3 = 'GRANDMOTHER'
4 = 'GRANDFATHER'
5 = 'OTHER';

* FORMAT YESNODK IS DEFINED FOR VARIABLES: F67HAVSC F67HAVST F67CHRON;

VALUE YESNODK

1 = 'YES'
2 = 'NO'
3 = 'DK';

- A. List of variables deleted **F68INIT F68NDATE F68LASTU F68LASTE F68ESTAT
F68VDATE F68DATE F68DFC F68FCB F68PBDAY**
- B. List of variables modified **F68BDATE F68MSTAT F68COHAB F68OTH**
- C. List of variables modified with a name change **NONE**
- D. Old name
- E. New name
- F. List of variables modified date to days since DOE

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G. Old name **F68DATE**

H. New name **JF68DATE**

I. Collection Information:

Form 68 (Psychosocial Questionnaire for Parents of SCD Patients 14-19 Years of Age) was to be completed by the parents of a random sample of HbSS patients between the ages of 14 and 19 years. The psychosocial requirements for this group of participants (GROUP 2) included completion of Form 68, the CHIP Coping Health Inventory, and the Family Environment Scale.

J. Data Collection Period: 05/84 – 10/87

K. Form Version Dates: 03/30/84

L. Files Used to Store Information:

SAS System Files: **R68.SD2**

Format Files: **R68.FMT**

M. Unique Record Identifiers: **ANONID, F68CYCLE**

Records within the dataset are sorted by **ANONID** and **F68CYCLE**

N. Number of Observations (Patients) in SAS Dataset: 90 (90)

O. Contents of SAS Dataset:

- Alphabetical Listing of Variables: See pp. 1-4
- Listing of Variables by Position: See pp. 5-8

A codebook for this dataset is not included in this manual.

P. Notes About Selected Variables: None

Q. Computed Variables: None

R. Inter-Relationship With Other Datasets:

Psychosocial data were also collected on

Phase 1 Forms	SAS Dataset	See Section
Form 67	R67.SD2	6.10.1
Form 69	R68.SD2	6.10.3
Form 73	R73.SD2	6.10.4
Form 74	R74.SD2	6.10.5
"Roster"	R09.SD2	1.0 (variable: PSYSTAT)

CODEBOOK FOR CSSCD PERSONAL DIARY
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CONTENTS OF SAS DATASET: R68.SD2
DATA FROM CSSCD FORM 68 - PSYCHOSOCIAL QUESTIONNAIRE
for PARENTS OF SCD PATIENTS 14-19 YEARS OF AGE
VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION
IN THE SAS DATASET AND ON FORM 68

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Data Set Name	OUT1.R68	Observations	90
Member Type	DATA	Variables	118
Engine	V9	Indexes	0
Created	16:09 Monday, November 6, 2006	Observation Length	944
Last Modified	16:09 Monday, November 6, 2006	Deleted Observations	0
Protection		Compressed	NO
Data Set Type		Sorted	NO
Label			
Data Representation	WINDOWS		
Encoding	wlatin1 Western (Windows)		

Engine/Host Dependent Information

Data Set Page Size	16384
Number of Data Set Pages	7
First Data Page	1
Max Obs per Page	17
Obs in First Data Page	2
Number of Data Set Repairs	0
File Name	r68.sas7bdat
Release Created	9.0000M0
Host Created	XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
16	F68ASSIT	Num	8	IF NO ONE, CHECK
52	F68ATGRD	Num	8	IF DROPPED OUT, AT WHICH GRADE
3	F68BDATE	Num	8	PATIENTS BIRTHDATE RECODE AGE AT VISIT
8	F68BROTH	Num	8	NUMBER OF BROTHERS
117	F68CHRON	Num	8	OTHER CHRONIC ILLNESS
28	F68CHUR	Num	8	CHURCH
37	F68CIVIL	Num	8	CIVIL SERVICE
6	F68COHAB	Num	8	NUMBER LIVING IN HOUSEHOLD
21	F68COMM	Num	8	COMMUNITY HEALTH WORKER
25	F68COUN	Num	8	COUNSELOR
2	F68CYCLE	Num	8	RECORD 68 CYCLE
31	F68DEPT	Num	8	DEPT. OF VOCATIONAL REHAB
17	F68DOCT	Num	8	DOCTOR
57	F68DYMIS	Num	8	DAYS MISSED FROM SCHOOL
55	F68EDUC	Num	8	REQUIRED SPECIAL EDUCATON
63	F68EFFCT	Num	8	WHAT KIND OF EFFECT
39	F68EMOT	Num	8	AFFECT YOU EMOTIONALLY
59	F68FAIL	Num	8	FAILED OR REPEATED A GRADE

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

32	F68FAMS	Num	8	FAMILY SERVICES
65	F68FEL1	Num	8	SADNESS
66	F68FEL2	Num	8	THINGS WORKING OUT
67	F68FEL3	Num	8	DOING THINGS
68	F68FEL4	Num	8	HAVING FUN
69	F68FEL5	Num	8	ACTING BAD
70	F68FEL6	Num	8	THINKING BAD
71	F68FEL7	Num	8	HATRED

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Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
72	F68FEL8	Num	8	FAULT OF BAD THINGS
73	F68FEL9	Num	8	SUICIDE
74	F68FEL10	Num	8	CRYING
75	F68FEL11	Num	8	THINGS THAT BOTHER
76	F68FEL12	Num	8	BEING WITH PEOPLE
77	F68FEL13	Num	8	DECIDING
78	F68FEL14	Num	8	SELF-APPEARANCE
79	F68FEL15	Num	8	SCHOOLWORK
80	F68FEL16	Num	8	SLEEPING
81	F68FEL17	Num	8	TIREDNESS
82	F68FEL18	Num	8	EATING
83	F68FEL19	Num	8	ACHES
84	F68FEL20	Num	8	FEELING ALONE
85	F68FEL21	Num	8	FUN AT SCHOOL
86	F68FEL22	Num	8	FRIENDS
87	F68FEL23	Num	8	SCHOOLWORK
88	F68FEL24	Num	8	CAN BE AS GOOD
89	F68FEL25	Num	8	FEELING LOVED
90	F68FEL26	Num	8	OBEDIENCE
91	F68FEL27	Num	8	GETTING ALONG
60	F68FGRD	Num	8	FAILED OR REPEATED WHICH GRADE
23	F68FRIEN	Num	8	FRIENDS
20	F68GENE	Num	8	GENETIC COUNSELOR
105	F68GOSHL	Num	8	HOW FAR WILL YOUR CHILD GO IN SCHOOL
48	F68GRADE	Num	8	GRADE 1 THRU COLLEGE
53	F68GRDS	Num	8	CHILD'S GRADES
115	F68HAVSC	Num	8	DO YOU HAVE SCD
116	F68HAVST	Num	8	DO YOU HAVE SICKLE CELL TRAIT
56	F68HOMBD	Num	8	REQUIRED HOMEBOUND INSTRUCTION
64	F68HOWFR	Num	8	HOW FAR TO GO IN SCHOOL
108	F68IDEA1	Num	8	SCD CAN BE CURED
109	F68IDEA2	Num	8	SCD CAN BE CAUGHT
110	F68IDEA3	Num	8	ALL WHO HAVE SCD HAVE SEVERE ILLNESS
111	F68IDEA4	Num	8	MOST PERSONS ARE DEPENDENT
112	F68IDEA5	Num	8	MOST LEAD USEFUL LIVES
113	F68IDEA6	Num	8	MOST CANNOT LEARN WELL
47	F68ILL	Num	8	HOW ILL IS CHILD
11	F68MMPI1	Num	8	WHAT IS GOING TO HAPPEN
12	F68MMPI2	Num	8	WHAT HAPPENS TO ME
13	F68MMPI3	Num	8	MAKING PLANS
14	F68MMPI4	Num	8	GETTING WHAT I WANT
15	F68MMPI5	Num	8	I HAVE LITTLE INFLUENCE
5	F68MSTAT	Num	8	PARENT'S MARITAL STATUS
62	F68MYREL	Num	8	COMPARE YOUR RELATIONSHIP
51	F68NTSCH	Num	8	NOT IN SCHOOL, GRADUATED OR DROPPED OUT
18	F68NURS	Num	8	NURSE
99	F68OLDR1	Num	8	PERSONALITY
100	F68OLDR2	Num	8	FINANCIAL STATUS

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101	F680LDR3	Num	8	SICKLE CELL DISEASE
102	F680LDR4	Num	8	EDUCATION
103	F680LDR5	Num	8	RACE
104	F680LDR6	Num	8	SEX

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Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
38	F68OTER	Num	8	OTHER
10	F68OTH	Num	8	NUMBER OF OTHER PEOPLE IN HH
26	F68OTHR	Num	8	OTHER
106	F68PAIN	Num	8	PAIN IS CAUSED BY
43	F68PHSY	Num	8	AFFECT PHYSICAL ACTIVITY
46	F68PLAN	Num	8	AFFECT PLANS FOR CHILDREN
24	F68PRIE	Num	8	PRIEST
4	F68PSEX	Num	8	SEX OF PARENT
33	F68PUBC	Num	8	PUBLIC ASSISTANCE
58	F68REAS	Num	8	MOST COMMON REASON FOR ABSENCES
61	F68REASN	Num	8	REASON FOR FAILURE
7	F68RELAT	Num	8	RELATIONSHIP TO CHILD
45	F68RELBR	Num	8	AFFECT RELATIONSHIP WITH SIBS
41	F68RELS	Num	8	RELATIONSHIP WITH SPOUSE
40	F68RELT	Num	8	AFFECT YOUR RELATIONSHIP
114	F68RELTN	Num	8	WHAT IS YOUR RELATIONSHIP TO PATIENT
22	F68RELTV	Num	8	RELATIVES
29	F68SCHL	Num	8	SCHOOL
44	F68SCLW	Num	8	AFFECT SCHOOL WORK
107	F68SICKL	Num	8	SICKLE CELL DISEASE MAY CAUSE
34	F68SIKLC	Num	8	SICKLE CELL PROGRAMS
9	F68SIST	Num	8	NUMBER OF SISTERS
42	F68SOCIA	Num	8	AFFECT FAMILY'S ACTIVITIES
30	F68SOCSC	Num	8	SOCIAL SECURITY
19	F68SOCW	Num	8	SOCIAL WORKER
50	F68SPED	Num	8	SPECIAL ED.,CHECKED YES OR NO
27	F68SUPP	Num	8	IF NONE, CHECK
49	F68TRADE	Num	8	TRADE SCHOOL,CHECKED YES OR NO
92	F68TRUE1	Num	8	MAKES ME AFRAID
93	F68TRUE2	Num	8	MAY DIE YOUNG
94	F68TRUE3	Num	8	MAKES A SCHOOL DIFFERENCE
95	F68TRUE4	Num	8	MAKES A CAREER DIFFERENCE
96	F68TRUE5	Num	8	MAKES PLANNING DIFFICULT
97	F68TRUE6	Num	8	MARRIAGE PLANS
98	F68TRUE7	Num	8	HAVING CHILDREN
54	F68TUTOR	Num	8	REQUIRED TUTORING
36	F68UNB	Num	8	UNION BENEFITS
35	F68VA	Num	8	V.A. BENEFITS
118	JF68DATE	Num	8	DATE OF VISIT - RECODE DAYS SINCE DOE

CODEBOOK FOR CSSCD PERSONAL DIARY
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* R68.FMT contains value labels for numerical codes assigned to
categorical *

* variables in the SAS dataset R68.SD2

*

*****;

* SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 12/25/99 09:45:14;

PROC FORMAT PRINT;

VALUE F68PSEX

1 = 'MALE'
2 = 'FEMALE';

VALUE F68MSTAT

1 = 'SINGL NEV MAR,SINGL DIVR,WIDOW,SEPARAT,LIV TOGE'
3 = 'MARRIED OR REMARRIED';

VALUE F68RELAT

1 = 'MOTHER'
2 = 'FATHER'
4 = 'STEP-MOTHER'
8 = 'STEP-FATHER'
16 = 'BROTHER'
32 = 'SISTER'
64 = 'GRANDMOTHER'
128 = 'GRANDFATHER'
256 = 'OTHER'
512 = 'NONE';

* FORMAT CHOICE IS DEFINED FOR VARIABLES: F68MMPI1-F68MMPI5;

VALUE CHOICE

1 = 'CHOICE A'
2 = 'CHOICE B';

VALUE F68ASSIT

1 = 'NO ONE';

* FORMAT HELPFUL IS DEFINED FOR VARIABLES: F68DOCT F68NURS F68SOCW
F68GENE

F68COMM F68RELTV F68FRIEN

F68PRIE

F68COUN F68CHUR F68SCHL

F68SOCSC

F68DEPT F68FAMS F68PUBC

F68SIKLC

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F68VA F68UNB F68CIVIL;

VALUE HELPFUL

1 = 'NOT USED'
2 = 'VERY HELPFUL'
3 = 'SOMEWHAT HELPFUL'
4 = 'NOT HELPFUL';

* FORMAT OTHER IS DEFINED FOR VARIABLES: F68OTHR F68OTER;

VALUE OTHER

1 = 'NOT USED'
2 = 'VERY HELPFUL'
4 = 'SOMEWHAT HELPFUL'
8 = 'NOT HELPFUL'
16 = 'WRITE-IN';

VALUE F68SUPP

1 = 'NONE';

VALUE F68EMOT

1 = 'LESS SUSPICIOUS'
2 = 'MORE SUSPICIOUS'
4 = 'LESS WORRIED'
8 = 'MORE WORRIED'
16 = 'LESS ANGRY'
32 = 'MORE ANGRY'
64 = 'NONE ABOVE';

VALUE F68RELT

1 = 'LESS CARING'
2 = 'MORE CARING'
4 = 'NOT AS CLOSE'
8 = 'I AM CLOSER'
16 = 'LESS PROTECTIVE'
32 = 'MORE PROTECTIVE'
64 = 'NONE';

VALUE F68RELSP

1 = 'NEVER MARRIED'
2 = 'NO'
4 = 'LESS CARING'
8 = 'MORE CARING'
16 = 'NOT AS CLOSE'
32 = 'CLOSER'
64 = 'LESS TIME'
128 = 'MORE TIME';

VALUE F68SOCIA

1 = 'ACTIVITY DECREASED'

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2 = 'ACTIVITY INCREASED'
3 = 'NOT AFFECTED';

VALUE F68PHSY

1 = 'ACTIVITY DECREASED'
2 = 'ACTIVITY INCREASED'
3 = 'ACTIVITY STAYED THE SAME';

VALUE F68SCLW

1 = 'FAVORABLY AFFECTED'
2 = 'UNFAVORABLY AFFECTED'
3 = 'NOT AFFECTED';

VALUE F68RELBR

1 = 'NO SIBLINGS'
2 = 'GET ALONG BETTER'
4 = 'GET ALONG WORSE'
8 = 'ARE CLOSER'
16 = 'NOT AS CLOSE'
32 = 'SPEND MORE TIME'
64 = 'SPEND LESS TIME'
128 = 'DOES NOT AFFECT';

VALUE F68PLAN

1 = 'CHOICE A'
2 = 'CHOICE B'
3 = 'CHOICE C'
4 = 'UNDECIDED';

VALUE F68ILL

1 = 'SEVERLY ILL'
2 = 'MODERATELY ILL'
3 = 'MILDLY ILL'
4 = 'NOT ILL';

VALUE F68GRADE

1 = 'IN 1ST GRADE'
2 = 'IN 2D GRADE'
3 = 'IN 3D GRADE'
4 = 'IN 4TH GRADE'
5 = 'IN 5TH GRADE'
6 = 'IN 6TH GRADE'
7 = 'IN 7TH GRADE'
8 = 'IN 8TH GRADE'
9 = 'IN 9TH GRADE'
10 = 'IN 10TH GRADE'
11 = 'IN 11TH GRADE'
12 = 'IN 12TH GRADE'
13 = '1ST YEAR COLLEGE'
14 = '2D YEAR COLLEGE'

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15 = '3D YEAR COLLEGE'
16 = '4TH YEAR COLLEGE';

* FORMAT CHECK IS DEFINED FOR VARIABLES: F68TRADE F68SPED;

VALUE CHECK

1 = 'NO, NOT CHECKED'
2 = 'YES, CHECKED';

VALUE F68NTSCH

1 = 'GRADUATED, NOT IN SCHOOL'
2 = 'DROPPED OUT, NOT IN SCHOOL';

VALUE F68ATGRD

1 = 'DROPPED OUT OF 1ST GRADE'
2 = 'DROPPED OUT OF 2D GRADE'
3 = 'DROPPED OUT OF 3D GRADE'
4 = 'DROPPED OUT OF 4TH GRADE'
5 = 'DROPPED OUT OF 5TH GRADE'
6 = 'DROPPED OUT OF 6TH GRADE'
7 = 'DROPPED OUT OF 7TH GRADE'
8 = 'DROPPED OUT OF 8TH GRADE'
9 = 'DROPPED OUT OF 9TH GRADE'
10 = 'DROPPED OUT OF 10TH GRADE'
11 = 'DROPPED OUT OF 11TH GRADE'
12 = 'DROPPED OUT OF 12TH GRADE'
13 = 'DROPPED OUT OF 1ST YR. COLL.'
14 = 'DROPPED OUT OF 2D YR. COLL.'
15 = 'DROPPED OUT OF 3D YR. COLL.'
16 = 'DROPPED OUT OF 4TH YR. COLL.';

VALUE F68GRDS

1 = 'EXCELLENT'
2 = 'ABOVE AVERAGE'
3 = 'AVERAGE'
4 = 'BELOW AVERAGE';

* FORMAT NO_YES IS DEFINED FOR VARIABLES: F68TUTOR F68EDUC F68HOMBD
F68FAIL;

VALUE NO_YES

1 = 'NO'
2 = 'YES';

VALUE F68DYMIS

1 = 'NONE'
2 = '1-5 DAYS'
3 = '6-10'
4 = '11-15'
5 = '16-20'

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6 = '21-30'
7 = 'OVER 30 DAYS';

VALUE F68REAS

1 = 'RELATED TO SCD'
2 = 'NOT RELATED TO SCD'
3 = 'FAMILY EVENT'
4 = 'LACK OF TRANSPORT'
5 = 'WEATHER'
6 = 'FINANCIAL'
7 = 'OTHER';

VALUE F68FGRD

1 = '1ST GRADE'
2 = '2D GRADE'
3 = '3D GRADE'
4 = '4TH GRADE'
5 = '5TH GRADE'
6 = '6TH GRADE'
7 = '7TH GRADE'
8 = '8TH GRADE'
9 = '9TH GRADE'
10 = '10TH GRADE'
11 = '11TH GRADE'
12 = '12TH GRADE'
13 = '1ST YR. COLL.'
14 = '2D YR. COLL.'
15 = '3D YR. COLL.'
16 = '4TH YR. COLL.';

VALUE F68REASN

1 = 'TOO ADVANCED'
2 = 'REPEATED ABSENCES'
4 = 'UNINTERESTED'
8 = 'DISLIKED CHILD'
16 = 'PREJUDICIAL'
32 = 'SCD ILLNESS'
64 = 'OTHER'
128 = 'NONE';

VALUE F68MYREL

1 = 'CLOSER'
2 = 'MORE PROTECTIVE'
4 = 'MORE CARING'
8 = 'LESS CLOSE'
16 = 'LESS PROTECTIVE'
32 = 'LESS CARING'
64 = 'NO OTHER CHILDREN'
128 = 'ALL HAVE SCD';

VALUE F68EFFCT

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1	=	'DECREASE LIFESPAN'
2	=	'INCREASE LIFESPAN'
3	=	'NO EFFECT'
4	=	'DONT KNOW';

VALUE F68HOWFR

1	=	'STOP NOW'
2	=	'HIGH SCHOOL'
3	=	'TRAINING PROGRAM'
4	=	'JUNIOR COLLEGE'
5	=	'COLLEGE'
6	=	'GRADUATE SCHOOL';

* FORMAT FEL1X IS DEFINED FOR VARIABLE F68FEL1;

VALUE FEL1X

1	=	'SOMETIMES'
2	=	'OFTEN'
3	=	'ALL THE TIME';

* FORMAT FEL2X IS DEFINED FOR VARIABLE F68FEL2;

VALUE FEL2X

1	=	'NEVER'
2	=	'NOT SURE'
3	=	'SURE';

* FORMAT FEL3X IS DEFINED FOR VARIABLE F68FEL3;

VALUE FEL3X

1	=	'MOST OK'
2	=	'MANY WRONG'
3	=	'ALL WRONG';

* FORMAT FEL4X IS DEFINED FOR VARIABLE F68FEL4;

VALUE FEL4X

1	=	'MANY THINGS'
2	=	'SOME THINGS'
3	=	'NOTHING';

* FORMAT FEL5X IS DEFINED FOR VARIABLE F68FEL5;

VALUE FEL5X

1	=	'ALL THE TIME'
2	=	'OFTEN'
3	=	'SELDOM';

* FORMAT FEL6X IS DEFINED FOR VARIABLE F68FEL6;

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VALUE FEL6X

1 = 'SELDOM'
2 = 'OFTEN'
3 = 'ALL THE TIME';

* FORMAT FEL7X IS DEFINED FOR VARIABLE F68FEL7;

VALUE FEL7X

1 = 'HATES'
2 = 'DOES NOT LIKE'
3 = 'LIKES';

* FORMAT FEL8X IS DEFINED FOR VARIABLE F68FEL8;

VALUE FEL8X

1 = 'ALL ARE'
2 = 'MANY ARE'
3 = 'SOME ARE';

* FORMAT FEL9X IS DEFINED FOR VARIABLE F68FEL9;

VALUE FEL9X

1 = 'DOES NOT'
2 = 'THINKS BUT WONT'
3 = 'DOES';

* FORMAT FEL10X IS DEFINED FOR VARIABLE F68FEL10;

VALUE FEL10X

1 = 'EVERY DAY'
2 = 'MANY DAYS'
3 = 'SELDOM';

* FORMAT FEL11X IS DEFINED FOR VARIABLE F68FEL11;

VALUE FEL11X

1 = 'ALL THE TIME'
2 = 'MANY TIMES'
3 = 'SELDOM';

* FORMAT FEL12X IS DEFINED FOR VARIABLE F68FEL12;

VALUE FEL12X

1 = 'LIKES'
2 = 'OFTEN DISLIKES'
3 = 'ALWAYS DISLIKES';

* FORMAT FEL13X IS DEFINED FOR VARIABLE F68FEL13;

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VALUE FEL13X

1	= 'CANNOT'
2	= 'HAS TROUBLE'
3	= 'EASY';

* FORMAT FEL14X IS DEFINED FOR VARIABLE F68FEL14;

VALUE FEL14X

1	= 'OK'
2	= 'SOME BAD'
3	= 'UGLY';

* FORMAT FEL15X IS DEFINED FOR VARIABLE F68FEL15;

VALUE FEL15X

1	= 'CONSTANT PUSH'
2	= 'OFTEN PUSH'
3	= 'NO BIG PROBLEM';

* FORMAT FEL16X IS DEFINED FOR VARIABLE F68FEL16;

VALUE FEL16X

1	= 'TROUBLE EVERY NIGHT'
2	= 'TROUBLE MANY NIGHTS'
3	= 'PRETTY WELL';

* FORMAT FEL17X IS DEFINED FOR VARIABLE F68FEL17;

VALUE FEL17X

1	= 'SELDOM'
2	= 'OFTEN'
3	= 'ALWAYS';

* FORMAT FEL18X IS DEFINED FOR VARIABLE F68FEL18;

VALUE FEL18X

1	= 'NO, MOST TIMES'
2	= 'NO, OFTEN'
3	= 'GOOD APPETITE';

* FORMAT FEL19X IS DEFINED FOR VARIABLE F68FEL19;

VALUE FEL19X

1	= 'NO WORRY'
2	= 'WORRY SOMETIMES'
3	= 'WORRIES';

* FORMAT FEL20X IS DEFINED FOR VARIABLE F68FEL20;

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

VALUE FEL20X

1	=	'DOES NOT'
2	=	'OFTEN'
3	=	'ALWAYS';

* FORMAT FEL21X IS DEFINED FOR VARIABLE F68FEL21;

VALUE FEL21X

1	=	'NEVER'
2	=	'SELDOM'
3	=	'MOST';

* FORMAT FEL22X IS DEFINED FOR VARIABLE F68FEL22;

VALUE FEL22X

1	=	'PLENTY'
2	=	'SOME'
3	=	'NONE'
4	=	'SATISFIED';

* FORMAT FEL23X IS DEFINED FOR VARIABLE F68FEL23;

VALUE FEL23X

1	=	'ALL RIGHT'
2	=	'NOT AS GOOD'
3	=	'VERY BADLY';

* FORMAT FEL24X IS DEFINED FOR VARIABLE F68FEL24;

VALUE FEL24X

1	=	'NEVER'
2	=	'PERHAPS'
3	=	'JUST AS';

* FORMAT FEL25X IS DEFINED FOR VARIABLE F68FEL25;

VALUE FEL25X

1	=	'NOBODY DOES'
2	=	'NOT SURE'
3	=	'SOMEBODY DOES';

* FORMAT FEL26X IS DEFINED FOR VARIABLE F68FEL26;

VALUE FEL26X

1	=	'USUALLY'
2	=	'NOT USUALLY'
3	=	'NEVER';

CODEBOOK FOR CSSCD PERSONAL DIARY
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* FORMAT FEL27X IS DEFINED FOR VARIABLE F68FEL27;

VALUE FEL27X

1	= 'OFTEN'
2	= 'FIGHTS OFTEN'
3	= 'ALWAYS FIGHTS';

* FORMAT TRUE IS DEFINED FOR VARIABLES: F68TRUE1-F68TRUE7;

VALUE TRUE

1	= 'VERY TRUE'
2	= 'SOMEWHAT TRUE'
3	= 'SOMEWHAT UNTRUE'
4	= 'VERY UNTRUE';

* FORMAT EFFECT IS DEFINED FOR VARIABLES: F68OLDR1-F68OLDR6;

VALUE EFFECT

1	= 'NO EFFECT'
2	= 'LITTLE'
3	= 'MODERATE'
4	= 'MUCH'
5	= 'VERY MUCH';

VALUE F68GOSHL

1	= 'STOP NOW'
2	= 'HIGH SCHOOL'
3	= 'TRAINING PROGRM'
4	= 'JUNIOR COLLEGE'
5	= '4 YEARS COLLEGE'
6	= 'GRAD SCHOOL'
7	= 'DONT KNOW';

VALUE F68PAIN

1	= 'LACK OF IRON'
2	= 'BLOCKAGE OF VESSELS'
3	= 'ARTHRITIS'
4	= 'ALL OF THE ABOVE'
5	= 'NOT SURE';

VALUE F68SICKL

1	= 'SCALY SKIN'
2	= 'OBESITY'
4	= 'PERIODS OF PAIN'
8	= 'LOSS OF HAIR'
16	= 'ALL OF THE ABOVE'
32	= 'NOT SURE';

* FORMAT T_F IS DEFINED FOR VARIABLES: F68IDEA1-F68IDEA6;

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VALUE T_F

1	= 'TRUE'
2	= 'FALSE'
3	= 'NOT SURE' ;

VALUE F68RELTN

1	= 'MOTHER'
2	= 'FATHER'
3	= 'GRANDMOTHER'
4	= 'GRANDFATHER'
5	= 'OTHER' ;

* FORMAT YESNODK IS DEFINED FOR VARIABLES: F68HAVSC F68HAVST F68CHRON;

VALUE YESNODK

1	= 'YES'
2	= 'NO'
3	= 'DK' ;

S. List of variables deleted **F69INIT F69NDATE F69LASTU F69LASTE F69ESTAT
F69VDATE F69DATE F69DFC F69FCB**

T. List of variables modified **F69BDATE**

U. List of variables modified with a name change **NONE**

V. Old name

W. New name

X. List of variables modified date to days since DOE

Y. Old name **F69DATE**

Z. New name **JF69DATE**

AA. Collection Information:

Form 69 (Psychosocial Questionnaire for SCD Patients 8-13 Years of Age)
was to be completed for a random sample of HbSS patients between the ages of 8
and 13 years. Psychosocial requirements for this group (GROUP 3) included
completion of Form 69 and the Piers-Harris test.

BB. Data Collection Period: 05/84-06/87

CC. Form Version Dates: 03/30/84

DD. Files Used to Store Information:

SAS System Files: **R69.SD2**

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Format Files: **R69.FMT**

EE. Unique Record Identifiers: **ANONID, F69CYCLE**

Records within the dataset are sorted by **ANONID** and **F69CYCLE**

FF. Number of Observations (Patients) in SAS Dataset: 89 (89)

GG. Contents of SAS Dataset:

- Alphabetical Listing of Variables: See pp. 1-3
- Listing of Variables by Position: See pp. 4-6

A codebook for this dataset is not included in this manual.

HH. Notes About Selected Variables: None

II. Computed Variables: None

JJ. Inter-Relationship With Other Datasets:

Psychosocial data were also collected on

Phase 1 Forms	SAS Dataset	See Section
Form 67	R67.SD2	6.10.1
Form 68	R68.SD2	6.10.2
Form 73	R73.SD2	6.10.4
Form 74	R74.SD2	6.10.5
"Roster"	R09.SD2	1.0 (variable: PSYSTAT)

CONTENTS OF SAS DATASET: R69.SD2
DATA FROM CSSCD FORM 69 - PSYCHOSOCIAL QUESTIONNAIRE
for SCD PATIENTS 8-13 YEARS OF AGE
VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION
IN THE SAS DATASET AND ON FORM 69

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Data Set Name	OUT1.R69	Observations	89
Member Type	DATA	Variables	82
Engine	V9	Indexes	0
Created	16:41 Monday, November 6, 2006	Observation Length	656
Last Modified	16:41 Monday, November 6, 2006	Deleted Observations	0
Protection		Compressed	NO
Data Set Type		Sorted	NO
Label			
Data Representation	WINDOWS		
Encoding	wlatin1 Western (Windows)		

Engine/Host Dependent Information

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Data Set Page Size	16384
Number of Data Set Pages	5
First Data Page	1
Max Obs per Page	24
Obs in First Data Page	9
Number of Data Set Repairs	0
File Name	r69.sas7bdat
Release Created	9.0000M0
Host Created	XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
42	F69ACT1	Num	8	BASEBALL
43	F69ACT2	Num	8	TALK
44	F69ACT3	Num	8	SWIMMING
45	F69ACT4	Num	8	DANCING
46	F69ACT5	Num	8	MOVIES
47	F69ACT6	Num	8	JOGGING
48	F69ACT7	Num	8	RIDING BIKE
49	F69ACT8	Num	8	COOKING
50	F69ACT9	Num	8	READING
51	F69ACT10	Num	8	SINGING
52	F69ACT11	Num	8	ART
53	F69ACT12	Num	8	WATCH TV
54	F69ACT13	Num	8	PLAY GAMES
55	F69ACT14	Num	8	LISTEN TO MUSIC
16	F69AFRAD	Num	8	MAKE YOU AFRAID
30	F69AGR1	Num	8	LITTLE CONTROL
31	F69AGR2	Num	8	DO MYSELF
32	F69AGR3	Num	8	OTHERS MY AGE
33	F69AGR4	Num	8	SPEND MORE TIME
34	F69AGR5	Num	8	MY PAIN KEEPS PARENTS
35	F69AGR6	Num	8	RATHER NOT TALK
36	F69AGR7	Num	8	PAY MORE ATTENTION
37	F69AGR8	Num	8	FUTURE DEPENDS ON ME
38	F69AGR9	Num	8	EXPECT WHAT I CAN'T DO
39	F69AGR10	Num	8	FAMILY DOESN'T UNDERSTAND
40	F69AGR11	Num	8	DO THINGS FOR ME

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Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
41	F69AGR12	Num	8	PUSHED AROUND
17	F69AHEAD	Num	8	PLANING AHEAD
3	F69BDATE	Num	8	PATIENTS BIRTHDATE RECODE AGE AT VISIT
2	F69CYCLE	Num	8	RECORD 69 CYCLE
56	F69FEL1	Num	8	SADNESS
57	F69FEL2	Num	8	THINGS WORKING OUT
58	F69FEL3	Num	8	DOING THINGS
59	F69FEL4	Num	8	HAVING FUN
60	F69FEL5	Num	8	ACTING BAD
61	F69FEL6	Num	8	THINKING BAD
62	F69FEL7	Num	8	HATRED
63	F69FEL8	Num	8	FAULT OF BAD THINGS
64	F69FEL9	Num	8	SUICIDE
65	F69FEL10	Num	8	CRYING
66	F69FEL11	Num	8	THINGS THAT BOTHER
67	F69FEL12	Num	8	BEING WITH PEOPLE
68	F69FEL13	Num	8	DECIDING
69	F69FEL14	Num	8	SELF-APPEARANCE
70	F69FEL15	Num	8	SCHOOLWORK
71	F69FEL16	Num	8	SLEEPING
72	F69FEL17	Num	8	TIREDNESS
73	F69FEL18	Num	8	EATING
74	F69FEL19	Num	8	ACHES
75	F69FEL20	Num	8	FEELING ALONE
76	F69FEL21	Num	8	FUN AT SCHOOL
77	F69FEL22	Num	8	FRIENDS
78	F69FEL23	Num	8	SCHOOLWORK
79	F69FEL24	Num	8	FEELING LOVED
80	F69FEL25	Num	8	OBEDIENCE
81	F69FEL26	Num	8	GETTING ALONG
12	F69HOWLG	Num	8	HOW LONG YOU LIVE
5	F69HWLIK	Num	8	LIKELY TO HAVE CAREER
6	F69OLDR1	Num	8	YOUR SEX
7	F69OLDR2	Num	8	YOUR RACE
8	F69OLDR3	Num	8	HOW FAR IN SCHOOL
9	F69OLDR4	Num	8	HOW MUCH MONEY
10	F69OLDR5	Num	8	SICKLE CELL
11	F69OLDR6	Num	8	YOUR PERSONALITY
18	F69PLAN1	Num	8	GETTING JOB
19	F69PLAN2	Num	8	MARRIAGE
20	F69PLAN3	Num	8	CHILDREN
21	F69PLAN4	Num	8	HIGH SCHOOL
22	F69PLAN5	Num	8	COLLEGE
23	F69PLAN6	Num	8	KIND OF JOB
14	F69PLAY	Num	8	PLAY WITH FRIENDS
24	F69SCA1	Num	8	CURED
25	F69SCA2	Num	8	CAUGHT
26	F69SCA3	Num	8	SEVERE

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27	F69SCA4	Num	8	DEPENDENT
28	F69SCA5	Num	8	PRODUCTIVE
29	F69SCA6	Num	8	CAN'T LEARN WELL
13	F69SCHWK	Num	8	DO WELL IN SCHOOL OR WORK

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

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The CONTENTS Procedure

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
4	F69SEX	Num	8	SEX OF PARENT
15	F69TREAT	Num	8	TREAT LIKE OTHER KIDS
82	JF69DATE	Num	8	DATE OF VISIT - RECODE DAYS SINCE DOE

CODEBOOK FOR CSSCD PERSONAL DIARY
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* R69.FMT contains value labels for numerical codes assigned to
categorical *

* variables in the SAS dataset R69.SD2

*

*****;

* SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 12/25/99 09:48:41;

PROC FORMAT PRINT;

VALUE F69SEX

1 = 'MALE'
2 = 'FEMALE';

VALUE F69HWLIK

1 = 'VERY UNLIKELY'
2 = 'SOMEWHAT UNLIKELY'
3 = 'DON" T KNOW'
4 = 'SOMEWHAT LIKELY'
5 = 'VERY LIKELY';

* FORMAT NSURE IS DEFINED FOR VARIABLES: F69OLDR1-F69OLDR6 F69PLAN1-
F69PLAN6;

VALUE NSURE

1 = 'NO'
2 = 'YES'
3 = 'NOT SURE';

VALUE F69HOWLG

1 = 'NOT LIVE AS LONG'
2 = 'LIVE LONGER'
3 = 'NO EFFECT'
4 = 'DO NOT KNOW';

* FORMAT NEVER IS DEFINED FOR VARIABLES: F69SCHWK F69PLAY F69TREAT
F69AFRAD F69AHEAD;

VALUE NEVER

1 = 'NEVER'
2 = 'SELDOM'
3 = 'SOMETIMES'
4 = 'OFTEN'
5 = 'ALL THE TIME';

* FORMAT FALSE IS DEFINED FOR VARIABLES: F69SCA1-F69SCA6;

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

VALUE FALSE

1	= 'FALSE'
2	= 'TRUE'
3	= 'NOT SURE' ;

* FORMAT AGREE IS DEFINED FOR VARIABLES: F69AGR1-F69AGR12;

VALUE AGREE

1	= 'AGREE'
2	= 'DISAGREE' ;

* FORMAT YESNO IS DEFINED FOR VARIABLES: F69ACT1-F69ACT14;

VALUE YESNO

1	= 'YES'
2	= 'NO' ;

* FORMAT FEL1X IS DEFINED FOR VARIABLE F69FEL1;

VALUE FEL1X

1	= 'SOMETIMES'
2	= 'OFTEN'
3	= 'ALL THE TIME' ;

* FORMAT FEL2X IS DEFINED FOR VARIABLE F69FEL2;

VALUE FEL2X

1	= 'NEVER'
2	= 'NOT SURE'
3	= 'SURE' ;

* FORMAT FEL3X IS DEFINED FOR VARIABLE F69FEL3;

VALUE FEL3X

1	= 'MOST OK'
2	= 'MANY WRONG'
3	= 'ALL WRONG' ;

* FORMAT FEL4X IS DEFINED FOR VARIABLE F69FEL4;

VALUE FEL4X

1	= 'MANY THINGS'
2	= 'SOME THINGS'
3	= 'NOTHING' ;

* FORMAT FEL5X IS DEFINED FOR VARIABLE F69FEL5;

CODEBOOK FOR CSSCD PERSONAL DIARY
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VALUE FEL5X

1	= 'ALL THE TIME'
2	= 'OFTEN'
3	= 'SELDOM' ;

* FORMAT FEL6X IS DEFINED FOR VARIABLE F69FEL6;

VALUE FEL6X

1	= 'SELDOM'
2	= 'OFTEN'
3	= 'ALL THE TIME' ;

* FORMAT FEL7X IS DEFINED FOR VARIABLE F69FEL7;

VALUE FEL7X

1	= 'HATES'
2	= 'DOES NOT LIKE'
3	= 'LIKES' ;

* FORMAT FEL8X IS DEFINED FOR VARIABLE F69FEL8;

VALUE FEL8X

1	= 'ALL ARE'
2	= 'MANY ARE'
3	= 'SOME ARE' ;

* FORMAT FEL9X IS DEFINED FOR VARIABLE F69FEL9;

VALUE FEL9X

1	= 'DOES NOT'
2	= 'THINKS BUT WONT'
3	= 'DOES' ;

* FORMAT FEL10X IS DEFINED FOR VARIABLE F69FEL10;

VALUE FEL10X

1	= 'EVERY DAY'
2	= 'MANY DAYS'
3	= 'SELDOM' ;

* FORMAT FEL11X IS DEFINED FOR VARIABLE F69FEL11;

VALUE FEL11X

1	= 'ALL THE TIME'
2	= 'MANY TIMES'
3	= 'SELDOM' ;

* FORMAT FEL12X IS DEFINED FOR VARIABLE F69FEL12;

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VALUE FEL12X

1 = 'LIKES'
2 = 'OFTEN DISLIKES'
3 = 'ALWAYS DISLIKES';

* FORMAT FEL13X IS DEFINED FOR VARIABLE F69FEL13;

VALUE FEL13X

1 = 'CANNOT'
2 = 'HAS TROUBLE'
3 = 'EASY';

* FORMAT FEL14X IS DEFINED FOR VARIABLE F69FEL14;

VALUE FEL14X

1 = 'OK'
2 = 'SOME BAD'
3 = 'UGLY';

* FORMAT FEL15X IS DEFINED FOR VARIABLE F69FEL15;

VALUE FEL15X

1 = 'CONSTANT PUSH'
2 = 'OFTEN PUSH'
3 = 'NO BIG PROBLEM';

* FORMAT FEL16X IS DEFINED FOR VARIABLE F69FEL16;

VALUE FEL16X

1 = 'TROUBLE EVERY NIGHT'
2 = 'TROUBLE MANY NIGHTS'
3 = 'PRETTY WELL';

* FORMAT FEL17X IS DEFINED FOR VARIABLE F69FEL17;

VALUE FEL17X

1 = 'SELDOM'
2 = 'OFTEN'
3 = 'ALWAYS';

* FORMAT FEL18X IS DEFINED FOR VARIABLE F69FEL18;

VALUE FEL18X

1 = 'NO, MOST TIMES'
2 = 'NO, OFTEN'
3 = 'GOOD APPETITE';

* FORMAT FEL19X IS DEFINED FOR VARIABLE F69FEL19;

CODEBOOK FOR CSSCD PERSONAL DIARY
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VALUE FEL19X

1 = 'NO WORRY'
2 = 'WORRY SOMETIMES'
3 = 'WORRIES';

* FORMAT FEL20X IS DEFINED FOR VARIABLE F69FEL20;

VALUE FEL20X

1 = 'DOES NOT'
2 = 'OFTEN'
3 = 'ALWAYS';

* FORMAT FEL21X IS DEFINED FOR VARIABLE F69FEL21;

VALUE FEL21X

1 = 'NEVER'
2 = 'SELDOM'
3 = 'MOST';

* FORMAT FEL22X IS DEFINED FOR VARIABLE F69FEL22;

VALUE FEL22X

1 = 'PLENTY'
2 = 'SOME'
3 = 'NONE'
4 = 'SATISFIED';

* FORMAT FEL23X IS DEFINED FOR VARIABLE F69FEL23;

VALUE FEL23X

1 = 'ALL RIGHT'
2 = 'NOT AS GOOD'
3 = 'VERY BADLY';

* FORMAT FEL24X IS DEFINED FOR VARIABLE F69FEL24;

VALUE FEL24X

1 = 'NOBODY DOES'
2 = 'NOT SURE'
3 = 'SOMEBODY DOES';

* FORMAT FEL25X IS DEFINED FOR VARIABLE F69FEL25;

VALUE FEL25X

1 = 'USUALLY'
2 = 'NOT USUALLY'
3 = 'NEVER';

* FORMAT FEL26X IS DEFINED FOR VARIABLE F69FEL26;

CODEBOOK FOR CSSCD PERSONAL DIARY
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VALUE FEL26X

- | | |
|---|---------------------|
| 1 | = 'OFTEN' |
| 2 | = 'FIGHTS OFTEN' |
| 3 | = 'ALWAYS FIGHTS' ; |

KK. List of variables deleted **F73INIT F73NDATE F78LASTU F73LASTE
F73ESTAT**

F73VDATE F73DATE F73DFC F73FCB

LL. List of variables modified **F73BDATE**

MM. List of variables modified with a name change **NONE**

NN. Old name

OO. New name

PP. List of variables modified date to days since DOE

QQ. Old name **F73DATE**

RR. New name **JF73DATE**

SS. Collection Information:

Form 73 (Psychosocial Questionnaire for SCD Patients 14-19 Years of Age)

was to be completed for a random sample of HbSS patients 14-19 years of age.

Psychosocial requirements for this group of patients (GROUP 4) included completion of Form 73, the Family Environment Scale (FES), and the STAI Anxiety Scale.

TT. Data Collection Period: 05/84-09/87

UU. Form Version Dates: 03/30/84

VV. Files Used to Store Information:

SAS System Files: **R73.SD2**

Format Files: **R73.FMT**

WW. Unique Record Identifiers: **ANONID, F73CYCLE**

Records within the dataset are sorted by **ANONID** and **F73CYCLE**

XX. Number of Observations (Patients) in SAS Dataset: 90 (90)

YY. Contents of SAS Dataset:

- Alphabetical Listing of Variables: See pp. 1-6
- Listing of Variables by Position: See pp. 7-12

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A codebook for this dataset is not included in this manual.

ZZ. Notes About Selected Variables: None

AAA. Computed Variables: None

BBB. Inter-Relationship With Other Datasets:

Psychosocial data were also collected on

Phase 1 Forms	SAS Dataset	See Section
Form 67	R67.SD2	6.10.1
Form 68	R68.SD2	6.10.2
Form 69	R69.SD2	6.10.3
Form 74	R74.SD2	6.10.5
"Roster"	R09.SD2	1.0 (variable: PSYSTAT)

CONTENTS OF SAS DATASET: R73.SD2
DATA FROM CSSCD FORM 73 - PSYCHOSOCIAL QUESTIONNAIRE
for SCD PATIENTS 8-13 YEARS OF AGE
VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION
IN THE SAS DATASET AND ON FORM 73

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Data Set Name	OUT1.R73	Observations	90
Member Type	DATA	Variables	207
Engine	V9	Indexes	0
Created	15:07 Tuesday, November 7, 2006	Observation Length	1656
Last Modified	15:07 Tuesday, November 7, 2006	Deleted Observations	0
Protection		Compressed	NO
Data Set Type		Sorted	NO
Label			
Data Representation	WINDOWS		
Encoding	wlatin1 Western (Windows)		

Engine/Host Dependent Information

Data Set Page Size	16384
Number of Data Set Pages	12
First Data Page	2
Max Obs per Page	9
Obs in First Data Page	5
Number of Data Set Repairs	0
File Name	r73.sas7bdat
Release Created	9.0000M0
Host Created	XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
---	----------	------	-----	-------

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1	ANONID	Char	8	ANONYMIZED ID #
81	F73ACT1	Num	8	BASEBALL
82	F73ACT2	Num	8	TALK WITH FRIENDS
83	F73ACT3	Num	8	SWIMMING
84	F73ACT4	Num	8	DANCING
85	F73ACT5	Num	8	MOVIES
86	F73ACT6	Num	8	JOGGING
87	F73ACT7	Num	8	BIKE
88	F73ACT8	Num	8	COOKING
89	F73ACT9	Num	8	READING
90	F73ACT10	Num	8	SINGING
91	F73ACT11	Num	8	ART
92	F73ACT12	Num	8	TV
93	F73ACT13	Num	8	PLAY GAMES
94	F73ACT14	Num	8	MUSIC
5	F73AFF1	Num	8	RELATIONSHIP WITH PARENTS
6	F73AFF2	Num	8	RELATIONSHIP WITH SIBLINGS
7	F73AFF3	Num	8	RELATIONSHIP WITH FRIENDS
8	F73AFF4	Num	8	PHYSICAL ACTIVITY
9	F73AFF5	Num	8	SOCIAL ACTIVITY
10	F73AFF6	Num	8	FEEL ABOUT OTHER PEOPLE
11	F73AFF7	Num	8	BEHAVE TOWARDS YOU
12	F73AFF8	Num	8	FEEL EMOTIONALLY
13	F73AFF9	Num	8	INTIMATE RELATIONSHIPS
14	F73AFRAD	Num	8	MAKE YOU AFRAID
15	F73AHEAD	Num	8	KEEP FROM PLANNING AHEAD
3	F73BDATE	Num	8	PATIENTS BIRTHDATE RECODE AGE AT VISIT

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Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
44	F73CAUSE	Num	8	SCD MAY CAUSE
156	F73CB1	Num	8	UPSET FAMILY
157	F73CB2	Num	8	ENGAGING IN RELATIONSHIPS
158	F73CB3	Num	8	TRUSTING PARENT(S)
159	F73CB4	Num	8	SLEEPING
160	F73CB5	Num	8	TALK WITH MEDICAL STAFF
161	F73CB6	Num	8	WILL GET BETTER
162	F73CB7	Num	8	KEEPING BUSY
163	F73CB8	Num	8	I AM STRONG
164	F73CB9	Num	8	PURCHASING GIFTS
165	F73CB10	Num	8	OTHERS HAVE MY PROBLEM
166	F73CB11	Num	8	BEING SURE
167	F73CB12	Num	8	EATING TO RELAX
168	F73CB13	Num	8	HELPING WITH CHORES
169	F73CB14	Num	8	BY MYSELF
170	F73CB15	Num	8	TALK WITH DOCTOR
171	F73CB16	Num	8	REALLY INTERESTED
172	F73CB17	Num	8	CLOSE RELATIONSHIPS
173	F73CB18	Num	8	BELIEVE IN GOD
174	F73CB19	Num	8	BETTER MYSELF
175	F73CB20	Num	8	SAME SITUATIONS
176	F73CB21	Num	8	DOING THINGS AS FAMILY
177	F73CB22	Num	8	INVESTING TIME AND ENERGY
178	F73CB23	Num	8	BEST CARE POSSIBLE
179	F73CB24	Num	8	FRIENDS OVER
180	F73CB25	Num	8	HANDLE THINGS
181	F73CB26	Num	8	THING WITH FAMILY
182	F73CB27	Num	8	SELF-RELIANT
183	F73CB28	Num	8	THANKFUL FOR
184	F73CB29	Num	8	HOBBIES
185	F73CB30	Num	8	PERSONAL SITUATION
186	F73CB31	Num	8	MORE INDEPENDENT
187	F73CB32	Num	8	IN SHAPE
188	F73CB33	Num	8	SOCIAL ACTIVITIES
189	F73CB34	Num	8	GOING OUT
190	F73CB35	Num	8	BEING SURE
191	F73CB36	Num	8	BUILDING RELATIONSHIP
192	F73CB37	Num	8	ALLOWING ANGRY
193	F73CB38	Num	8	GIVING MORE
194	F73CB39	Num	8	TALKING TO SOMEONE
195	F73CB40	Num	8	READING MORE
196	F73CB41	Num	8	PERSONAL FEELINGS
197	F73CB42	Num	8	GET AWAY
198	F73CB43	Num	8	SEEING DOC
199	F73CB44	Num	8	ALWAYS WORK OUT
200	F73CB45	Num	8	WITH SIBLINGS OR PARENTS
201	F73CEMP	Num	8	CURRENTLY EMPLOYED
72	F73COMM1	Num	8	CHURCH

CODEBOOK FOR CSSCD PERSONAL DIARY
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73	F73COMM2	Num	8	SOCIAL CLUBS
74	F73COMM3	Num	8	SICKLE CELL GROUPS
75	F73COMM4	Num	8	CIVIC ORGANIZATIONS
76	F73COMM5	Num	8	BLOCK CLUBS

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CSSCD FULL COHORT PATIENTS

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Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
77	F73COMM6	Num	8	POLITICAL GROUPS
78	F73COMM7	Num	8	YOUTH GROUPS
79	F73COMM8	Num	8	OTHER
61	F73COPE	Num	8	COPING MECHANISMS
2	F73CYCLE	Num	8	RECORD 73 CYCLE
203	F73DENYJ	Num	8	DENIED JOB
64	F73EXTA1	Num	8	COMPETITIVE SPORTS
65	F73EXTA2	Num	8	SCHOOL COMMITTEE
66	F73EXTA3	Num	8	ACADEMIC CLUBS
67	F73EXTA4	Num	8	STUDENT GOVERNMENT
68	F73EXTA5	Num	8	CHEERLEADER
69	F73EXTA6	Num	8	BAND
70	F73EXTA7	Num	8	CHOIR
71	F73EXTA8	Num	8	OTHER
124	F73FEEL0	Num	8	SATISFIED WITH MYSELF
125	F73FEEL1	Num	8	NO GOOD AT ALL
126	F73FEEL2	Num	8	GOOD QUALITIES
127	F73FEEL3	Num	8	AS WELL AS MOST
128	F73FEEL4	Num	8	PROUD OF
129	F73FEEL5	Num	8	USELESS AT TIMES
130	F73FEEL6	Num	8	PERSON OF WORTH
131	F73FEEL7	Num	8	MORE RESPECT
132	F73FEEL8	Num	8	FAILURE
133	F73FEEL9	Num	8	POSITIVE ATTITUDE
134	F73FEL1	Num	8	FEEL SAD
135	F73FEL2	Num	8	DISCOURAGED
136	F73FEL3	Num	8	FAILURE
137	F73FEL4	Num	8	SATISFACTION
138	F73FEL5	Num	8	GUILTY
139	F73FEL6	Num	8	PUNISHED
140	F73FEL7	Num	8	DISAPPOINTED
141	F73FEL8	Num	8	BLAME MYSELF
142	F73FEL9	Num	8	SUICIDE
143	F73FEL10	Num	8	CRY
144	F73FEL11	Num	8	IRRITATED
145	F73FEL12	Num	8	LOST INTEREST
146	F73FEL13	Num	8	MAKE DECISIONS
147	F73FEL14	Num	8	LOOKS
148	F73FEL15	Num	8	WORK AS WELL
149	F73FEL16	Num	8	SLEEP
150	F73FEL17	Num	8	TIRED
151	F73FEL18	Num	8	APPETITE
152	F73FEL19	Num	8	LOST WEIGHT
154	F73FEL20	Num	8	WORRIED ABOUT HEALTH
155	F73FEL21	Num	8	INTEREST IN SEX
204	F73FIREJ	Num	8	FIRED FROM JOB
62	F73GRADE	Num	8	GRADE COMPLETED
206	F73HELDJ	Num	8	HELD ONE JOB

CODEBOOK FOR CSSCD PERSONAL DIARY
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58	F73HOWLG	Num	8	HOW LONG YOU LIVE
63	F73HWFAR	Num	8	HOW FAR WILL YOU GO
51	F73HWLIK	Num	8	HOW LIKELY
25	F73ILL1	Num	8	OWN BEHAVIOR

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CSSCD FULL COHORT PATIENTS

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Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
26	F73ILL2	Num	8	NO MATTER WHAT
27	F73ILL3	Num	8	REGULAR CONTACT
28	F73ILL4	Num	8	ACCIDENT
29	F73ILL5	Num	8	CONSULT
30	F73ILL6	Num	8	CONTROL
31	F73ILL7	Num	8	FAMILY
32	F73ILL8	Num	8	BLAME SELF
33	F73ILL9	Num	8	LUCK AFFECTS RECOVERY RATE
34	F73ILL10	Num	8	PROFESSIONALS CONTROL
35	F73ILL11	Num	8	GOOD FORTUNE
36	F73ILL12	Num	8	I MYSELF DO
37	F73ILL13	Num	8	IF I TAKE CARE OF MYSELF
38	F73ILL14	Num	8	WHEN I RECOVER
39	F73ILL15	Num	8	NO MATTER WHAT, LIKELY
40	F73ILL16	Num	8	IF IT'S MEANT TO BE
41	F73ILL17	Num	8	IF I TAKE THE RIGHT ACTIONS
42	F73ILL18	Num	8	REGARDING MY HEALTH
95	F73LME1	Num	8	MORE AGGRESSIVE
96	F73LME2	Num	8	SHYNESS
97	F73LME3	Num	8	COMPLAIN TO WAITER
98	F73LME4	Num	8	AVOID HURTING
99	F73LME5	Num	8	SAYING NO
100	F73LME6	Num	8	KNOWING WHY
101	F73LME7	Num	8	VIGOROUS ARGUMENT
102	F73LME8	Num	8	GET AHEAD
103	F73LME9	Num	8	TAKE ADVANAGE
104	F73LME10	Num	8	STARTING CONVERSATIONS
105	F73LME11	Num	8	ATTRACTIVE PERSONS
106	F73LME12	Num	8	CALLS TO BUSINESS
107	F73LME13	Num	8	APPLY BY WRITING
108	F73LME14	Num	8	EMBARASSING TO RETURN
109	F73LME15	Num	8	SMOTHER MY FEELINGS
110	F73LME16	Num	8	SOUNDING STUPID
111	F73LME17	Num	8	SHAKE ALL OVER
112	F73LME18	Num	8	FAMED LECTURER
113	F73LME19	Num	8	ARGUING OVER PRICES
114	F73LME20	Num	8	LET OTHERS KNOW
115	F73LME21	Num	8	OPEN AND FRANK
116	F73LME22	Num	8	SPREADING STORIES
117	F73LME23	Num	8	SAYING NO
118	F73LME24	Num	8	BOTTLE EMOTIONS
119	F73LME25	Num	8	POOR SERVICE
120	F73LME26	Num	8	GIVEN COMPLIMENT
121	F73LME27	Num	8	COUPLE NEAR ME
122	F73LME28	Num	8	PUSH AHEAD
123	F73LME29	Num	8	EXPRESS OPINIONS
153	F73LOSWT	Num	8	PURPOSELY LOSE WEIGHT
20	F73MMP11	Num	8	FATE

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21	F73MMPI2	Num	8	CONTROL
22	F73MMPI3	Num	8	PLANS
23	F73MMPI4	Num	8	LUCK
24	F73MMPI5	Num	8	INFLUENCE

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Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
80	F73OFFIC	Num	8	HOLD AN OFFICE
52	F73OLDR1	Num	8	YOUR SEX
53	F73OLDR2	Num	8	YOUR RACE
54	F73OLDR3	Num	8	HOW FAR IN SCHOOL
55	F73OLDR4	Num	8	MONEY
56	F73OLDR5	Num	8	SCD
57	F73OLDR6	Num	8	PERSONALITY
43	F73PAIN	Num	8	PAIN IN SCD
202	F73PEMP	Num	8	PAST 12 MONTHS
16	F73PLAN1	Num	8	GETTING JOB YOU WANT
17	F73PLAN2	Num	8	GETTING MARRIED
18	F73PLAN3	Num	8	HAVING CHILDREN
19	F73PLAN4	Num	8	JOB YOU WANT
205	F73QUITJ	Num	8	QUIT JOB
45	F73SCA1	Num	8	CAN BE CURED
46	F73SCA2	Num	8	CAUGHT LIKE COLD
47	F73SCA3	Num	8	VERY SEVERE ILLNESS
48	F73SCA4	Num	8	COMPLETELY DEPENDENT
49	F73SCA5	Num	8	USEFUL AND PRODUCTIVE
50	F73SCA6	Num	8	CANNOT LEARN
59	F73SCHWK	Num	8	DO WELL IN SCHOOL OR WORK
4	F73SEX	Num	8	SEX OF PARENT
60	F73SITU	Num	8	STRESSFUL SITUATIONS
207	JF73DATE	Num	8	DATE OF VISIT - RECODE DAYS SINCE DOE

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

* R73.FMT contains value labels for numerical codes assigned to
categorical *
* variables in the SAS dataset R73.SD2
*

*****;

* SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 12/25/99 09:53:34;
PROC FORMAT PRINT;

VALUE F73SEX
1 = 'MALE'
2 = 'FEMALE';

* FORMAT FAVOR IS DEFINED FOR VARIABLES: F73AFF1-F73AFF9;

VALUE FAVOR
1 = 'YES, VERY UNFAVORABLY'
2 = 'YES, SOMEWHAT UNFAVORABLY'
3 = 'NOT AT ALL'
4 = 'YES, SOMEWHAT FAVORABLY'
5 = 'YES, VERY FAVORABLY';

* FORMAT NEVER IS DEFINED FOR VARIABLES: F73AFRAD F73AHEAD F73SCHWK
F73SITU;

VALUE NEVER
1 = 'NEVER'
2 = 'SELDOM'
3 = 'SOMETIMES'
4 = 'OFTEN'
5 = 'ALL THE TIME';

* FORMAT NSURE IS DEFINED FOR VARIABLES: F73PLAN1-F73PLAN4;

VALUE NSURE
1 = 'NO'
2 = 'YES'
3 = 'NOT SURE';

* FORMAT CHOICE IS DEFINED FOR VARIABLES: F73MMPI1-F73MMPI5;

VALUE CHOICE
1 = 'CHOICE A'
2 = 'CHOICE B';

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

* FORMAT AGREE IS DEFINED FOR VARIABLES: F73ILL1-F73ILL18;

VALUE AGREE

1 = 'STRONGLY DISAGREE'
2 = 'MODERATELY DISAGREE'
3 = 'SLIGHTLY DISAGREE'
4 = 'SLIGHTLY AGREE'
5 = 'MODERATELY AGREE'
6 = 'STRONGLY AGREE';

VALUE F73PAIN

1 = 'LACK OF IRON'
2 = 'BLOCKAGE OF VESSELS'
3 = 'ARTHRITIS'
4 = 'ALL OF THE ABOVE'
5 = 'NOT SURE';

VALUE F73CAUSE

1 = 'DRY SCALY SKIN'
2 = 'OBESITY (OVERWEIGHT)'
3 = 'PERIODS OF PAIN'
4 = 'LOSS OF HAIR'
5 = 'ALL OF THE ABOVE'
6 = 'NOT SURE';

* FORMAT FALSE IS DEFINED FOR VARIABLES: F73SCA1-F73SCA6;

VALUE FALSE

1 = 'FALSE'
2 = 'TRUE'
3 = 'NOT SURE';

* FORMAT LIKELY IS DEFINED FOR VARIABLE F73HWLIK;

VALUE LIKELY

1 = 'VERY LIKELY'
2 = 'SOMEWHAT LIKELY'
3 = 'DON" T KNOW'
4 = 'SOMEWHAT UNLIKELY'
5 = 'VERY UNLIKELY';

* FORMAT NOYES IS DEFINED FOR VARIABLES: F73OLDR1-F73OLDR6 F73EXTA1-F73EXTA8

F73CEMP F73COMM1-F73COMM8 F73OFFIC
F73PEMP F73LOSWT;

VALUE NOYES

1 = 'NO'
2 = 'YES';

CODEBOOK FOR CSSCD PERSONAL DIARY
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VALUE F73HOWLG

1	= 'NOT LIVE AS LONG'
2	= 'LIVE LONGER'
3	= 'NO EFFECT'
4	= 'DO NOT KNOW';

VALUE F73COPE

1	= 'RELAXATION TECHNIQUES'
2	= 'BREATHING EXERCISES'
4	= 'IMAGERY/ SELF-HYPNOSIS'
8	= 'MEDITATION'
16	= 'OTHER'
32	= 'NONE';

VALUE F73GRADE

1	= 'NO FORMAL SCHOOLING'
2	= 'KINDERGARTEN - 4TH GRADE'
3	= 'IN 5TH GRADE'
4	= 'IN 6TH GRADE'
5	= 'IN 7TH GRADE'
6	= 'IN 8TH GRADE'
7	= 'IN 9TH GRADE'
8	= 'IN 10TH GRADE'
9	= 'IN 11TH GRADE'
10	= 'IN 12TH GRADE'
11	= '1ST YEAR COLLEGE'
12	= '2D YEAR COLLEGE'
13	= '3D YEAR COLLEGE'
14	= '4TH YEAR COLLEGE'
15	= 'TRADE/ VOCATIONAL SCHOOL';

VALUE F73HWFAR

1	= 'STOP NOW'
2	= 'FINISH HIGH SCHOOL'
3	= 'FINISH A TRAINING PROGRAM'
4	= 'FINISH JUNIOR COLLEGE'
5	= 'FINISH 4 YEARS COLLEGE'
6	= 'FINISH GRADUATE, PRO. SCHOOL';

* FORMAT YESNO IS DEFINED FOR VARIABLES: F73ACT1-F73ACT14;

VALUE YESNO

1	= 'YES'
2	= 'NO';

* FORMAT TRUE IS DEFINED FOR VARIABLES: F73LME1-F73LME29;

VALUE TRUE

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

1	=	'VERY TRUE'
2	=	'RATHER TRUE'
3	=	'SOMEWHAT TRUE'
4	=	'SOMEWHAT UNTRUE'
5	=	'RATHER UNTRUE'
6	=	'VERY UNTRUE';

* FORMAT AGREE IS DEFINED FOR VARIABLES: F73FEEL0-F73FEEL9;

VALUE AGREE

1	=	'STRONGLY AGREE'
2	=	'AGREE'
3	=	'DISAGREE'
4	=	'STRONGLY DISAGREE';

* FORMAT FEL1X IS DEFINED FOR VARIABLE F73FEL1;

VALUE FEL1X

1	=	'DO NOT FEEL SAD'
2	=	'FEEL SAD'
3	=	'SAD ALL THE TIME'
4	=	'SO SAD I CAN"T STAND IT';

* FORMAT FEL2X IS DEFINED FOR VARIABLE F73FEL2;

VALUE FEL2X

1	=	'NOT PARTICULARLY DISCOURAGED'
2	=	'FEEL DISCOURAGED'
3	=	'NOTHING TO LOOK FORWARD TO'
4	=	'FUTURE IS HOPELESS';

* FORMAT FEL3X IS DEFINED FOR VARIABLE F73FEL3;

VALUE FEL3X

1	=	'DO NOT FEEL LIKE A FAILURE'
2	=	'FAILED MORE THAN AVERAGE'
3	=	'LOOKING BACK, A LOT OF FAILURES'
4	=	'COMPLETE FAILURE';

* FORMAT FEL4X IS DEFINED FOR VARIABLE F73FEL4;

VALUE FEL4X

1	=	'AS MUCH SATISFACTION'
2	=	'DON"T ENJOY LIKE USED TO'
3	=	'NO SATISFACTION FROM ANYTING'
4	=	'DISSATISFIED WITH EVERYTHING';

* FORMAT FEL5X IS DEFINED FOR VARIABLE F73FEL5;

CODEBOOK FOR CSSCD PERSONAL DIARY
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VALUE FEL5X

1	= 'DON"T FEEL PARTICULARLY GUILTY'
2	= 'GUILTY GOOD PART OF THE TIME'
3	= 'QUITE GUILTY MOST OF THE TIME'
4	= 'GUILTY ALL OF THE TIME';

* FORMAT FEL6X IS DEFINED FOR VARIABLE F73FEL6;

VALUE FEL6X

1	= 'DON"T FEEL PUNISHED'
2	= 'MAY BE PUNISHED'
3	= 'EXPECT TO BE PUNISHED'
4	= 'FEEL PUNISHED';

* FORMAT FEL7X IS DEFINED FOR VARIABLE F73FEL7;

VALUE FEL7X

1	= 'DON"T FEEL DISAPPOINTED'
2	= 'AM DISSAPOINTEED'
3	= 'AM DISGUSTED'
4	= 'HATE';

* FORMAT FEL8X IS DEFINED FOR VARIABLE F73FEL8;

VALUE FEL8X

1	= 'NO WORSE THAN ANYBODY ELSE'
2	= 'CRITICAL OF WEAKNESSES'
3	= 'BLAME SELF FOR FAILURE'
4	= 'BLAME SELF FOR EVERYTHING';

* FORMAT FEL9X IS DEFINED FOR VARIABLE F73FEL9;

VALUE FEL9X

1	= 'NO THOUGHTS OF KILLING SELF'
2	= 'THOUGHT BUT NOT CARRY OUT'
3	= 'WOULD LIKE TO'
4	= 'WOULD IF HAD THE CHANCE';

* FORMAT FEL10X IS DEFINED FOR VARIABLE F73FEL10;

VALUE FEL10X

1	= 'DON"T CRY MORE THAN USUAL'
2	= 'MORE NOW THAN USED TO'
3	= 'ALL THE TIME NOW'
4	= 'CAN"T EVEN THOUGH WANT TO';

* FORMAT FEL11X IS DEFINED FOR VARIABLE F73FEL11;

VALUE FEL11X

CODEBOOK FOR CSSCD PERSONAL DIARY
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1 = 'NO MORE IRRITATED THAN EVER'
2 = 'ANNOYED MORE EASILY'
3 = 'IRRITATED ALL THE TIME'
4 = 'DON"T GET IRRITATED AT ALL';

* FORMAT FEL12X IS DEFINED FOR VARIABLE F73FEL12;

VALUE FEL12X

1 = 'HAVE LOST INTEREST'
2 = 'LESS INTERESTED THAN USED TO BE'
3 = 'LOST MOST OF INTEREST'
4 = 'LOST ALL OF INTEREST';

* FORMAT FEL13X IS DEFINED FOR VARIABLE F73FEL13;

VALUE FEL13X

1 = 'MAKE AS WELL AS EVER COULD'
2 = 'PUT OFF MORE THAN I USED TO'
3 = 'GREATER DIFFCULTY THAN BEFORE'
4 = 'CAN"T MAKE DECISIONS AT ALL';

* FORMAT FEL14X IS DEFINED FOR VARIABLE F73FEL14;

VALUE FEL14X

1 = 'DON"T LOOK ANY WORSE THAN USUAL'
2 = 'LOOKING OLD OR UNATTRACTIVE'
3 = 'PERMANENT CHANGES'
4 = 'UGLY';

* FORMAT FEL15X IS DEFINED FOR VARIABLE F73FEL15;

VALUE FEL15X

1 = 'WORK AS WELL AS BEFORE'
2 = 'EXTRA EFFORT'
3 = 'PUSH HARD'
4 = 'CAN"T DO WORK AT ALL';

* FORMAT FEL16X IS DEFINED FOR VARIABLE F73FEL16;

VALUE FEL16X

1 = 'SLEEP AS WELL AS USUAL'
2 = 'DON"T SLEEP AS WELL'
3 = 'HARD TO GET BACK TO SLEEP'
4 = 'CANNOT GET BACK TO SLEEP';

* FORMAT FEL17X IS DEFINED FOR VARIABLE F73FEL17;

VALUE FEL17X

1 = 'NO MORE TIRED THAN USUAL'
2 = 'TIRE MORE EASILY'

CODEBOOK FOR CSSCD PERSONAL DIARY
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3 = 'TIRED FROM ALMOST ANYTHING'
4 = 'TOO TIRED';

* FORMAT FEL18X IS DEFINED FOR VARIABLE F73FEL18;

VALUE FEL18X

1 = 'APPETITE NO WORSE THAN USUAL'
2 = 'APPETITE NOT AS GOOD'
3 = 'APPETITE IS WORSE NOW'
4 = 'NO APPETITE AT ALL';

* FORMAT FEL19X IS DEFINED FOR VARIABLE F73FEL19;

VALUE FEL19X

1 = 'HAVEN" T LOST MUCH WEIGHT'
2 = 'LOST MORE THAN 5 POUNDS'
3 = 'LOST MORE THAN 10 POUNDS'
4 = 'LOST MORE THAN 15 POUNDS';

* FORMAT FEL20X IS DEFINED FOR VARIABLE F73FEL20;

VALUE FEL20X

1 = 'NO MORE WORRIED'
2 = 'AM WORRIED'
3 = 'AM VERY WORRIED'
4 = 'AM SO WORRIED';

* FORMAT FEL21X IS DEFINED FOR VARIABLE F73FEL21;

VALUE FEL21X

1 = 'NO RECENT CHANGE'
2 = 'LESS INTERESTED'
3 = 'MUCH LESS INTERESTED'
4 = 'LOST INTEREST';

* FORMAT HELPFUL IS DEFINED FOR VARIABLES: F73CB1-F73CB45;

VALUE HELPFUL

0 = 'NOT HELPFUL'
1 = 'MINIMALLY HELPFUL'
2 = 'MODERATELY HELPFUL'
3 = 'EXTREMELY HELPFUL'
4 = 'CHOSE NOT TO'
5 = 'NOT POSSIBLE';

* FORMAT SCD IS DEFINED FOR VARIABLES: F73DENYJ F73FIREJ F73QUITJ;

VALUE SCD

1 = 'NO'

CODEBOOK FOR CSSCD PERSONAL DIARY
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2 = 'YES, BECAUSE OF SCD'
3 = 'YES, NOT BECAUSE OF SCD'
4 = 'YES, DON" T KNOW';

* FORMAT JOB IS DEFINED FOR VARIABLE F73HELDJ;

VALUE JOB
1 = '0 - 6 MONTHS'
2 = '7 MONTHS TO ONE YEAR'
3 = '1 - 3 YEARS'
4 = '3 - 5 YEARS'
5 = 'MORE THAN 5 YEARS';

CCC. List of variables deleted **F74INIT F74NDATE F74LASTU F74LASTE
F74ESTAT**

F74VDATE F74DATE F74DFC F74FCB

DDD. List of variables modified **F74BDATE F74MSTAT F74COHAB F74OTH**

EEE. List of variables modified with a name change **NONE**

FFF. Old name

GGG. New name

HHH. List of variables modified date to days since DOE

III. Old name **F74DATE**

JJJ. New name **JF74DATE**

KKK. Collection Information:

Form 74 (Psychosocial Questionnaire for SCD Patients Age 20 and Older)

was to be completed by a random sample of HbSS patients 20 years of age and older.

LLL. Data Collection Period: 04/84-07/87

MMM. Form Version Dates: 03/30/84

NNN. Files Used to Store Information:

SAS System Files: **R74.SD2**

Format Files: **R74.FMT**

OOO. Unique Record Identifiers: **ANONID, F74CYCLE**

Records within the dataset are sorted by **ANONID** and **F74CYCLE**

PPP. Number of Observations (Patients) in SAS Dataset: 122 (122)

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QQQ. Contents of SAS Dataset:

- Alphabetical Listing of Variables: See pp. 1-6
- Listing of Variables by Position: See pp. 7-12

A codebook for this dataset is not included in this manual.

RRR. Notes About Selected Variables: None

SSS. Computed Variables: None

TTT. Inter-Relationship With Other Datasets:

Psychosocial data were also collected on

Phase 1 Forms	SAS Dataset	See Section
Form 67	R67.SD2	6.10.1
Form 68	R68.SD2	6.10.2
Form 69	R69.SD2	6.10.3
Form 73	R73.SD2	6.10.4
“Roster”	R09.SD2	1.0 (variable: PSYSTAT)

CONTENTS OF SAS DATASET: R74.SD2
DATA FROM CSSCD FORM 74 - PSYCHOSOCIAL QUESTIONNAIRE
for SCD PATIENTS AGE 20 AND OLDER
VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION
IN THE SAS DATASET AND ON FORM 74
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Data Set Name	OUT1.R74	Observations	122
Member Type	DATA	Variables	224
Engine	V9	Indexes	0
Created	15:14 Tuesday, November 7, 2006	Observation Length	1792
Last Modified	15:14 Tuesday, November 7, 2006	Deleted Observations	0
Protection		Compressed	NO
Data Set Type		Sorted	NO
Label			
Data Representation	WINDOWS		
Encoding	wlatin1 Western (Windows)		

Engine/Host Dependent Information

Data Set Page Size	16384
Number of Data Set Pages	16
First Data Page	2
Max Obs per Page	9
Obs in First Data Page	3
Number of Data Set Repairs	0
File Name	r74.sas7bdat
Release Created	9.0000M0

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

Host Created XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
11	F74AFF1	Num	8	RELATIONSHIP WITH PARENTS
12	F74AFF2	Num	8	RELATIONSHIP WITH SIBLINGS
13	F74AFF3	Num	8	RELATIONSHIP WITH FRIENDS
14	F74AFF4	Num	8	PHYSICAL ACTIVITY
15	F74AFF5	Num	8	SOCIAL ACTIVITY
16	F74AFF6	Num	8	FEEL ABOUT OTHER PEOPLE
17	F74AFF7	Num	8	BEHAVE TOWARDS YOU
18	F74AFF8	Num	8	FEEL EMOTIONALLY
19	F74AFF9	Num	8	INTIMATE RELATIONSHIPS
20	F74AFRAD	Num	8	MAKE YOU AFRAID
21	F74AHEAD	Num	8	KEEP FROM PLANNING AHEAD
201	F74ASSIT	Num	8	IF NO ONE, CHECK
3	F74BDATE	Num	8	PATIENTS BIRTHDATE RECODE AGE AT VISIT
8	F74BROTH	Num	8	NUMBER OF BROTHERS
50	F74CAUSE	Num	8	SCD MAY CAUSE
148	F74CB1	Num	8	UPSET FAMILY
149	F74CB2	Num	8	ENGAGING IN RELATIONSHIPS
150	F74CB3	Num	8	TRUSTING PARENT(S)
151	F74CB4	Num	8	SLEEPING
152	F74CB5	Num	8	TALK WITH MEDICAL STAFF
153	F74CB6	Num	8	WILL GET BETTER
154	F74CB7	Num	8	KEEPING BUSY
155	F74CB8	Num	8	I AM STRONG
156	F74CB9	Num	8	PURCHASING GIFTS
157	F74CB10	Num	8	OTHERS HAVE MY PROBLEM
158	F74CB11	Num	8	BEING SURE

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#	Variable	Type	Len	Label
159	F74CB12	Num	8	EATING TO RELAX
160	F74CB13	Num	8	HELPING WITH CHORES
161	F74CB14	Num	8	BY MYSELF
162	F74CB15	Num	8	TALK WITH DOCTOR
163	F74CB16	Num	8	REALLY INTERESTED
164	F74CB17	Num	8	CLOSE RELATIONSHIPS
165	F74CB18	Num	8	BELIEVE IN GOD
166	F74CB19	Num	8	BETTER MYSELF
167	F74CB20	Num	8	SAME SITUATIONS
168	F74CB21	Num	8	DOING THINGS AS FAMILY
169	F74CB22	Num	8	INVESTING TIME AND ENERGY
170	F74CB23	Num	8	BEST CARE POSSIBLE
171	F74CB24	Num	8	FRIENDS OVER
172	F74CB25	Num	8	HANDLE THINGS
173	F74CB26	Num	8	THING WITH FAMILY
174	F74CB27	Num	8	SELF-RELIANT
175	F74CB28	Num	8	THANKFUL FOR
176	F74CB29	Num	8	HOBBIES
177	F74CB30	Num	8	PERSONAL SITUATION
178	F74CB31	Num	8	MORE INDEPENDENT
179	F74CB32	Num	8	IN SHAPE
180	F74CB33	Num	8	SOCIAL ACTIVITIES
181	F74CB34	Num	8	GOING OUT
182	F74CB35	Num	8	BEING SURE
183	F74CB36	Num	8	BUILDING RELATIONSHIP
184	F74CB37	Num	8	ALLOWING ANGRY
185	F74CB38	Num	8	GIVING MORE
186	F74CB39	Num	8	TALKING TO SOMEONE
187	F74CB40	Num	8	READING MORE
188	F74CB41	Num	8	PERSONAL FEELINGS
189	F74CB42	Num	8	GET AWAY
190	F74CB43	Num	8	SEEING DOC
191	F74CB44	Num	8	ALWAYS WORK OUT
192	F74CB45	Num	8	WITH SIBLINGS OR PARENTS
193	F74CEMP	Num	8	CURRENTLY EMPLOYED
213	F74CHUR	Num	8	CHURCH
222	F74CIVIL	Num	8	CIVIL SERVICE
6	F74COHAB	Num	8	NUMBER LIVING IN HOUSEHOLD
206	F74COMM	Num	8	COMMUNITY HEALTH WORKER
78	F74COMM1	Num	8	CHURCH
79	F74COMM2	Num	8	SOCIAL CLUBS
80	F74COMM3	Num	8	SICKLE CELL GROUPS
81	F74COMM4	Num	8	CIVIC ORGANIZATIONS
82	F74COMM5	Num	8	BLOCK CLUBS
83	F74COMM6	Num	8	POLITICAL GROUPS
84	F74COMM7	Num	8	YOUTH GROUPS
85	F74COMM8	Num	8	OTHER
67	F74COPE	Num	8	COPING MECHANISMS

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210	F74COUN	Num	8	COUNSELOR
2	F74CYCLE	Num	8	RECORD 73 CYCLE
200	F74DENOP	Num	8	DENIED OPPORTUNITY
195	F74DENYJ	Num	8	DENIED JOB

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#	Variable	Type	Len	Label
216	F74DEPT	Num	8	DEPT. OF VOCATIONAL REHAB
202	F74DOCT	Num	8	DOCTOR
70	F74EXTA1	Num	8	COMPETITIVE SPORTS
71	F74EXTA2	Num	8	SCHOOL COMMITTEE
72	F74EXTA3	Num	8	ACADEMIC CLUBS
73	F74EXTA4	Num	8	STUDENT GOVERNMENT
74	F74EXTA5	Num	8	CHEERLEADER
75	F74EXTA6	Num	8	BAND
76	F74EXTA7	Num	8	CHOIR
77	F74EXTA8	Num	8	OTHER
217	F74FAMS	Num	8	FAMILY SERVICES
116	F74FEEL0	Num	8	SATISFIED WITH MYSELF
117	F74FEEL1	Num	8	NO GOOD AT ALL
118	F74FEEL2	Num	8	GOOD QUALITIES
119	F74FEEL3	Num	8	AS WELL AS MOST
120	F74FEEL4	Num	8	PROUD OF
121	F74FEEL5	Num	8	USELESS AT TIMES
122	F74FEEL6	Num	8	PERSON OF WORTH
123	F74FEEL7	Num	8	MORE RESPECT
124	F74FEEL8	Num	8	FAILURE
125	F74FEEL9	Num	8	POSITIVE ATTITUDE
126	F74FEL1	Num	8	FEEL SAD
127	F74FEL2	Num	8	DISCOURAGED
128	F74FEL3	Num	8	FAILURE
129	F74FEL4	Num	8	SATISFACTION
130	F74FEL5	Num	8	GUILTY
131	F74FEL6	Num	8	PUNISHED
132	F74FEL7	Num	8	DISAPPOINTED
133	F74FEL8	Num	8	BLAME MYSELF
134	F74FEL9	Num	8	SUICIDE
135	F74FEL10	Num	8	CRY
136	F74FEL11	Num	8	IRRITATED
137	F74FEL12	Num	8	LOST INTEREST
138	F74FEL13	Num	8	MAKE DECISIONS
139	F74FEL14	Num	8	LOOKS
140	F74FEL15	Num	8	WORK AS WELL
141	F74FEL16	Num	8	SLEEP
142	F74FEL17	Num	8	TIRED
143	F74FEL18	Num	8	APPETITE
144	F74FEL19	Num	8	LOST WEIGHT
146	F74FEL20	Num	8	WORRIED ABOUT HEALTH
147	F74FEL21	Num	8	INTEREST IN SEX
196	F74FIREJ	Num	8	FIRED FROM JOB
208	F74FRIEN	Num	8	FRIENDS
205	F74GENE	Num	8	GENETIC COUNSELOR
68	F74GRADE	Num	8	GRADE COMPLETED
198	F74HELDJ	Num	8	HELD ONE JOB
64	F74HOWLG	Num	8	HOW LONG YOU LIVE

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69	F74HWFAR	Num	8	HOW FAR WILL YOU GO
57	F74HWLIK	Num	8	HOW LIKELY
31	F74ILL1	Num	8	OWN BEHAVIOR
32	F74ILL2	Num	8	NO MATTER WHAT

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#	Variable	Type	Len	Label
33	F74ILL3	Num	8	REGULAR CONTACT
34	F74ILL4	Num	8	ACCIDENT
35	F74ILL5	Num	8	CONSULT
36	F74ILL6	Num	8	CONTROL
37	F74ILL7	Num	8	FAMILY
38	F74ILL8	Num	8	BLAME SELF
39	F74ILL9	Num	8	LUCK AFFECTS RECOVERY RATE
40	F74ILL10	Num	8	PROFESSIONALS CONTROL
41	F74ILL11	Num	8	GOOD FORTUNE
42	F74ILL12	Num	8	I MYSELF DO
43	F74ILL13	Num	8	IF I TAKE CARE OF MYSELF
44	F74ILL14	Num	8	WHEN I RECOVER
45	F74ILL15	Num	8	NO MATTER WHAT, LIKELY
46	F74ILL16	Num	8	IF IT'T MEANT TO BE
47	F74ILL17	Num	8	IF I TAKE THE RIGHT ACTIONS
48	F74ILL18	Num	8	REGARDING MY HEALTH
199	F74LEAVJ	Num	8	WHY LEAVE JOB
87	F74LME1	Num	8	MORE AGGRESSIVE
88	F74LME2	Num	8	SHYNESS
89	F74LME3	Num	8	COMPLAIN TO WAITER
90	F74LME4	Num	8	AVOID HURTING
91	F74LME5	Num	8	SAYING NO
92	F74LME6	Num	8	KNOWING WHY
93	F74LME7	Num	8	VIGOROUS ARGUMENT
94	F74LME8	Num	8	GET AHEAD
95	F74LME9	Num	8	TAKE ADVANTAGE
96	F74LME10	Num	8	STARTING CONVERSATIONS
97	F74LME11	Num	8	ATTRACTIVE PERSONS
98	F74LME12	Num	8	CALLS TO BUSINESS
99	F74LME13	Num	8	APPLY BY WRITING
100	F74LME14	Num	8	EMBARASSING TO RETURN
101	F74LME15	Num	8	SMOTHER MY FEELINGS
102	F74LME16	Num	8	SOUNDING STUPID
103	F74LME17	Num	8	SHAKE ALL OVER
104	F74LME18	Num	8	FAMED LECTURER
105	F74LME19	Num	8	ARGUING OVER PRICES
106	F74LME20	Num	8	LET OTHERS KNOW
107	F74LME21	Num	8	OPEN AND FRANK
108	F74LME22	Num	8	SPREADING STORIES
109	F74LME23	Num	8	SAYING NO
110	F74LME24	Num	8	BOTTLE EMOTIONS
111	F74LME25	Num	8	POOR SERVICE
112	F74LME26	Num	8	GIVEN COMPLIMENT
113	F74LME27	Num	8	COUPLE NEAR ME
114	F74LME28	Num	8	PUSH AHEAD
115	F74LME29	Num	8	EXPRESS OPINIONS
145	F74LOSWT	Num	8	PURPOSELY LOSE WEIGHT
26	F74MMP11	Num	8	FATE

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27	F74MMPI2	Num	8	CONTROL
28	F74MMPI3	Num	8	PLANS
29	F74MMPI4	Num	8	LUCK
30	F74MMPI5	Num	8	INFLUENCE

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#	Variable	Type	Len	Label
5	F74MSTAT	Num	8	PATIENT'S MARITAL STATUS
203	F74NURS	Num	8	NURSE
86	F74OFFIC	Num	8	HOLD AN OFFICE
58	F74OLDR1	Num	8	YOUR SEX
59	F74OLDR2	Num	8	YOUR RACE
60	F74OLDR3	Num	8	HOW FAR IN SCHOOL
61	F74OLDR4	Num	8	MONEY
62	F74OLDR5	Num	8	SCD
63	F74OLDR6	Num	8	PERSONALITY
223	F74OTER	Num	8	OTHER
10	F74OTH	Num	8	NUMBER OF OTHER PEOPLE IN HH
211	F74OTHR	Num	8	OTHER
49	F74PAIN	Num	8	PAIN IN SCD
194	F74PEMP	Num	8	PAST 12 MONTHS
22	F74PLAN1	Num	8	GETTING JOB YOU WANT
23	F74PLAN2	Num	8	GETTING MARRIED
24	F74PLAN3	Num	8	HAVING CHILDREN
25	F74PLAN4	Num	8	JOB YOU WANT
209	F74PRIE	Num	8	PRIEST
218	F74PUBC	Num	8	PUBLIC ASSISTANCE
197	F74QUITJ	Num	8	QUIT JOB
7	F74RELAT	Num	8	RELATIONSHIP TO CHILD
207	F74RELTV	Num	8	RELATIVES
51	F74SCA1	Num	8	CAN BE CURED
52	F74SCA2	Num	8	CAUGHT LIKE COLD
53	F74SCA3	Num	8	VERY SEVERE ILLNESS
54	F74SCA4	Num	8	COMPLETELY DEPENDENT
55	F74SCA5	Num	8	USEFUL AND PRODUCTIVE
56	F74SCA6	Num	8	CANNOT LEARN
214	F74SCHL	Num	8	SCHOOL
65	F74SCHWK	Num	8	DO WELL IN SCHOOL OR WORK
4	F74SEX	Num	8	SEX OF PATIENT
219	F74SIKLC	Num	8	SICKLE CELL PROGRAMS
9	F74SIST	Num	8	NUMBER OF SISTERS
66	F74SITU	Num	8	STRESSFUL SITUATIONS
215	F74SOCSC	Num	8	SOCIAL SECURITY
204	F74SOCW	Num	8	SOCIAL WORKER
212	F74SUPP	Num	8	IF NONE, CHECK
221	F74UNB	Num	8	UNION BENEFITS
220	F74VA	Num	8	V.A. BENEFITS
224	JF74DATE	Num	8	DATE OF VISIT - RECODE DAYS SINCE DOE

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* R74.FMT contains value labels for numerical codes assigned to
categorical *
* variables in the SAS dataset R74.SD2
*

*****;

* SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 12/25/99 09:55:56;

PROC FORMAT PRINT;

VALUE F74SEX
1 = 'MALE'
2 = 'FEMALE';

VALUE F74MSTAT
1 = 'SINGL NEV MAR,SINGL DIVR,WIDOW,SEPARAT,LIV TOGE'
3 = 'MARRIED OR REMARRIED';

VALUE F74RELAT
1 = 'MOTHER'
2 = 'FATHER'
4 = 'STEP-MOTHER'
8 = 'STEP-FATHER'
16 = 'BROTHER'
32 = 'SISTER'
64 = 'GRANDMOTHER'
128 = 'GRANDFATHER'
256 = 'OTHER'
512 = 'NONE';

* FORMAT FAVOR IS DEFINED FOR VARIABLES: F74AFF1-F74AFF9;

VALUE FAVOR
1 = 'YES, VERY UNFAVORABLY'
2 = 'YES, SOMEWHAT UNFAVORABLY'
3 = 'NOT AT ALL'
4 = 'YES, SOMEWHAT FAVORABLY'
5 = 'YES, VERY FAVORABLY';

* FORMAT OFTEN IS DEFINED FOR VARIABLES: F74AFRAD F74AHEAD F74SCHWK
F74SITU;

VALUE OFTEN
1 = 'NEVER'
2 = 'SELDOM'
3 = 'SOMETIMES'
4 = 'OFTEN'

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5 = 'ALL THE TIME';

* FORMAT NSURE IS DEFINED FOR VARIABLES: F74PLAN1-F74PLAN4;

VALUE NSURE

1 = 'NO'
2 = 'YES'
3 = 'NOT SURE';

* FORMAT CHOICE IS DEFINED FOR VARIABLES: F74MMPI1-F74MMPI5;

VALUE CHOICE

1 = 'CHOICE A'
2 = 'CHOICE B';

* FORMAT AGREE IS DEFINED FOR VARIABLES: F74ILL1-F74ILL18;

VALUE AGREE

1 = 'STRONGLY DISAGREE'
2 = 'MODERATELY DISAGREE'
3 = 'SLIGHTLY DISAGREE'
4 = 'SLIGHTLY AGREE'
5 = 'MODERATELY AGREE'
6 = 'STRONGLY AGREE';

VALUE F74PAIN

1 = 'LACK OF IRON'
2 = 'BLOCKAGE OF VESSELS'
3 = 'ARTHRITIS'
4 = 'ALL OF THE ABOVE'
5 = 'NOT SURE';

VALUE F74CAUSE

1 = 'DRY SCALY SKIN'
2 = 'OBESITY (OVERWEIGHT)'
3 = 'PERIODS OF PAIN'
4 = 'LOSS OF HAIR'
5 = 'ALL OF THE ABOVE'
6 = 'NOT SURE';

* FORMAT FALSE IS DEFINED FOR VARIABLES: F74SCA1-F74SCA6;

VALUE FALSE

1 = 'FALSE'
2 = 'TRUE'
3 = 'NOT SURE';

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VALUE F74HWLIK

1 = 'VERY LIKELY'
2 = 'SOMEWHAT LIKELY'
3 = 'DON" T KNOW'
4 = 'SOMEWHAT UNLIKELY'
5 = 'VERY UNLIKELY';

* FORMAT NOYES IS DEFINED FOR VARIABLES: F74OLDR1-F74OLDR6 F74EXTA1-F74EXTA8

F74COMM1-F74COMM8 F74OFFIC

F74LOSWT

F74CEMP F74PEMP;

VALUE NOYES

1 = 'NO'
2 = 'YES';

VALUE F74HOWLG

1 = 'NOT LIVE AS LONG'
2 = 'LIVE LONGER'
3 = 'NO EFFECT'
4 = 'DO NOT KNOW';

VALUE F74COPE

1 = 'RELAXATION TECHNIQUES'
2 = 'BREATHING EXERCISES'
4 = 'IMAGERY/ SELF-HYPNOSIS'
8 = 'MEDITATION'
16 = 'OTHER'
32 = 'NONE';

VALUE F74GRADE

1 = 'NO FORMAL SCHOOLING'
2 = 'KINDERGARTEN - 4TH GRADE'
3 = 'IN 5TH GRADE'
4 = 'IN 6TH GRADE'
5 = 'IN 7TH GRADE'
6 = 'IN 8TH GRADE'
7 = 'IN 9TH GRADE'
8 = 'IN 10TH GRADE'
9 = 'IN 11TH GRADE'
10 = 'IN 12TH GRADE'
11 = '1ST YEAR COLLEGE'
12 = '2D YEAR COLLEGE'
13 = '3D YEAR COLLEGE'
14 = '4TH YEAR COLLEGE'
15 = 'TRADE/ VOCATIONAL SCHOOL';

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VALUE F74HWFAR

1	=	'STOP NOW'
2	=	'FINISH HIGH SCHOOL'
3	=	'FINISH A TRAINING PROGRAM'
4	=	'FINISH JUNIOR COLLEGE'
5	=	'FINISH 4 YEARS COLLEGE'
6	=	'FINISH GRADUATE, PRO. SCHOOL';

* FORMAT TRUE IS DEFINED FOR VARIABLES: F74LME1-F74LME29;

VALUE TRUE

1	=	'VERY TRUE'
2	=	'RATHER TRUE'
3	=	'SOMEWHAT TRUE'
4	=	'SOMEWHAT UNTRUE'
5	=	'RATHER UNTRUE'
6	=	'VERY UNTRUE';

* FORMAT STRONGLY IS DEFINED FOR VARIABLES: F74FEEL0-F74FEEL9;

VALUE STRONGLY

1	=	'STRONGLY AGREE'
2	=	'AGREE'
3	=	'DISAGREE'
4	=	'STRONGLY DISAGREE';

* FORMAT FEL1X IS DEFINED FOR VARIABLE F74FEL1;

VALUE FEL1X

1	=	'DO NOT FEEL SAD'
2	=	'FEEL SAD'
3	=	'SAD ALL THE TIME'
4	=	'SO SAD I CAN"T STAND IT';

* FORMAT FEL2X IS DEFINED FOR VARIABLE F74FEL2;

VALUE FEL2X

1	=	'NOT PARTICULARLY DISCOURAGED'
2	=	'FEEL DISCOURAGED'
3	=	'NOTHING TO LOOK FORWARD TO'
4	=	'FUTURE IS HOPELESS';

* FORMAT FEL3X IS DEFINED FOR VARIABLE F74FEL3;

VALUE FEL3X

1	=	'DO NOT FEEL LIKE A FAILURE'
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2 = 'FAILED MORE THAN AVERAGE'
3 = 'LOOKING BACK, A LOT OF FAILURES'
4 = 'COMPLETE FAILURE';

* FORMAT FEL4X IS DEFINED FOR VARIABLE F74FEL4;

VALUE FEL4X

1 = 'AS MUCH SATISFACTION'
2 = 'DON"T ENJOY LIKE USED TO'
3 = 'NO SATISFACTION FROM ANYTHING'
4 = 'DISSATISFIED WITH EVERYTHING';

* FORMAT FEL5X IS DEFINED FOR VARIABLE F74FEL5;

VALUE FEL5X

1 = 'DON"T FEEL PARTICULARLY GUILTY'
2 = 'GUILTY GOOD PART OF THE TIME'
3 = 'QUITE GUILTY MOST OF THE TIME'
4 = 'GUILTY ALL OF THE TIME';

* FORMAT FEL6X IS DEFINED FOR VARIABLE F74FEL6;

VALUE FEL6X

1 = 'DON"T FEEL PUNISHED'
2 = 'MAY BE PUNISHED'
3 = 'EXPECT TO BE PUNISHED'
4 = 'FEEL PUNISHED';

* FORMAT FEL7X IS DEFINED FOR VARIABLE F74FEL7;

VALUE FEL7X

1 = 'DON"T FEEL DISAPPOINTED'
2 = 'AM DISSAPOINTEED'
3 = 'AM DISGUSTED'
4 = 'HATE';

* FORMAT FEL8X IS DEFINED FOR VARIABLE F74FEL8;

VALUE FEL8X

1 = 'NO WORSE THAN ANYBODY ELSE'
2 = 'CRITICAL OF WEAKNESSES'
3 = 'BLAME SELF FOR FAILURE'
4 = 'BLAME SELF FOR EVERYTHING';

* FORMAT FEL9X IS DEFINED FOR VARIABLE F74FEL9;

VALUE FEL9X

1 = 'NO THOUGHTS OF KILLING SELF'
2 = 'THOUGHT BUT NOT CARRY OUT'
3 = 'WOULD LIKE TO'

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4 = 'WOULD IF HAD THE CHANCE';

* FORMAT FEL10X IS DEFINED FOR VARIABLE F74FEL10;

VALUE FEL10X

1 = 'DON"T CRY MORE THAN USUAL'
2 = 'MORE NOW THAN USED TO'
3 = 'ALL THE TIME NOW'
4 = 'CAN"T EVEN THOUGH WANT TO';

* FORMAT FEL11X IS DEFINED FOR VARIABLE F74FEL11;

VALUE FEL11X

1 = 'NO MORE IRRITATED THAN EVER'
2 = 'ANNOYED MORE EASILY'
3 = 'IRRITATED ALL THE TIME'
4 = 'DON"T GET IRRITATED AT ALL';

* FORMAT FEL12X IS DEFINED FOR VARIABLE F74FEL12;

VALUE FEL12X

1 = 'HAVE LOST INTEREST'
2 = 'LESS INTERESTED THAN USED TO BE'
3 = 'LOST MOST OF INTEREST'
4 = 'LOST ALL OF INTEREST';

* FORMAT FEL13X IS DEFINED FOR VARIABLE F74FEL13;

VALUE FEL13X

1 = 'MAKE AS WELL AS EVER COULD'
2 = 'PUT OFF MORE THAN I USED TO'
3 = 'GREATER DIFFCULTY THAN BEFORE'
4 = 'CAN"T MAKE DECISIONS AT ALL';

* FORMAT FEL14X IS DEFINED FOR VARIABLE F74FEL14;

VALUE FEL14X

1 = 'DON"T LOOK ANY WORSE THAN USUAL'
2 = 'LOOKING OLD OR UNATTRACTIVE'
3 = 'PERMANENT CHANGES'
4 = 'UGLY';

* FORMAT FEL15X IS DEFINED FOR VARIABLE F74FEL15;

VALUE FEL15X

1 = 'WORK AS WELL AS BEFORE'
2 = 'EXTRA EFFORT'
3 = 'PUSH HARD'
4 = 'CAN"T DO WORK AT ALL';

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* FORMAT FEL16X IS DEFINED FOR VARIABLE F74FEL16;

VALUE FEL16X

1	= 'SLEEP AS WELL AS USUAL'
2	= 'DON" T SLEEP AS WELL'
3	= 'HARD TO GET BACK TO SLEEP'
4	= 'CANNOT GET BACK TO SLEEP';

* FORMAT FEL17X IS DEFINED FOR VARIABLE F74FEL17;

VALUE FEL17X

1	= 'NO MORE TIRED THAN USUAL'
2	= 'TIRE MORE EASILY'
3	= 'TIRED FROM ALMOST ANYTHING'
4	= 'TOO TIRED';

* FORMAT FEL18X IS DEFINED FOR VARIABLE F74FEL18;

VALUE FEL18X

1	= 'APPETITE NO WORSE THAN USUAL'
2	= 'APPETITE NOT AS GOOD'
3	= 'APPETITE IS WORSE NOW'
4	= 'NO APPETITE AT ALL';

* FORMAT FEL19X IS DEFINED FOR VARIABLE F74FEL19;

VALUE FEL19X

1	= 'HAVEN" T LOST MUCH WEIGHT'
2	= 'LOST MORE THAN 5 POUNDS'
3	= 'LOST MORE THAN 10 POUNDS'
4	= 'LOST MORE THAN 15 POUNDS';

* FORMAT FEL20X IS DEFINED FOR VARIABLE F74FEL20;

VALUE FEL20X

1	= 'NO MORE WORRIED'
2	= 'AM WORRIED'
3	= 'AM VERY WORRIED'
4	= 'AM SO WORRIED';

* FORMAT FEL21X IS DEFINED FOR VARIABLE F74FEL21;

VALUE FEL21X

1	= 'NO RECENT CHANGE'
2	= 'LESS INTERESTED'
3	= 'MUCH LESS INTERESTED'
4	= 'LOST INTEREST';

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* FORMAT HELPFUL IS DEFINED FOR VARIABLES: F74CB1-F74CB45;

VALUE HELPFUL

0	=	'NOT HELPFUL'
1	=	'MINIMALLY HELPFUL'
2	=	'MODERATELY HELPFUL'
3	=	'EXTREMELY HELPFUL'
4	=	'CHOSE NOT TO'
5	=	'NOT POSSIBLE';

* FORMAT SCD IS DEFINED FOR VARIABLES: F74DENYJ F74FIREJ F74QUITJ;

VALUE SCD

1	=	'NO'
2	=	'YES, BECAUSE OF SCD'
3	=	'YES, NOT BECAUSE OF SCD'
4	=	'YES, DON" T KNOW';

VALUE F74HELDJ

1	=	'0 - 6 MONTHS'
2	=	'7 MONTHS TO ONE YEAR'
3	=	'1 - 3 YEARS'
4	=	'3 - 5 YEARS'
5	=	'MORE THAN 5 YEARS';

VALUE F74LEAVJ

1	=	'NOT LEFT YET'
2	=	'TO ATTEND SCHOOL'
3	=	'FOR A BETTER JOB'
4	=	'RELOCATED'
5	=	'WAS FIRED'
6	=	'LAID OFF'
7	=	'DUE TO SICKLE CELL'
8	=	'PHYSICAL, EMOTIONAL'
9	=	'OTHER REASONS';

VALUE F74DENOP

1	=	'HOUSING'
2	=	'HEALTH INSURANCE'
3	=	'LIFE INSURANCE'
4	=	'EDUCATIONAL OPPORTUNITY'
5	=	'MILITARY ENLISTMENT'
6	=	'EMPLOYMENT'
7	=	'OTHER';

CODEBOOK FOR CSSCD PERSONAL DIARY
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VALUE F74ASSIT
1 = 'NO ONE';

* FORMAT USAGE IS DEFINED FOR VARIABLES: F74DOCT F74NURS F74SOCW
F74GENE F74COMM F74RELTV
F74FRIEN F74PRIE F74COUN
F74CHUR F74SCHL F74SOCSC
F74DEPT F74FAMS F74PUBC
F74SIKLC F74VA F74UNB
F74CIVIL;

VALUE USAGE
1 = 'NOT USED'
2 = 'VERY HELPFUL'
3 = 'SOMEWHAT HELPFUL'
4 = 'NOT HELPFUL';

* FORMAT OTHER IS DEFINED FOR VARIABLES: F74OTHR F74OTER;

VALUE OTHER
1 = 'NOT USED'
2 = 'VERY HELPFUL'
4 = 'SOMEWHAT HELPFUL'
8 = 'NOT HELPFUL'
16 = 'WRITE-IN';

VALUE F74SUPP
1 = 'NONE';

UUU. List of variables deleted F55LASTU F55LASTE F55ESTAT F55DATE

VVV. List of variables modified NONE

WWW. List of variables modified with a name change NONE

XXX. Old name

YYY. New name

ZZZ. List of variables modified date to days since DOE

AAAA. Old name F55DATE

BBBB. New name JF55DATE

CCCC. Collection Information:

“Form 55” (CSSCD Personal Diary) was to be filled out everyday for two weeks
by a random sample of SCD patients \geq 6 years of age. The diary contains a daily

CODEBOOK FOR CSSCD PERSONAL DIARY
 CSSCD FULL COHORT PATIENTS

record of pain events and treatment for a 2-week period. A separate diary was completed for each of the two weeks – i.e., each patient was expected to submit two diaries to the SCC – one for week 1 and one for week 2.

DDDD. Data Collection Period: 01/82-09/84

EEEE. Form Version Dates: N/A

FFFF. Files Used to Store Information:

SAS System Files: **R55.SD2**

Format Files: **R55.FMT**

GGGG. Unique Record Identifiers: **ANONID, F55CYCLE, F55WEEK**

Records within the dataset are sorted by **ANONID** and **F55CYCLE, F55WEEK**

HHHH. Number of Observations (Patients) in SAS Dataset: 1061 (547)

IIII. Contents of SAS Dataset:

- Alphabetical Listing of Variables: See pp. 1-2
- Listing of Variables by Position: See pp. 3-4

JJJJ. Notes About Selected Variables: None

KKKK. Computed Variables: None

LLLL. Inter-Relationship With Other Datasets:

Other sources of information related to painful events include

Phase 1 Forms	SAS Dataset	See Section
Form 30	R30.SD2	7.1.1
“Form” 61	R61.SD2	7.1.2
Form 56	R56.SD2	6.12

CONTENTS OF SAS DATASET: R55.SD2
 DATA FROM CSSCD "FORM" 55 - DIARY
 VARIABLES ARE LISTED IN ALPHABETICAL ORDER AND IN ORDER OF THEIR POSITION
 IN THE SAS DATASET AND ON "FORM" 55

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Data Set Name	OUT1.R55	Observations	1061
Member Type	DATA	Variables	47
Engine	V9	Indexes	0
Created	15:19 Tuesday, November 7, 2006	Observation Length	376

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Last Modified	15:19 Tuesday, November 7, 2006	Deleted Observations	0
Protection		Compressed	NO
Data Set Type		Sorted	NO
Label			
Data Representation	WINDOWS		
Encoding	wlatin1 Western (Windows)		

Engine/Host Dependent Information

Data Set Page Size	16384
Number of Data Set Pages	26
First Data Page	1
Max Obs per Page	43
Obs in First Data Page	26
Number of Data Set Repairs	0
File Name	r55.sas7bdat
Release Created	9.0000M0
Host Created	XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
8	F55ACT1	Num	8	USUAL ACTIVITIES DAY1
14	F55ACT2	Num	8	USUAL ACTIVITIES DAY2
20	F55ACT3	Num	8	USUAL ACTIVITIES DAY3
26	F55ACT4	Num	8	USUAL ACTIVITIES DAY4
32	F55ACT5	Num	8	USUAL ACTIVITIES DAY5
38	F55ACT6	Num	8	USUAL ACTIVITIES DAY6
44	F55ACT7	Num	8	USUAL ACTIVITIES DAY7
2	F55CYCLE	Num	8	CYCLE
4	F55DAY1	Num	8	DAY OF THE WEEK
5	F55HLT1	Num	8	HEALTH DAY1
11	F55HLT2	Num	8	HEALTH DAY2
17	F55HLT3	Num	8	HEALTH DAY3
23	F55HLT4	Num	8	HEALTH DAY4
29	F55HLT5	Num	8	HEALTH DAY5
35	F55HLT6	Num	8	HEALTH DAY6
41	F55HLT7	Num	8	HEALTH DAY7
7	F55LOC1	Num	8	PAIN LOCATION DAY1
13	F55LOC2	Num	8	PAIN LOCATION DAY2
19	F55LOC3	Num	8	PAIN LOCATION DAY3
25	F55LOC4	Num	8	PAIN LOCATION DAY4
31	F55LOC5	Num	8	PAIN LOCATION DAY5
37	F55LOC6	Num	8	PAIN LOCATION DAY6
43	F55LOC7	Num	8	PAIN LOCATION DAY7
10	F55MED1	Num	8	MEDICATIONS TAKEN DAY1
16	F55MED2	Num	8	MEDICATIONS TAKEN DAY2
22	F55MED3	Num	8	MEDICATIONS TAKEN DAY3

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

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The CONTENTS Procedure

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
28	F55MED4	Num	8	MEDICATIONS TAKEN DAY4
34	F55MED5	Num	8	MEDICATIONS TAKEN DAY5
40	F55MED6	Num	8	MEDICATIONS TAKEN DAY6
46	F55MED7	Num	8	MEDICATIONS TAKEN DAY7
9	F55MIS1	Num	8	WHY ACTIVITIES MISSED DAY1
15	F55MIS2	Num	8	WHY ACTIVITIES MISSED DAY2
21	F55MIS3	Num	8	WHY ACTIVITIES MISSED DAY3
27	F55MIS4	Num	8	WHY ACTIVITIES MISSED DAY4
33	F55MIS5	Num	8	WHY ACTIVITIES MISSED DAY5
39	F55MIS6	Num	8	WHY ACTIVITIES MISSED DAY6
45	F55MIS7	Num	8	WHY ACTIVITIES MISSED DAY7
6	F55PN1	Num	8	PAIN DAY1
12	F55PN2	Num	8	PAIN DAY2
18	F55PN3	Num	8	PAIN DAY3
24	F55PN4	Num	8	PAIN DAY4
30	F55PN5	Num	8	PAIN DAY5
36	F55PN6	Num	8	PAIN DAY6
42	F55PN7	Num	8	PAIN DAY7
3	F55WEEK	Num	8	WEEK OF DIARY
47	JF55DATE	Num	8	DATE OF VISIT - RECODE DAYS SINCE DOE

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

* R55.FMT contains value labels for numerical codes assigned to
categorical*
* variables in the SAS dataset R55.SD2
*

*****;

PROC FORMAT;

* FORMAT F55DAY IS DEFINED FOR VARIABLE F55DAY1;

VALUE F55DAY

1	= 'SUNDAY'
2	= 'MONDAY'
3	= 'TUESDAY'
4	= 'WEDNESDAY'
5	= 'THURSDAY'
6	= 'FRIDAY'
7	= 'SATURDAY';

* FORMAT HEALTH IS DEFINED FOR VARIABLES: F55HLT1 F55HLT2 F55HLT3
F55HLT4

F55HLT5 F55HLT6 F55HLT7;

VALUE HEALTH

1	= 'MUCH BETTER THAN AVERAGE'
2	= 'BETTER THAN AVERAGE'
3	= 'ABOUT AVERAGE'
4	= 'WORSE THAN AVERAGE'
5	= 'MUCH WORSE THAN AVERAGE';

* FORMAT PAIN IS DEFINED FOR VARIABLES: F55PN1 F55PN2 F55PN3 F55PN4
F55PN5

F55PN6 F55PN7;

VALUE PAIN

1	= 'YES, HAD SICKLE CELL PAIN'
2	= 'NO, DID NOT HAVE PAIN';

* FORMAT LOCATION IS DEFINED FOR VARIABLES F55LOC1 F55LOC2 F55LOC3
F55LOC4

F55LOC5 F55LOC6 F55LOC7;

VALUE LOCATION

1	= 'HEAD (1)'
2	= 'ARMS (2)'
4	= 'LEGS (4)'

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8	= 'BACK (8)'
16	= 'STOMACH (16)'
32	= 'ALL OVER (32)'
64	= 'CHEST (64)'
128	= 'OTHER (128)';

* FORMAT ACT IS DEFINED FOR VARIABLES F55ACT1 F55ACT2 F55ACT3 F55ACT4
F55ACT5

F55ACT6 F55ACT7;

VALUE ACT

1	= 'YES, DID USUAL ACTIVITIES'
2	= 'NO, DID NOT DO USUAL ACTIVITIES';

* FORMAT WHY IS DEFINED FOR VARIABLES F55MIS1 F55MIS2 F55MIS3 F55MIS4
F55MIS5

F55MIS6 F55MIS7;

VALUE WHY

1	= 'SICKLE CELL PAIN (1)'
2	= 'ACCIDENT, INJURY (2)'
4	= 'OTHER SICKNESS (4)'
8	= 'DOCTOR-HOSPITAL-ER VISIT (8)'
16	= 'OTHER (16)';

* FORMAT MED IS DEFINED FOR VARIABLES F55MED1 F55MED2 F55MED3 F55MED4
F55MED5

F55MED6 F55MED7;

VALUE MED

1	= 'NON-PRESCRIPTION PAIN MED (1)'
2	= 'PRESCRIPTION PAIN MED (2)'
4	= 'OTHER (4)'
8	= 'NONE (8)';

* FORMAT MMDDYY8.

F55DAY1 F55DAY.
F55HLT1 F55HLT2 F55HLT3 F55HLT4
F55HLT5 F55HLT6 F55HLT7 HEALTH.
F55PN1 F55PN2 F55PN3 F55PN4 F55PN5
F55PN6 F55PN7 PAIN.
F55LOC1 F55LOC2 F55LOC3 F55LOC4
F55LOC5 F55LOC6 F55LOC7 LOCATION.
F55ACT1 F55ACT2 F55ACT3 F55ACT4 F55ACT5
F55ACT6 F55ACT7 ACT.
F55MIS1 F55MIS2 F55MIS3 F55MIS4 F55MIS5
F55MIS6 F55MIS7 WHY.
F55MED1 F55MED2 F55MED3 F55MED4 F55MED5
F55MED6 F55MED7 MED.;

RUN;
QUIT;

CODEBOOK FOR CSSCD PERSONAL DIARY
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F55CYCLE ----- CYCLE

type: numeric (float)

range: [1,1] units: 1
unique values: 1 coded missing: 0 / 1061

tabulation: Freq. Value
1061 1

F55WEEK ----- WEEK OF DIARY

type: numeric (float)

range: [1,2] units: 1
unique values: 2 coded missing: 0 / 1061

tabulation: Freq. Value
543 1
518 2

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

F55DAY1 ----- DAY OF THE WEEK

type: numeric (float)
label: F55DAY1

range: [1,7] units: 1
unique values: 7 coded missing: 0 / 1061

tabulation:	Freq.	Numeric	Label
	229	1	SUNDAY
	230	2	MONDAY
	137	3	TUESDAY
	151	4	WEDNESDAY
	194	5	THURSDAY
	87	6	FRIDAY
	33	7	SATURDAY

F55HLT1 ----- HEALTH DAY1

type: numeric (float)
label: F55HLT1

range: [1,5] units: 1
unique values: 5 coded missing: 16 / 1061

tabulation:	Freq.	Numeric	Label
	158	1	MUCH BETTER THAN AVERAGE
	181	2	BETTER THAN AVERAGE
	541	3	ABOUT AVERAGE
	137	4	WORSE THAN AVERAGE
	28	5	MUCH WORSE THAN AVERAGE

F55PN1 ----- PAIN DAY1

type: numeric (float)
label: F55PN1

range: [1,2] units: 1
unique values: 2 coded missing: 9 / 1061

tabulation:	Freq.	Numeric	Label
	267	1	YES, HAD SICKLE CELL PAIN
	785	2	NO, DID NOT HAVE PAIN

CODEBOOK FOR CSSCD PERSONAL DIARY
 CSSCD FULL COHORT PATIENTS

F55LOC1 ----- PAIN LOCATION DAY1

type: numeric (float)
 label: F55LOC1
 range: [1,124] units: 1
 unique values: 47 coded missing: 794 / 1061

tabulation:	Freq.	Numeric	Label
	21	1	HEAD (1)
	24	2	ARMS (2)
	4	3	
	31	4	LEGS (4)
	3	5	
	15	6	
	2	7	
	25	8	BACK (8)
	1	9	
	2	10	
	10	12	
	3	13	
	6	14	
	1	15	
	12	16	STOMACH (16)
	2	17	
	1	18	
	8	20	
	1	21	
	3	22	
	7	24	
	1	25	
	2	26	
	1	30	
	17	32	ALL OVER (32)
	1	37	
	1	42	
	1	43	
	1	48	
	2	63	
	26	64	CHEST (64)
	2	65	
	2	66	
	7	68	
	1	69	
	5	70	
	1	72	
	1	73	
	1	79	
	3	80	
	2	81	
	1	84	
	2	88	
	1	93	
	1	96	
	1	97	
	1	124	
	0	128	OTHER (128)

F55LOC1:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

F55ACT1 ----- USUAL ACTIVITIES DAY1

type: numeric (float)
label: F55ACT1

range: [1,2] units: 1
unique values: 2 coded missing: 798 / 1061

tabulation:	Freq.	Numeric	Label
	116	1	YES, DID USUAL ACTIVITIES
	147	2	NO, DID NOT DO USUAL ACTIVITIES

F55MIS1 ----- WHY ACTIVITIES MISSED DAY1

type: numeric (float)
label: F55MIS1

range: [1,20] units: 1
unique values: 9 coded missing: 919 / 1061

tabulation:	Freq.	Numeric	Label
	88	1	SICKLE CELL PAIN (1)
	0	2	ACCIDENT, INJURY (2)
	1	3	
	6	4	OTHER SICKNESS (4)
	3	5	
	16	8	DOCTOR-HOSPITAL-ER VISIT (8)
	11	9	
	9	16	OTHER (16)
	7	17	
	1	20	

F55MIS1:

1. Binary coded variable. See Part II for explanations of binary coded variables.

F55MED1 ----- MEDICATIONS TAKEN DAY1

type: numeric (float)
label: F55MED1

range: [1,14] units: 1
unique values: 9 coded missing: 800 / 1061

tabulation:	Freq.	Numeric	Label
	63	1	NON-PRESCRIPTION PAIN MED (1)
	80	2	PRESCRIPTION PAIN MED (2)
	78	4	OTHER (4)
	11	6	
	14	8	NONE (8)
	1	9	
	4	10	
	9	12	
	1	14	

F55MED1:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

F55HLT2 ----- HEALTH DAY2

type: numeric (float)
label: F55HLT2

range: [1,5] units: 1
unique values: 5 coded missing: 13 / 1061

tabulation:	Freq.	Numeric	Label
	158	1	MUCH BETTER THAN AVERAGE
	202	2	BETTER THAN AVERAGE
	520	3	ABOUT AVERAGE
	141	4	WORSE THAN AVERAGE
	27	5	MUCH WORSE THAN AVERAGE

F55PN2 ----- PAIN DAY2

type: numeric (float)
label: F55PN2

range: [1,2] units: 1
unique values: 2 coded missing: 6 / 1061

tabulation:	Freq.	Numeric	Label
	259	1	YES, HAD SICKLE CELL PAIN
	796	2	NO, DID NOT HAVE PAIN

F55LOC2 ----- PAIN LOCATION DAY2

type: numeric (float)
label: F55LOC2
range: [1,85]

unique values: 38 units: 1
coded missing: 798 / 1061

tab:	Freq.	Numeric	Label	tab:	Freq.	Numeric	Label
	15	1	HEAD (1)		1	25	
	14	2	ARMS (2)		2	30	
	6	3			1	31	
	42	4	LEGS (4)		15	32	ALL OVER (32)
	2	5			1	36	
	19	6			19	64	CHEST (64)
	3	7			1	65	
	17	8	BACK (8)		4	66	
	2	9			1	67	
	5	10			7	68	
	1	11			2	69	
	11	12			4	70	
	4	13			5	72	
	6	14			1	74	
	2	15			2	79	
	26	16	STOMACH (16)		2	80	
	3	17			2	81	
	9	20			1	85	
	3	22			0		128 OTHER (128)
	2	24					

F55LOC2:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

F55ACT2 ----- USUAL ACTIVITIES DAY2

type: numeric (float)

label: F55ACT2

range: [1,2] units: 1

unique values: 2 coded missing: 802 / 1061

tabulation:	Freq.	Numeric	Label
	111	1	YES, DID USUAL ACTIVITIES
	148	2	NO, DID NOT DO USUAL ACTIVITIES

F55MIS2 ----- WHY ACTIVITIES MISSED DAY2

type: numeric (float)

label: F55MIS2

range: [1,25] units: 1

unique values: 13 coded missing: 917 / 1061

tabulation:	Freq.	Numeric	Label
	90	1	SICKLE CELL PAIN (1)
	2	2	ACCIDENT, INJURY (2)
	1	3	
	6	4	OTHER SICKNESS (4)
	4	5	
	15	8	DOCTOR-HOSPITAL-ER VISIT (8)
	16	9	
	1	12	
	2	13	
	3	16	OTHER (16)
	2	17	
	1	21	
	1	25	

F55MIS2:

1. Binary coded variable. See Part II for explanations of binary coded variables.

F55MED2 ----- MEDICATIONS TAKEN DAY2

type: numeric (float)

label: F55MED2

range: [1,14] units: 1

unique values: 9 coded missing: 807 / 1061

tabulation:	Freq.	Numeric	Label
	65	1	NON-PRESCRIPTION PAIN MED (1)
	70	2	PRESCRIPTION PAIN MED (2)
	81	4	OTHER (4)
	10	6	
	16	8	NONE (8)
	1	9	
	4	10	
	5	12	
	2	14	

F55MED2:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

F55HLT3 ----- HEALTH DAY3

type: numeric (float)
label: F55HLT3

range: [1,5] units: 1
unique values: 5 coded missing: 19 / 1061

tabulation:	Freq.	Numeric	Label
	162	1	MUCH BETTER THAN AVERAGE
	186	2	BETTER THAN AVERAGE
	539	3	ABOUT AVERAGE
	123	4	WORSE THAN AVERAGE
	32	5	MUCH WORSE THAN AVERAGE

F55PN3 ----- PAIN DAY3

type: numeric (float)
label: F55PN3

range: [1,2] units: 1
unique values: 2 coded missing: 4 / 1061

tabulation:	Freq.	Numeric	Label
	250	1	YES, HAD SICKLE CELL PAIN
	807	2	NO, DID NOT HAVE PAIN

F55LOC3 ----- PAIN LOCATION DAY3

type: numeric (float)
label: F55LOC3

range: [1,91] units: 1
unique values: 39 coded missing: 810 / 1061

tab:	Freq.	Numeric	Label	tab:	Freq.	Numeric	Label
	13	1	HEAD (1)		2	28	
	13	2	ARMS (2)		1	30	
	44	4	LEGS (4)		1	31	
	1	5			17	32	ALL OVER (32)
	16	6			1	33	
	18	8	BACK (8)		1	36	
	8	9			1	41	
	4	10			1	42	
	8	12			29	64	CHEST (64)
	1	13			3	65	
	8	14			3	66	
	1	15			6	68	
	13	16	STOMACH (16)		9	70	
	1	17			1	71	
	2	18			3	72	
	10	20			1	75	
	1	21			1	76	
	2	22			1	88	
	3	24			1	91	
	1	26			0	128	OTHER (128)

F55LOC3:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

F55ACT3 ----- USUAL ACTIVITIES DAY3

```

    type: numeric (float)
    label: F55ACT3
    range: [1,2]
    unique values: 2
    tabulation: Freq.  Numeric  Label
                 109      1  YES, DID USUAL ACTIVITIES
                 140      2  NO, DID NOT DO USUAL ACTIVITIES
    units: 1
    coded missing: 812 / 1061

```

F55MIS3 ----- WHY ACTIVITIES MISSED DAY3

```

    type: numeric (float)
    label: F55MIS3
    range: [1,21]
    unique values: 13
    tabulation: Freq.  Numeric  Label
                 90      1  SICKLE CELL PAIN (1)
                  2      2  ACCIDENT, INJURY (2)
                  4      4  OTHER SICKNESS (4)
                  3      5
                  12     8  DOCTOR-HOSPITAL-ER VISIT (8)
                  11     9
                   1     11
                   1     12
                   1     13
                   5     16  OTHER (16)
                   4     17
                   1     20
                   1     21
    units: 1
    coded missing: 925 / 1061

```

F55MIS3:

1. Binary coded variable. See Part II for explanations of binary coded variables.

F55MED3 ----- MEDICATIONS TAKEN DAY3

```

    type: numeric (float)
    label: F55MED3
    range: [1,14]
    unique values: 9
    tabulation: Freq.  Numeric  Label
                 57      1  NON-PRESCRIPTION PAIN MED (1)
                 70      2  PRESCRIPTION PAIN MED (2)
                 72      4  OTHER (4)
                 15      6
                 10      8  NONE (8)
                   2      9
                   6     10
                   7     12
                   1     14
    units: 1
    coded missing: 821 / 1061

```

F55MED3:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

F55HLT4 ----- HEALTH DAY4

type: numeric (float)
label: F55HLT4
range: [1,5] units: 1
unique values: 5 coded missing: 15 / 1061

tabulation:	Freq.	Numeric	Label
	162	1	MUCH BETTER THAN AVERAGE
	195	2	BETTER THAN AVERAGE
	543	3	ABOUT AVERAGE
	121	4	WORSE THAN AVERAGE
	25	5	MUCH WORSE THAN AVERAGE

F55PN4 ----- PAIN DAY4

type: numeric (float)
label: F55PN4
range: [1,2] units: 1
unique values: 2 coded missing: 5 / 1061

tabulation:	Freq.	Numeric	Label
	252	1	YES, HAD SICKLE CELL PAIN
	804	2	NO, DID NOT HAVE PAIN

F55LOC4 ----- PAIN LOCATION DAY4

type: numeric (float)
label: F55LOC4
range: [1,88] units: 1
unique values: 43 coded missing: 809 / 1061

tab:	Freq.	Numeric	Label	tab:	Freq.	Numeric	Label
	10	1	HEAD (1)		1	29	
	21	2	ARMS (2)		3	30	
	3	3			16	32	ALL OVER (32)
	49	4	LEGS (4)		1	36	
	1	5			1	42	
	15	6			1	44	
	1	7			1	45	
	24	8	BACK (8)		1	63	
	5	9			18	64	CHEST (64)
	5	10			4	65	
	1	11			1	66	
	8	12			1	67	
	8	14			3	68	
	1	15			4	70	
	17	16	STOMACH (16)		2	72	
	3	17			1	73	
	1	18			1	74	
	1	19			2	76	
	8	20			1	80	
	3	22			1	82	
	1	24			1	88	
	1	26			0	128	OTHER (128)

F55LOC4:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD PERSONAL DIARY
 CSSCD FULL COHORT PATIENTS

F55ACT4 ----- USUAL ACTIVITIES DAY4

type: numeric (float)

label: F55ACT4

range: [1,2] units: 1

unique values: 2 coded missing: 816 / 1061

tabulation:	Freq.	Numeric	Label
	114	1	YES, DID USUAL ACTIVITIES
	131	2	NO, DID NOT DO USUAL ACTIVITIES

F55MIS4 ----- WHY ACTIVITIES MISSED DAY4

type: numeric (float)

label: F55MIS4

range: [1,29] units: 1

unique values: 13 coded missing: 931 / 1061

tabulation:	Freq.	Numeric	Label
	86	1	SICKLE CELL PAIN (1)
	1	2	ACCIDENT, INJURY (2)
	1	3	
	5	4	OTHER SICKNESS (4)
	3	5	
	11	8	DOCTOR-HOSPITAL-ER VISIT (8)
	11	9	
	4	16	OTHER (16)
	4	17	
	1	20	
	1	21	
	1	24	
	1	29	

F55MIS4:

1. Binary coded variable. See Part II for explanations of binary coded variables.

F55MED4 ----- MEDICATIONS TAKEN DAY4

type: numeric (float)

label: F55MED4

range: [1,14] units: 1

unique values: 9 coded missing: 821 / 1061

tabulation:	Freq.	Numeric	Label
	55	1	NON-PRESCRIPTION PAIN MED (1)
	72	2	PRESCRIPTION PAIN MED (2)
	70	4	OTHER (4)
	10	6	
	13	8	NONE (8)
	4	9	
	5	10	
	9	12	
	2	14	

F55MED4:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

F55HLT5 ----- HEALTH DAYS

```

    type: numeric (float)
    label: F55HLT5
    range: [1,5]                      units: 1
unique values: 5                      coded missing: 21 / 1061
  tabulation: Freq.  Numeric  Label
                157      1  MUCH BETTER THAN AVERAGE
                197      2  BETTER THAN AVERAGE
                543      3  ABOUT AVERAGE
                118      4  WORSE THAN AVERAGE
                 25      5  MUCH WORSE THAN AVERAGE
  
```

F55PN5 ----- PAIN DAYS

```

    type: numeric (float)
    label: F55PN5
    range: [1,2]                      units: 1
unique values: 2                      coded missing: 9 / 1061
  tabulation: Freq.  Numeric  Label
                235      1  YES, HAD SICKLE CELL PAIN
                 87      2  NO, DID NOT HAVE PAIN
  
```

F55LOC5 ----- PAIN LOCATION DAYS

```

    type: numeric (float)
    label: F55LOC5
    range: [1,96]                    units: 1
unique values: 40                    coded missing: 824 / 1061
  
```

tab:	Freq.	Numeric	Label	tab:	Freq.	Numeric	Label
	9	1	HEAD (1)		1	33	
	12	2	ARMS (2)		1	40	
	3	3			1	41	
	51	4	LEGS (4)		1	42	
	5	5			1	44	
	15	6			1	57	
	1	7			22	64	CHEST (64)
	17	8	BACK (8)		3	65	
	6	9			2	66	
	15	12			1	67	
	4	14			2	68	
	16	16	STOMACH (16)		4	70	
	1	17			1	72	
	1	18			1	76	
	9	20			1	80	
	1	21			1	84	
	2	22			1	86	
	4	24			1	88	
	2	28			1	96	
	1	29				128	OTHER (128)
	15	32	ALL OVER (32)				

F55LOC5:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

F55ACT5 ----- USUAL ACTIVITIES DAYS

type: numeric (float)
 label: F55ACT5
 range: [1,2] units: 1
 unique values: 2 coded missing: 828 / 1061

tabulation:	Freq.	Numeric	Label
	99	1	YES, DID USUAL ACTIVITIES
	134	2	NO, DID NOT DO USUAL ACTIVITIES

F55MIS5 ----- WHY ACTIVITIES MISSED DAYS

type: numeric (float)
 label: F55MIS5
 range: [1,24] units: 1
 unique values: 13 coded missing: 935 / 1061

tabulation:	Freq.	Numeric	Label
	82	1	SICKLE CELL PAIN (1)
	1	2	ACCIDENT, INJURY (2)
	1	3	
	4	4	OTHER SICKNESS (4)
	4	5	
	10	8	DOCTOR-HOSPITAL-ER VISIT (8)
	12	9	
	1	10	
	5	16	OTHER (16)
	3	17	
	1	20	
	1	21	
	1	24	

F55MIS5:

1. Binary coded variable. See Part II for explanations of binary coded variables.

F55MED5 ----- MEDICATIONS TAKEN DAYS

type: numeric (float)
 label: F55MED5
 range: [1,14] units: 1
 unique values: 9 coded missing: 833 / 1061

tabulation:	Freq.	Numeric	Label
	60	1	NON-PRESCRIPTION PAIN MED (1)
	70	2	PRESCRIPTION PAIN MED (2)
	65	4	OTHER (4)
	10	6	
	12	8	NONE (8)
	1	9	
	4	10	
	5	12	
	1	14	

F55MED5:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

F55HLT6 ----- HEALTH DAY6

type: numeric (float)
label: F55HLT6
range: [1,5] units: 1
unique values: 5 coded missing: 29 / 1061

tabulation:	Freq.	Numeric	Label
	170	1	MUCH BETTER THAN AVERAGE
	197	2	BETTER THAN AVERAGE
	539	3	ABOUT AVERAGE
	110	4	WORSE THAN AVERAGE
	16	5	MUCH WORSE THAN AVERAGE

F55PN6 ----- PAIN DAY6

type: numeric (float)
label: F55PN6
range: [1,2] units: 1
unique values: 2 coded missing: 16 / 1061

tabulation:	Freq.	Numeric	Label
	219	1	YES, HAD SICKLE CELL PAIN
	826	2	NO, DID NOT HAVE PAIN

F55LOC6 ----- PAIN LOCATION DAY6

type: numeric (float)
label: F55LOC6
range: [1,127] units: 1
unique values: 40 coded missing: 839 / 1061

tab:	Freq.	Numeric	Label	tab:	Freq.	Numeric	Label
	11	1	HEAD (1)		22	64	CHEST (64)
	16	2	ARMS (2)		2	65	
	1	3			2	66	
	48	4	LEGS (4)		1	68	
	2	5			1	69	
	12	6			3	70	
	19	8	BACK (8)		2	72	
	3	9			1	73	
	2	10			2	74	
	13	12			1	75	
	2	13			2	76	
	5	14			1	80	
	13	16	STOMACH (16)		1	81	
	1	17			1	82	
	5	20			1	84	
	1	21			1	86	
	2	22			1	118	
	1	23			1	121	
	1	24			2	127	
	2	28			0	128	OTHER (128)
	14	32	ALL OVER (32)				

F55LOC6:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

F55ACT6 ----- USUAL ACTIVITIES DAY6

type: numeric (float)
label: F55ACT6

range: [1,2] units: 1
unique values: 2 coded missing: 845 / 1061

tabulation:	Freq.	Numeric	Label
	104	1	YES, DID USUAL ACTIVITIES
	112	2	NO, DID NOT DO USUAL ACTIVITIES

F55MIS6 ----- WHY ACTIVITIES MISSED DAY6

type: numeric (float)
label: F55MIS6

range: [1,24] units: 1
unique values: 10 coded missing: 954 / 1061

tabulation:	Freq.	Numeric	Label
	72	1	SICKLE CELL PAIN (1)
	1	2	ACCIDENT, INJURY (2)
	3	4	OTHER SICKNESS (4)
	5	5	
	10	8	DOCTOR-HOSPITAL-ER VISIT (8)
	9	9	
	4	16	OTHER (16)
	1	17	
	1	21	
	1	24	

F55MIS6:

1. Binary coded variable. See Part II for explanations of binary coded variables.

F55MED6 ----- MEDICATIONS TAKEN DAY6

type: numeric (float)
label: F55MED6

range: [1,14] units: 1
unique values: 9 coded missing: 850 / 1061

tabulation:	Freq.	Numeric	Label
	58	1	NON-PRESCRIPTION PAIN MED (1)
	60	2	PRESCRIPTION PAIN MED (2)
	58	4	OTHER (4)
	10	6	
	13	8	NONE (8)
	1	9	
	4	10	
	6	12	
	1	14	

F55MED6:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD PERSONAL DIARY
CSSCD FULL COHORT PATIENTS

F55HLT7 ----- HEALTH DAY7

type: numeric (float)
label: F55HLT7
range: [1,5] units: 1
unique values: 5 coded missing: 45 / 1061

tabulation:	Freq.	Numeric	Label
	171	1	MUCH BETTER THAN AVERAGE
	175	2	BETTER THAN AVERAGE
	543	3	ABOUT AVERAGE
	105	4	WORSE THAN AVERAGE
	22	5	MUCH WORSE THAN AVERAGE

F55PN7 ----- PAIN DAY7

type: numeric (float)
label: F55PN7
range: [1,2] units: 1
unique values: 2 coded missing: 43 / 1061

tabulation:	Freq.	Numeric	Label
	220	1	YES, HAD SICKLE CELL PAIN
	798	2	NO, DID NOT HAVE PAIN

F55LOC7 ----- PAIN LOCATION DAY7

type: numeric (float)
label: F55LOC7
range: [1,96] units: 1
unique values: 42 coded missing: 836 / 1061

tab:	Freq.	Numeric	Label			
				1	30	
				1	31	
	14	1	HEAD (1)	18	32	ALL OVER (32)
	10	2	ARMS (2)	1	33	
	2	3		1	40	
	49	4	LEGS (4)	1	46	
	1	5		12	64	CHEST (64)
	14	6		1	65	
	1	7		2	66	
	18	8	BACK (8)	6	68	
	2	9		1	69	
	4	10		2	70	
	1	11		1	72	
	10	12		1	75	
	1	13		1	76	
	5	14		2	80	
	12	16	STOMACH (16)	2	88	
	6	17		1	90	
	2	18		1	96	
	5	20		0	128	OTHER (128)
	1	22				
	1	23				
	5	24				
	2	25				

tab:	Freq.	Numeric	Label
	3	28	

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F55LOC7:

1. Binary coded variable. See Part II for explanations of binary coded variables.

CODEBOOK FOR CSSCD FORM 56
COMFORT MEASURES FOR PAINFUL EPISODE FORM
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F55ACT7 ----- USUAL ACTIVITIES DAY7

type: numeric (float)
label: F55ACT7
range: [1,2] units: 1
unique values: 2 coded missing: 840 / 1061

tabulation:	Freq.	Numeric	Label
	97	1	YES, DID USUAL ACTIVITIES
	124	2	NO, DID NOT DO USUAL ACTIVITIES

F55MIS7 ----- WHY ACTIVITIES MISSED DAY7

type: numeric (float)
label: F55MIS7
range: [1,21] units: 1
unique values: 10 coded missing: 941 / 1061

tabulation:	Freq.	Numeric	Label
	78	1	SICKLE CELL PAIN (1)
	1	2	ACCIDENT, INJURY (2)
	9	4	OTHER SICKNESS (4)
	5	5	
	5	8	DOCTOR-HOSPITAL-ER VISIT (8)
	16	9	
	2	16	OTHER (16)
	2	17	
	1	20	
	1	21	

F55MIS7:

1. Binary coded variable. See Part II for explanations of binary coded variables.

F55MED7 ----- MEDICATIONS TAKEN DAY7

type: numeric (float)
label: F55MED7
range: [1,14] units: 1
unique values: 8 coded missing: 848 / 1061

tabulation:	Freq.	Numeric	Label
	54	1	NON-PRESCRIPTION PAIN MED (1)
	65	2	PRESCRIPTION PAIN MED (2)
	57	4	OTHER (4)
	13	6	
	14	8	NONE (8)
	3	10	
	6	12	
	1	14	

F55MED7:

1. Binary coded variable. See Part II for explanations of binary coded variables.

_dta:

CODEBOOK FOR CSSCD FORM 56
COMFORT MEASURES FOR PAINFUL EPISODE FORM
CSSCD FULL COHORT PATIENTS

1. Created 7/26/2000

A. List of variables deleted F56INIT F56NDATE F56LASTU F56LASTE F56ESTAT
F56VDATE F56BDATE F56DFC F56FCB F56DATE

B. List of variables modified NONE

C. List of variables modified with a name change NONE

D. Old name

E. New name

F. List of variables modified date to days since DOE

G. Old name F56DATE

H. New name JF56DATE

I. Collection Information:

Form 56 (Comfort Measures for Painful Episode Form) was administered to a randomly selected group of HbSS patients who were at least 12 years of age at the time of a routine study visit. If a patient was not able to come to the center, the questionnaire was administered by telephone. A painful episode was defined by the CSSCD as pain occurring in the extremities, back, abdomen, chest, or head that lasted at least two hours, led to a clinic visit, and could not be explained except by sickle cell disease. The definition specifically excluded pain that was treated entirely at home. The focus of the comfort measures ancillary study, however, included pain experienced and treated at home. The purpose of this study, initiated by CSSCD nurses, was to examine measures of comfort and characteristics of self-management used by patients with sickle cell anemia during painful episodes.

J. Data Collection Period: 05/86-09/88

K. Form Version Dates: 05/01/86

L. Files Used to Store Information:

SAS System Files: R56.SD2

Format Files: R56.FMT

M. Unique Record Identifiers: ANONID

N. Number of Observations (Patients) in SAS Dataset: 473 (473)

O. Contents of SAS Dataset:

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COMFORT MEASURES FOR PAINFUL EPISODE FORM
CSSCD FULL COHORT PATIENTS

File Name r56.sas7bdat
Release Created 9.0000MO
Host Created XP_PRO

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
1	ANONID	Char	8	ANONYMIZED ID #
55	F56AFF1	Num	8	NOISE AFFECTS COMFORT LEVEL
56	F56AFF2	Num	8	NO HEAT, NO AIR AFFECTS COMFORT LEVEL
57	F56AFF3	Num	8	NO PRIVACY AFFECTS COMFORT LEVEL
58	F56AFF4	Num	8	SOMETHING ELSE AFFECTS COMFORT LEVEL
49	F56CHNG1	Num	8	WORRY TOO MUCH
50	F56CHNG2	Num	8	NOT WORRY ENOUGH
51	F56CHNG3	Num	8	KEEP YOU FROM DOING THINGS YOU LIKE
52	F56CHNG4	Num	8	MAKE YOU DO THINGS YOU DON'T LIKE
53	F56CHNG5	Num	8	HAVE YOU DRINK MORE FLUIDS
54	F56CHNG6	Num	8	OTHERS
59	F56DIFT1	Num	8	ACUPUNCTURE
60	F56DIFT2	Num	8	HERBAL MEDICINE
61	F56DIFT3	Num	8	CHIROPRACTOR
62	F56DIFT4	Num	8	MASSEUR
63	F56DIFT5	Num	8	HYPNOTIST
64	F56DIFT6	Num	8	OTHER
65	F56DIFTS	Num	8	METHOD OF TREATMENT IS WAS SUCCESSFUL?
6	F56INTFR	Num	8	PAIN INTERFERE USUAL ACTIVITIES
31	F56MED1A	Num	8	TAKE TYLENOL (PLAIN)
37	F56MED1B	Num	8	TAKE DEMEROL
32	F56MED2A	Num	8	TAKE EXCEDRIN
38	F56MED2B	Num	8	TAKE TYLENOL WITH CODEINE
33	F56MED3A	Num	8	TAKE PERCOGESIC
39	F56MED3B	Num	8	TAKE DARVON
34	F56MED4A	Num	8	TAKE ANACIN
40	F56MED4B	Num	8	TAKE TALWIN

CODEBOOK FOR CSSCD FORM 56
COMFORT MEASURES FOR PAINFUL EPISODE FORM
CSSCD FULL COHORT PATIENTS

The SAS System

14:09 Monday, November 13, 2006 17

The CONTENTS Procedure

Alphabetic List of Variables and Attributes

#	Variable	Type	Len	Label
35	F56MED5A	Num	8	TAKE MOTRIN
41	F56MED5B	Num	8	TAKE PERCOCET
36	F56MED6A	Num	8	OTHER NON-PRESCRIPTION MEDICINES
42	F56MED6B	Num	8	OTHER PRESCRIBED MEDICINES TAKEN
30	F56MEDIC	Num	8	MEDICATION TAKEN
4	F56NUMP	Num	8	HOW MANY PAINFUL EPISODES?
3	F56PAIN	Num	8	PAIN DUE TO SCD IN LAST YEAR
5	F56PLAST	Num	8	TIME PAINFUL EPISODES LAST
15	F56PRVNT	Num	8	PREVENT THE PAIN
16	F56RDUC	Num	8	REDUCE THE PAIN
7	F56RSN1	Num	8	WEATHER CHANGE CAUSES PAIN
8	F56RSN2	Num	8	SOCIAL EVENTS CAUSE PAIN
9	F56RSN3	Num	8	PHYSICAL ACTIVITY CAUSES PAIN
10	F56RSN4	Num	8	MENSTRUATION CAUSES PAIN
11	F56RSN5	Num	8	EMOTIONAL UPSET CAUSES PAIN
12	F56RSN6	Num	8	ILLNESS CAUSES PAIN
13	F56RSN7	Num	8	OTHERS
2	F56SEX	Num	8	SEX
14	F56SIGN	Num	8	SIGN TO HAVE PAINFUL EPISODES
48	F56SUCCS	Num	8	MANAGE PAIN AT HOME SUCCESSFULLY
19	F56TEC1	Num	8	RELAXATION
20	F56TEC2	Num	8	DISTRACTION: RADIO, TV, ETC.
21	F56TEC3	Num	8	DECREASE ACTIVITY
22	F56TEC4	Num	8	INCREASE ACTIVITY
23	F56TEC5	Num	8	HEAT APPLICATION
24	F56TEC6	Num	8	COLD APPLICATION
25	F56TEC7	Num	8	WARM BATH
26	F56TEC8	Num	8	MASSAGE
27	F56TEC9	Num	8	INCREASE FLUIDS
28	F56TEC10	Num	8	SLEEP
29	F56TEC11	Num	8	OTHER NON-MEDICATION TECHNIQUES
18	F56TECH	Num	8	ANY NON-MEDICATION TECHS TO RELIEVE PAIN
43	F56TIME	Num	8	TIME OF DAY INFLUENCE PAIN
44	F56TIME1	Num	8	WHICH QUARTER OF THE DAY
17	F56TREAT	Num	8	HOW TO TREAT THE PAIN FR SCD
45	F56WAY1	Num	8	TO TALK TO SOMEONE
46	F56WAY2	Num	8	TO BE LEFT ALONE
47	F56WAY3	Num	8	TO HAVE SOMEONE CLOSE BY
66	JF56DATE	Num	8	DATE OF VISIT - RECODE DAYS SINCE DOE

CODEBOOK FOR CSSCD FORM 56
COMFORT MEASURES FOR PAINFUL EPISODE FORM
CSSCD FULL COHORT PATIENTS

* R56.FMT contains value labels for numerical codes assigned to
categorical *
* variables in the SAS dataset R56.SD2
*

*****;

* SIR/DBMS 2.2 SAS PROC STEP FROM DATABASE: CSSCD 12/24/99 12:04:44;

PROC FORMAT;

VALUE F56SEX
1 = 'FEMALE'
2 = 'MALE';

* FORMAT YES_NO IS DEFINED FOR VARIABLES: F56PAIN F56SIGN F56TECH
F56MEDIC F56TIME F56CHNG1-F56CHNG6 F56DIFT1-
F56DIFT6;

VALUE YES_NO
1 = 'YES'
2 = 'NO';

VALUE F56PLAST
1 = '1 DAY OR LESS'
2 = '2-5 DAYS'
3 = 'MORE THAN 5 DAYS';

* FORMAT NEVER IS DEFINED FOR VARIABLES: F56INTFR F56RSN1-F56RSN7
F56PRVNT F56RDUC F56TEC1-F56TEC11 F56MED1A-
F56MED6A F56MED1B-F56MED6B F56WAY1-
F56WAY3 F56SUCCS F56DIFTS;

VALUE NEVER
1 = 'ALL OF THE TIME'
2 = 'MOST OF THE TIME'
3 = 'SOME OF THE TIME'
4 = 'HARDLY EVER'
5 = 'NEVER';

VALUE F56TREAT
1 = 'TREAT IT AT HOME'

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CSSCD FULL COHORT PATIENTS

2 = 'TREAT IT AT HOME FIRST'
3 = 'ER, HOSPITAL ETC.'
4 = 'DO USUAL ACTIVITIES'
5 = 'OTHER';

* FORMAT TIME1X IS DEFINED FOR VARIABLE F56TIME1;

VALUE TIME1X

1 = '12:00 AM - 6:00 AM'
2 = '6:00 AM - 12:00 PM'
3 = '12:00 PM - 6:00 PM'
4 = '6:00 PM - 12:00 AM';

* FORMAT AFFECT IS DEFINED FOR VARIABLES: F56AFF1-F56AFF4;

VALUE AFFECT

1 = 'AFFECTS FAVORABLY'
2 = 'AFFECTS UNFAVORABLY'
3 = 'DOES NOT AFFECT';

* FORMAT MMDDYY8.

F56SEX F56SEX.
F56PAIN F56SIGN F56TECH F56MEDIC F56TIME F56CHNG1-F56CHNG6
F56DIFT1-F56DIFT6 YES_NO.
F56PLAST F56PLAST.
F56INTFR F56RSN1-F56RSN7 F56PRVNT F56RDUC F56TEC1-F56TEC11
F56MED1A F56MED2A F56MED3A F56MED4A F56MED5A F56MED6A
F56MED1B F56MED2B F56MED3B F56MED4B F56MED5B F56MED6B
F56WAY1-F56WAY3 F56SUCCS F56DIFTS NEVER.
F56TREAT F56TREAT.
F56TIME1 TIME1X.
F56AFF1-F56AFF4 AFFECT.;

RUN;
QUIT;

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COMFORT MEASURES FOR PAINFUL EPISODE FORM - PAGE 1
CSSCD FULL COHORT PATIENTS

F56VDATE ----- VERSION DATE DELETED

type: numeric daily date (int)
label: datelab

range: [9617,9617] units: 1
or equivalently: [01may1986,01may1986] units: days
unique values: 1 coded missing: 0 / 473

tabulation:	Freq.	Numeric	Label
	473	9617	05/01/86

F56SEX ----- SEX

type: numeric (float)
label: F56SEX

range: [1,2] units: 1
unique values: 2 coded missing: 2 / 473

tabulation:	Freq.	Numeric	Label
	210	1	FEMALE
	261	2	MALE

F56PAIN ----- PAIN DUE TO SCD IN LAST YEAR

type: numeric (float)
label: F56PAIN

range: [1,2] units: 1
unique values: 2 coded missing: 2 / 473

tabulation:	Freq.	Numeric	Label
	370	1	YES
	101	2	NO

F56NUMP ----- HOW MANY PAINFUL EPISODES?

type: numeric (float)

range: [1,99] units: 1
unique values: 24 coded missing: 131 / 473

mean: 7.10819
std. dev: 8.46885

percentiles:	10%	25%	50%	75%	90%
	1	3	5	9	15

F56NUMP:

1. Required only if F56PAIN=1.

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COMFORT MEASURES FOR PAINFUL EPISODE FORM - PAGE 1
CSSCD FULL COHORT PATIENTS

F56PLAST ----- TIME PAINFUL EPISODES LAST

type: numeric (float)
label: F56PLAST

range: [1,3] units: 1
unique values: 3 coded missing: 102 / 473

tabulation:	Freq.	Numeric	Label
	81	1	1 DAY OR LESS
	197	2	2-5 DAYS
	93	3	MORE THAN 5 DAYS

F56INTFR ----- PAIN INTERFERE USUAL ACTIVITIES

type: numeric (float)
label: F56INTFR

range: [1,5] units: 1
unique values: 5 coded missing: 104 / 473

tabulation:	Freq.	Numeric	Label
	70	1	ALL OF THE TIME
	113	2	MOST OF THE TIME
	144	3	SOME OF THE TIME
	30	4	HARDLY EVER
	12	5	NEVER

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F56RSN1 ----- WEATHER CHANGE CAUSES PAIN

type: numeric (float)
label: F56RSN1

range: [1,5] units: 1
unique values: 5 coded missing: 102 / 473

tabulation:	Freq.	Numeric	Label
	42	1	ALL OF THE TIME
	93	2	MOST OF THE TIME
	161	3	SOME OF THE TIME
	27	4	HARDLY EVER
	48	5	NEVER

F56RSN2 ----- SOCIAL EVENTS CAUSE PAIN

type: numeric (float)
label: F56RSN2

range: [1,5] units: 1
unique values: 5 coded missing: 111 / 473

tabulation:	Freq.	Numeric	Label
	5	1	ALL OF THE TIME
	15	2	MOST OF THE TIME
	93	3	SOME OF THE TIME
	84	4	HARDLY EVER
	165	5	NEVER

F56RSN3 ----- PHYSICAL ACTIVITY CAUSES PAIN

type: numeric (float)
label: F56RSN3

range: [1,5] units: 1
unique values: 5 coded missing: 106 / 473

tabulation:	Freq.	Numeric	Label
	27	1	ALL OF THE TIME
	72	2	MOST OF THE TIME
	141	3	SOME OF THE TIME
	53	4	HARDLY EVER
	74	5	NEVER

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F56RSN4 ----- MENSTRUATION CAUSES PAIN

type: numeric (float)
 label: F56RSN4

range: [1,5] units: 1
 unique values: 5 coded missing: 208 / 473

tabulation:	Freq.	Numeric	Label
	19	1	ALL OF THE TIME
	21	2	MOST OF THE TIME
	42	3	SOME OF THE TIME
	29	4	HARDLY EVER
	154	5	NEVER

F56RSN5 ----- EMOTIONAL UPSET CAUSES PAIN

type: numeric (float)
 label: F56RSN5

range: [1,5] units: 1
 unique values: 5 coded missing: 108 / 473

tabulation:	Freq.	Numeric	Label
	23	1	ALL OF THE TIME
	54	2	MOST OF THE TIME
	128	3	SOME OF THE TIME
	40	4	HARDLY EVER
	120	5	NEVER

F56RSN6 ----- ILLNESS CAUSES PAIN

type: numeric (float)
 label: F56RSN6

range: [1,5] units: 1
 unique values: 5 coded missing: 110 / 473

tabulation:	Freq.	Numeric	Label
	61	1	ALL OF THE TIME
	66	2	MOST OF THE TIME
	132	3	SOME OF THE TIME
	37	4	HARDLY EVER
	67	5	NEVER

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F56RSN7 ----- OTHERS

type: numeric (float)
label: F56RSN7

range: [1,5] units: 1
unique values: 5 coded missing: 363 / 473

tabulation:	Freq.	Numeric	Label
	13	1	ALL OF THE TIME
	17	2	MOST OF THE TIME
	23	3	SOME OF THE TIME
	1	4	HARDLY EVER
	56	5	NEVER

F56SIGN ----- SIGN TO HAVE PAINFUL EPISODES

type: numeric (float)
label: F56SIGN

range: [1,2] units: 1
unique values: 2 coded missing: 104 / 473

tabulation:	Freq.	Numeric	Label
	229	1	YES
	140	2	NO

F56PRVNT ----- PREVENT THE PAIN

type: numeric (float)
label: F56PRVNT

range: [1,5] units: 1
unique values: 5 coded missing: 183 / 473

tabulation:	Freq.	Numeric	Label
	8	1	ALL OF THE TIME
	59	2	MOST OF THE TIME
	135	3	SOME OF THE TIME
	43	4	HARDLY EVER
	45	5	NEVER

F56PRVNT:

1. Required only if F56SIGN=1.

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F56RDUC ----- REDUCE THE PAIN

type: numeric (float)
label: F56RDUC

range: [1,5] units: 1
unique values: 5 coded missing: 186 / 473

tabulation:	Freq.	Numeric	Label
	13	1	ALL OF THE TIME
	67	2	MOST OF THE TIME
	155	3	SOME OF THE TIME
	27	4	HARDLY EVER
	25	5	NEVER

F56RDUC:

1. Required only if F56SIGN=1.

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F56TREAT ----- HOW TO TREAT THE PAIN FR SCD

type: numeric (float)
 label: F56TREAT

range: [1,4] units: 1
 unique values: 4 coded missing: 102 / 473

tabulation:	Freq.	Numeric	Label
	47	1	TREAT IT AT HOME
	306	2	TREAT IT AT HOME FIRST
	12	3	ER, HOSPITAL ETC.
	6	4	DO USUAL ACTIVITIES

F56TECH ----- ANY NON-MEDICATION TECHS TO RELIEVE PAIN

type: numeric (float)
 label: F56TECH

range: [1,2] units: 1
 unique values: 2 coded missing: 113 / 473

tabulation:	Freq.	Numeric	Label
	303	1	YES
	57	2	NO

F56TEC1 ----- RELAXATION

type: numeric (float)
 label: F56TEC1

range: [1,5] units: 1
 unique values: 5 coded missing: 186 / 473

tabulation:	Freq.	Numeric	Label
	25	1	ALL OF THE TIME
	50	2	MOST OF THE TIME
	123	3	SOME OF THE TIME
	36	4	HARDLY EVER
	53	5	NEVER

F56TEC1:

1. Required only if F56TECH=1.

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F56TEC2 ----- DISTRACTION: RADIO, TV, ETC.

type: numeric (float)
label: F56TEC2

range: [1,5] units: 1
unique values: 5 coded missing: 184 / 473

tabulation:	Freq.	Numeric	Label
	11	1	ALL OF THE TIME
	26	2	MOST OF THE TIME
	99	3	SOME OF THE TIME
	42	4	HARDLY EVER
	111	5	NEVER

F56TEC2:

1. Required only if F56TECH=1.

F56TEC3 ----- DECREASE ACTIVITY

type: numeric (float)
label: F56TEC3

range: [1,5] units: 1
unique values: 5 coded missing: 173 / 473

tabulation:	Freq.	Numeric	Label
	44	1	ALL OF THE TIME
	60	2	MOST OF THE TIME
	128	3	SOME OF THE TIME
	20	4	HARDLY EVER
	48	5	NEVER

F56TEC3:

1. Required only if F56TECH=1.

F56TEC4 ----- INCREASE ACTIVITY

type: numeric (float)
label: F56TEC4

range: [1,5] units: 1
unique values: 5 coded missing: 188 / 473

tabulation:	Freq.	Numeric	Label
	2	1	ALL OF THE TIME
	9	2	MOST OF THE TIME
	34	3	SOME OF THE TIME
	18	4	HARDLY EVER
	222	5	NEVER

F56TEC4:

1. Required only if F56TECH=1.

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F56TEC5 ----- HEAT APPLICATION

type: numeric (float)
label: F56TEC5

range: [1,5] units: 1
unique values: 5 coded missing: 177 / 473

tabulation:	Freq.	Numeric	Label
	24	1	ALL OF THE TIME
	61	2	MOST OF THE TIME
	133	3	SOME OF THE TIME
	28	4	HARDLY EVER
	50	5	NEVER

F56TEC5:

1. Required only if F56TECH=1.

F56TEC6 ----- COLD APPLICATION

type: numeric (float)
label: F56TEC6

range: [1,5] units: 1
unique values: 5 coded missing: 201 / 473

tabulation:	Freq.	Numeric	Label
	2	1	ALL OF THE TIME
	2	2	MOST OF THE TIME
	16	3	SOME OF THE TIME
	17	4	HARDLY EVER
	235	5	NEVER

F56TEC6:

1. Required only if F56TECH=1.

F56TEC7 ----- WARM BATH

type: numeric (float)
label: F56TEC7

range: [1,5] units: 1
unique values: 5 coded missing: 181 / 473

tabulation:	Freq.	Numeric	Label
	25	1	ALL OF THE TIME
	51	2	MOST OF THE TIME
	122	3	SOME OF THE TIME
	29	4	HARDLY EVER
	65	5	NEVER

F56TEC7:

1. Required only if F56TECH=1.

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F56TEC8 ----- MESSAGE

type: numeric (float)
label: F56TEC8

range: [1,5] units: 1
unique values: 5 coded missing: 181 / 473

tabulation:	Freq.	Numeric	Label
	23	1	ALL OF THE TIME
	43	2	MOST OF THE TIME
	96	3	SOME OF THE TIME
	29	4	HARDLY EVER
	101	5	NEVER

F56TEC8:

1. Required only if F56TECH=1.

F56TEC9 ----- INCREASE FLUIDS

type: numeric (float)
label: F56TEC9

range: [1,5] units: 1
unique values: 5 coded missing: 166 / 473

tabulation:	Freq.	Numeric	Label
	85	1	ALL OF THE TIME
	86	2	MOST OF THE TIME
	90	3	SOME OF THE TIME
	23	4	HARDLY EVER
	23	5	NEVER

F56TEC9:

1. Required only if F56TECH=1.

F56TEC10 ----- SLEEP

type: numeric (float)
label: F56TEC10

range: [1,5] units: 1
unique values: 5 coded missing: 175 / 473

tabulation:	Freq.	Numeric	Label
	42	1	ALL OF THE TIME
	79	2	MOST OF THE TIME
	84	3	SOME OF THE TIME
	40	4	HARDLY EVER
	53	5	NEVER

F56TEC10:

1. Required only if F56TECH=1.

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F56TEC11 ----- OTHER NON-MEDICATION TECHNIQUES

type: numeric (float)
label: F56TEC11

range: [1,5] units: 1
unique values: 4 coded missing: 412 / 473

tabulation:	Freq.	Numeric	Label
	9	1	ALL OF THE TIME
	12	2	MOST OF THE TIME
	13	3	SOME OF THE TIME
	27	5	NEVER

F56TEC11:

1. Required only if F56TECH=1.

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F56MEDIC ----- MEDICATION TAKEN

type: numeric (float)
 label: F56MEDIC

range: [1,2] units: 1
 unique values: 2 coded missing: 107 / 473

tabulation:	Freq.	Numeric	Label
	349	1	YES
	17	2	NO

F56MED1A ----- TAKE TYLENOL (PLAIN)

type: numeric (float)
 label: F56MED1A

range: [1,5] units: 1
 unique values: 5 coded missing: 141 / 473

tabulation:	Freq.	Numeric	Label
	60	1	ALL OF THE TIME
	52	2	MOST OF THE TIME
	107	3	SOME OF THE TIME
	36	4	HARDLY EVER
	77	5	NEVER

F56MED1A:
 1. Required only if F56MEDIC=1.

F56MED2A ----- TAKE EXCEDRIN

type: numeric (float)
 label: F56MED2A

range: [2,5] units: 1
 unique values: 4 coded missing: 179 / 473

tabulation:	Freq.	Numeric	Label
	11	2	MOST OF THE TIME
	13	3	SOME OF THE TIME
	17	4	HARDLY EVER
	253	5	NEVER

F56MED2A:
 1. Required only if F56MEDIC=1.

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F56MED3A ----- TAKE PERCOGESIC

type: numeric (float)
label: F56MED3A

range: [1,5] units: 1
unique values: 5 coded missing: 185 / 473

tabulation:	Freq.	Numeric	Label
	2	1	ALL OF THE TIME
	5	2	MOST OF THE TIME
	8	3	SOME OF THE TIME
	7	4	HARDLY EVER
	266	5	NEVER

F56MED3A:

1. Required only if F56MEDIC=1.

F56MED4A ----- TAKE ANACIN

type: numeric (float)
label: F56MED4A

range: [1,5] units: 1
unique values: 5 coded missing: 182 / 473

tabulation:	Freq.	Numeric	Label
	3	1	ALL OF THE TIME
	4	2	MOST OF THE TIME
	31	3	SOME OF THE TIME
	16	4	HARDLY EVER
	237	5	NEVER

F56MED4A:

1. Required only if F56MEDIC=1.

F56MED5A ----- TAKE MOTRIN

type: numeric (float)
label: F56MED5A

range: [1,5] units: 1
unique values: 5 coded missing: 168 / 473

tabulation:	Freq.	Numeric	Label
	10	1	ALL OF THE TIME
	21	2	MOST OF THE TIME
	65	3	SOME OF THE TIME
	23	4	HARDLY EVER
	186	5	NEVER

F56MED5A:

1. Required only if F56MEDIC=1.

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F56MED6A ----- OTHER NON-PRESCRIPTION MEDICINES

type: numeric (float)
label: F56MED6A

range: [1,5] units: 1
unique values: 5 coded missing: 233 / 473

tabulation:	Freq.	Numeric	Label
	13	1	ALL OF THE TIME
	21	2	MOST OF THE TIME
	40	3	SOME OF THE TIME
	7	4	HARDLY EVER
	159	5	NEVER

F56MED6A:

1. Required only if F56MEDIC=1.

F56MED1B ----- TAKE DEMEROL

type: numeric (float)
label: F56MED1B

range: [1,5] units: 1
unique values: 5 coded missing: 176 / 473

tabulation:	Freq.	Numeric	Label
	26	1	ALL OF THE TIME
	25	2	MOST OF THE TIME
	43	3	SOME OF THE TIME
	24	4	HARDLY EVER
	179	5	NEVER

F56MED1B:

1. Required only if F56MEDIC=1.

F56MED2B ----- TAKE TYLENOL WITH CODEINE

type: numeric (float)
label: F56MED2B

range: [1,5] units: 1
unique values: 5 coded missing: 136 / 473

tabulation:	Freq.	Numeric	Label
	82	1	ALL OF THE TIME
	89	2	MOST OF THE TIME
	72	3	SOME OF THE TIME
	18	4	HARDLY EVER
	76	5	NEVER

F56MED2B:

1. Required only if F56MEDIC=1.

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F56MED3B ----- TAKE DARVON

type: numeric (float)
label: F56MED3B

range: [1,5] units: 1
unique values: 5 coded missing: 191 / 473

tabulation:	Freq.	Numeric	Label
	2	1	ALL OF THE TIME
	10	2	MOST OF THE TIME
	14	3	SOME OF THE TIME
	17	4	HARDLY EVER
	239	5	NEVER

F56MED3B:

1. Required only if F56MEDIC=1.

F56MED4B ----- TAKE TALWIN

type: numeric (float)
label: F56MED4B

range: [1,5] units: 1
unique values: 5 coded missing: 191 / 473

tabulation:	Freq.	Numeric	Label
	3	1	ALL OF THE TIME
	5	2	MOST OF THE TIME
	9	3	SOME OF THE TIME
	9	4	HARDLY EVER
	256	5	NEVER

F56MED4B:

1. Required only if F56MEDIC=1.

F56MED5B ----- TAKE PERCOCET

type: numeric (float)
label: F56MED5B

range: [1,5] units: 1
unique values: 5 coded missing: 176 / 473

tabulation:	Freq.	Numeric	Label
	14	1	ALL OF THE TIME
	23	2	MOST OF THE TIME
	28	3	SOME OF THE TIME
	9	4	HARDLY EVER
	223	5	NEVER

F56MED5B:

1. Required only if F56MEDIC=1.

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F56MED6B ----- OTHER PRESCRIBED MEDICINES TAKEN

type: numeric (float)
label: F56MED6B

range: [1,5] units: 1
unique values: 5 coded missing: 234 / 473

tabulation:	Freq.	Numeric	Label
	12	1	ALL OF THE TIME
	23	2	MOST OF THE TIME
	22	3	SOME OF THE TIME
	9	4	HARDLY EVER
	173	5	NEVER

F56MED6B:

1. Required only if F56MEDIC=1.

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F56TIME ----- TIME OF DAY INFLUENCE PAIN

type: numeric (float)
 label: F56TIME

range: [1,2] units: 1
 unique values: 2 coded missing: 105 / 473

tabulation:	Freq.	Numeric	Label
	183	1	YES
	185	2	NO

F56TIME1 ----- WHICH QUARTER OF THE DAY

type: numeric (float)

range: [.00001157,.0000463] units: 1.000e-12
 unique values: 4 coded missing: 287 / 473

tabulation:	Freq.	Numeric	Label
	119	1	12:00 AM - 6:00 AM
	13	2	6:00 AM - 12:00 PM
	12	3	12:00 PM - 6:00 PM
	42	4	6:00 PM - 12:00 AM

F56TIME1:

1. Required only if F56TIME=1.

F56WAY1 ----- TO TALK TO SOMEONE

type: numeric (float)
 label: F56WAY1

range: [1,5] units: 1
 unique values: 5 coded missing: 128 / 473

tabulation:	Freq.	Numeric	Label
	29	1	ALL OF THE TIME
	26	2	MOST OF THE TIME
	60	3	SOME OF THE TIME
	77	4	HARDLY EVER
	153	5	NEVER

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F56WAY2 ----- TO BE LEFT ALONE

type: numeric (float)
label: F56WAY2

range: [1,5] units: 1
unique values: 5 coded missing: 118 / 473

tabulation:	Freq.	Numeric	Label
	126	1	ALL OF THE TIME
	83	2	MOST OF THE TIME
	67	3	SOME OF THE TIME
	31	4	HARDLY EVER
	48	5	NEVER

F56WAY3 ----- TO HAVE SOMEONE CLOSE BY

type: numeric (float)
label: F56WAY3

range: [1,5] units: 1
unique values: 5 coded missing: 115 / 473

tabulation:	Freq.	Numeric	Label
	109	1	ALL OF THE TIME
	75	2	MOST OF THE TIME
	88	3	SOME OF THE TIME
	29	4	HARDLY EVER
	57	5	NEVER

F56SUCCS ----- MANAGE PAIN AT HOME SUCCESSFULLY

type: numeric (float)
label: F56SUCCS

range: [1,5] units: 1
unique values: 5 coded missing: 105 / 473

tabulation:	Freq.	Numeric	Label
	21	1	ALL OF THE TIME
	150	2	MOST OF THE TIME
	169	3	SOME OF THE TIME
	24	4	HARDLY EVER
	4	5	NEVER

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F56CHNG1 ----- WORRY TOO MUCH

type: numeric (float)
label: F56CHNG1

range: [1,2] units: 1
unique values: 2 coded missing: 128 / 473

tabulation:	Freq.	Numeric	Label
	191	1	YES
	154	2	NO

F56CHNG2 ----- NOT WORRY ENOUGH

type: numeric (float)
label: F56CHNG2

range: [1,2] units: 1
unique values: 2 coded missing: 147 / 473

tabulation:	Freq.	Numeric	Label
	47	1	YES
	279	2	NO

F56CHNG3 ----- KEEP YOU FROM DOING THINGS YOU LIKE

type: numeric (float)
label: F56CHNG3

range: [1,2] units: 1
unique values: 2 coded missing: 144 / 473

tabulation:	Freq.	Numeric	Label
	136	1	YES
	193	2	NO

F56CHNG4 ----- MAKE YOU DO THINGS YOU DON'T LIKE

type: numeric (float)
label: F56CHNG4

range: [1,2] units: 1
unique values: 2 coded missing: 146 / 473

tabulation:	Freq.	Numeric	Label
	96	1	YES
	231	2	NO

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F56CHNG5 ----- HAVE YOU DRINK MORE FLUIDS

type: numeric (float)
label: F56CHNG5

range: [1,2] units: 1
unique values: 2 coded missing: 144 / 473

tabulation:	Freq.	Numeric	Label
	117	1	YES
	212	2	NO

F56CHNG6 ----- OTHERS

type: numeric (float)
label: F56CHNG6

range: [1,2] units: 1
unique values: 2 coded missing: 314 / 473

tabulation:	Freq.	Numeric	Label
	36	1	YES
	123	2	NO

**6.10.1: Psychosocial Questionnaire for Parents of SCD Patients 8-13 Years of Age
Form 67**

F56AFF1 ----- NOISE AFFECTS COMFORT LEVEL

type: numeric (float)
label: F56AFF1

range: [1,2] units: 1
unique values: 2 coded missing: 313 / 473

tabulation:	Freq.	Numeric	Label
	14	1	AFFECTS FAVORABLY
	146	2	AFFECTS UNFAVORABLY

F56AFF2 ----- NO HEAT, NO AIR AFFECTS COMFORT LEVEL

type: numeric (float)
label: F56AFF2

range: [1,2] units: 1
unique values: 2 coded missing: 298 / 473

tabulation:	Freq.	Numeric	Label
	16	1	AFFECTS FAVORABLY
	159	2	AFFECTS UNFAVORABLY

F56AFF3 ----- NO PRIVACY AFFECTS COMFORT LEVEL

type: numeric (float)
label: F56AFF3

range: [1,2] units: 1
unique values: 2 coded missing: 401 / 473

tabulation:	Freq.	Numeric	Label
	16	1	AFFECTS FAVORABLY
	56	2	AFFECTS UNFAVORABLY

F56AFF4 ----- SOMETHING ELSE AFFECTS COMFORT LEVEL

type: numeric (float)
label: F56AFF4

range: [1,2] units: 1
unique values: 2 coded missing: 358 / 473

tabulation:	Freq.	Numeric	Label
	49	1	AFFECTS FAVORABLY
	66	2	AFFECTS UNFAVORABLY

**6.10.1: Psychosocial Questionnaire for Parents of SCD Patients 8-13 Years of Age
Form 67**

F56DIFT1 ----- ACUPUNCTURE

type: numeric (float)
label: F56DIFT1

range: [1,2] units: 1
unique values: 2 coded missing: 109 / 473

tabulation:	Freq.	Numeric	Label
	10	1	YES
	354	2	NO

F56DIFT2 ----- HERBAL MEDICINE

type: numeric (float)
label: F56DIFT2

range: [1,2] units: 1
unique values: 2 coded missing: 109 / 473

tabulation:	Freq.	Numeric	Label
	19	1	YES
	345	2	NO

F56DIFT3 ----- CHIROPRACTOR

type: numeric (float)
label: F56DIFT3

range: [1,2] units: 1
unique values: 2 coded missing: 111 / 473

tabulation:	Freq.	Numeric	Label
	26	1	YES
	336	2	NO

F56DIFT4 ----- MASSEUR

type: numeric (float)
label: F56DIFT4

range: [1,2] units: 1
unique values: 2 coded missing: 110 / 473

tabulation:	Freq.	Numeric	Label
	14	1	YES
	349	2	NO

F56DIFT5 ----- HYPNOTIST

**6.10.1: Psychosocial Questionnaire for Parents of SCD Patients 8-13 Years of Age
Form 67**

type: numeric (float)
label: F56DIFT5

range: [1,2] units: 1
unique values: 2 coded missing: 109 / 473

tabulation:	Freq.	Numeric	Label
	12	1	YES
	352	2	NO

F56DIFT6 ----- OTHER

type: numeric (float)
label: F56DIFT6

range: [1,2] units: 1
unique values: 2 coded missing: 145 / 473

tabulation:	Freq.	Numeric	Label
	13	1	YES
	315	2	NO

F56DIFTS ----- METHOD OF TREATMENT IS WAS SUCCESSFUL?

type: numeric (float)
label: F56DIFTS

range: [1,5] units: 1
unique values: 5 coded missing: 411 / 473

tabulation:	Freq.	Numeric	Label
	3	1	ALL OF THE TIME
	5	2	MOST OF THE TIME
	31	3	SOME OF THE TIME
	8	4	HARDLY EVER
	15	5	NEVER

F56DIFTS:

1. Required only if F56DIFT1=1 or F56DIFT2=1 or F56DIFT3=1 or F56DIFT4=1 or F56DIFT5=1 or F56DIFT6=1.

_dta:

1. Created 07/31/00.

S. List of variables deleted F67INIT F67NDATE F67LASTU F67LASTE F67ESTAT

F67VDATE F67DATE F67DFC F67FCB F67PBDAY

T. List of variables modified F67BDATE F67MSTAT F67COHAB F67OTH

U. List of variables modified with a name change NONE

6.10.1: Psychosocial Questionnaire for Parents of SCD Patients 8-13 Years of Age Form 67

V. Old name

W. New name

X. List of variables modified date to days since DOE

Y. Old name **F67DATE**

Z. New name **JF67DATE**

AA. Collection Information:

Form 67 (Psychosocial Questionnaire for Parents of SCD Patients 8-13 Years of Age) was to be completed by the parents of a random sample of HbSS patients between the ages of 8 and 13 years. Psychosocial requirements for this group of participants (GROUP 1) included completion of Form 67, the CHIP Coping Health Inventory, and the Family Environment Scale (FES).

BB. Data Collection Period: 05/84 – 06/87

CC. Form Version Dates: 03/30/84

DD. Files Used to Store Information:

SAS System Files: **R67.SD2**

Format Files: **R67.FMT**

EE. Unique Record Identifiers: **ANONID, F67CYCLE**

Records within the dataset are sorted by **ANONID** and **F67CYCLE**

FF. Number of Observations (Patients) in SAS Dataset: 89 (89)

GG. Contents of SAS Dataset:

- Alphabetical Listing of Variables: See pp. 1-5
- Listing of Variables by Position: See pp. 6-10

A codebook for this dataset is not included in the manual.

HH. Notes About Selected Variables: None

II. Computed Variables: None

JJ. Inter-Relationship With Other Datasets:

Psychosocial data were also collected on

Phase 1 Forms
68

SAS Dataset
R68.SD2

See Section
6.10.2

**6.10.1: Psychosocial Questionnaire for Parents of SCD Patients 8-13 Years of Age
Form 67**

69	R69.SD2	6.10.3
73	R73.SD2	6.10.4
74	R74.SD2	6.10.5
"Roster"	R09.SD2	1.0 (variable: PSYSTAT)