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Shared Decision Making In Self-Care Management And Health Outcomes Of Adolescents And Young Adults With Sickle Cell Disease

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SHARED DECISION MAKING IN SELF-CARE MANAGEMENT AND HEALTH OUTCOMES OF ADOLESCENTS AND YOUNG ADULTS WITH SICKLE CELL DISEASE

A DISSERTATION
SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN NURSING
THE UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT HOUSTON
CIZIK SCHOOL OF NURSING
BY
JUDITH M. ODITYO, MSN, MBA, RN, CPN

MAY 2023

UTHealth | Cizik
The University of Texas Health Science Center at Houston | School of Nursing

Approval Form D-3

March 2, 2023
Date

To the Dean of the Cizik School of Nursing:

I am submitting a dissertation written by Judith Odityo and entitled "Shared Decision Making in Self-Care Management and Health Outcomes of Adolescents and Young Adults with Sickle Cell Disease." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing.

Geri L. Wood
Committee Chair

We have read this dissertation
and recommend its acceptance:

Cathy Rozmus

Accepted

Dean for the Cizik School of
Nursing

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I am so grateful to my classmates/cohort members whom I had the pleasure of learning with and from. Thanks to the librarians, guest speakers, statisticians, editors, and technicians from the school of nursing who have influenced and inspired me.

It would be remiss in not mentioning my family. With gratitude I acknowledge my late parents for the values they instilled in me. Special thanks to my siblings for their prayers and invaluable support.

Judith M Odityo

Shared Decision Making in Self-Care Management and Health Outcomes of Adolescents and Young adults with Sickle Cell Disease

May 2023

Abstract

Background: Despite improvements in sickle cell disease (SCD) management, adolescents and young adults (AYA) with the condition persistently show higher morbidity, premature mortality, and poor health outcomes. Data suggest that AYA with SCD routinely lack the skills and confidence needed to effectively manage their condition. A model of care with a potential to foster disease self-care management and promote optimal health outcomes in AYA with SCD is shared decision making (SDM). SDM is one of the hallmark elements of patient centered care that encourages and empowers patients to assume a proactive role in their care.

Aims: To identify the perceived involvement of AYA with SCD in the SDM process and examine its association with self-care management and health outcomes.

Methods: Data were collected from a major sickle cell center. Using a cross-sectional design, participants completed surveys and data were analyzed with descriptive statistics, analysis of variance, and correlational statistics.

Results: Participants (N=27) were on average 22.72 years old (SD = 0.46) and 56% (N=14) female. Scores on the Perceived Involvement in Care Scale (PICS) were moderately positive, indicating an inclination toward agreement. Perceived Involvement in SDM showed significant positive moderate associations with *self-care ability* as follows: Overall PICS (r = .515**, p = .008); the PICS subscale of *Information Sharing between Patient and Provider* (r = .433*, p = .031); and the PICS subscale of *patient*

Involvement in Medical Decision Making (*r* = .407*, *p* = .044). S*elf-care ability* showed significant moderate positive associations with the PICS subscale of *Perceived Level of Information Sharing between Patient and Provider* (*r* = .524*, *p* = .007). Perceived Involvement in SDM showed a significant negative moderate association with *Pain* (*r* = -.0.423*, *p* = .040).

Conclusion: The modified version of the Transformation Model of Communication and Health Outcomes is partially useful in explaining the role of SDM in self-care management and health outcomes. Study findings underscore the significance of SDM during the clinical encounters of AYA with SCD.

Keywords: Shared Decision Making, Sickle Cell Disease, Adolescents, Young Adults, Self-Care Management, Health Outcomes.

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Summary of Study

The research protocol “Shared Decision Making in Self-Care Management and Health Outcomes of Adolescents and Young adults with Sickle Cell Disease” began following approval from the Committee for the Protection of Human Subjects (CPHS) of The University of Texas Health Science Center at Houston on July 28, 2022. The aims of the descriptive cross-sectional study were as follows:

1. To identify perceived level of involvement of AYA with SCD in shared decision making (SDM) during clinical encounters.
2. To investigate the association between perceived level of involvement of AYA with SCD in SDM and self-care management.
3. To investigate the association between perceived involvement of AYA with SCD in SDM and health outcomes.

Data collection began on September 17, 2022 and ended on January 31, 2023. One hundred and sixty-two AYA with SCD met the inclusion criteria. They were all invited to participate via email. Of the 162 potential participants, 27 consented to participate in the study, 24 responded to all surveys, one opted out after consenting, one only responded to two surveys, and another omitted one survey.

Descriptive statistics were performed to describe sample characteristics of the AYA with SCD and determine the Perceived Level of Involvement in SDM. The correlation coefficient, Pearson’s *r*, was used to determine the strength and direction of the associations between variables. Reliability of each instrument was estimated using Cronbach’s alpha.

The overall mean score of Perceived Involvement in SDM was positive. Amongst the three PICS subscales, the *Perceived Level of Information Sharing between Patient and Provider* showed significant associations with both *self-care ability* and *self-care actions*. Perceived Involvement in SDM and health outcomes showed a significant negative moderate association with Pain.

A manuscript was written describing the background and significance of the research aims and included the methods, results, implications for nursing practice and nursing research. Appendixes A-Q include supplemental information from the study – D2 approval form, CPHS approval documents, study consent form, study flyer, letter of invitation, original study instruments, REDCap version of study instruments, demographics form, and human subjects research training certificates.

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June 2022

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Shared Decision Making in Self-Care Management and Health Outcomes of Adolescents and Young Adults with Sickle Cell Disease

Approximately 100,000 individuals in the United States (US) live with sickle cell disease (SCD), an inherited hemoglobin disorder known to have a significant impact on quality of life, increased morbidity, and premature mortality (Center for Disease Control [CDC], 2020. According to CDC (2020) nearly 1 in 13 African American babies are born with sickle cell trait; 1 out of 365 African American births results in SCD; and 1 out of every 16,300 Hispanic-American births results in SCD. Today however, most children with sickle cell anemia (93.9%) a severe form of SCD and approximately all children with milder forms (98.4%) survive into adulthood (Quin et al., 2010). Survivorship is attributed to the introduction of newborn screening, pneumococcal prophylaxis, comprehensive care, and disease modifying therapies such as hydroxyurea, bone marrow transplantation, and chronic blood transfusion (Quinn, 2013; Bakshi et al., 2017). Despite these preventive measures and disease-modifying therapies, patients, particularly young adults with SCD ages 20-24 years continue to experience severe disease-related complications and premature mortality (Peek et al., 2014). The Dallas Newborn Cohort study (Quinn et al., 2010) found an elevated risk of mortality in young adults during the transition period between pediatric and adult healthcare. This finding was substantiated by a second study which reported a marked increase in deaths from 0.6/100,000 for age 15–19 years to 1.4/100,000 for age 20-24 years during 1999–2009 (Hamideh & Alvarez, 2013). Other studies have highlighted a rise in acute care utilization, hospitalizations, readmissions, and poor health outcomes for adolescents and young adults (AYA) ages 18-30 with SCD (Guarino et al., 2022).

Management of SCD requires the use of problem solving and positive disease management skills (Treadwell et al., 2011), yet data suggest that AYA with SCD routinely lack the skills and confidence needed to effectively manage their disease (McPherson et al., 2009; Stollon et al., 2015). Inadequate self-care management is manifested by ignoring symptoms such as fevers, missing clinic appointments, and poor adherence to medications, which precipitate further health complications requiring urgent and costly treatments (Brousseau et al., 2010). Data supporting perceived involvement in self-care management in this group is lacking.

The aim of this study is to identify from the perspective of AYA with SCD, their involvement in the shared decision making (SDM) process and the role of SDM in (1) self-care management, defined as self-care ability and self-care actions; and (2) health outcomes defined as disease severity. To achieve this aim, the study will (1) identify from the perspective of AYA with SCD, how healthcare providers involve them in the SDM process during clinical encounters, and (2) examine the association of perceived SDM with self-care management (self-ability and self-care actions) and health outcomes (disease severity).

Specific Aims

Aim 1. To identify perceived level of involvement of AYA with SCD in shared decision making during clinical encounters.

Aim 2. To investigate the association between perceived level of involvement of AYA with SCD in shared decision making and self-care management (self-ability and self-care actions).

Hypothesis 2.1. It is hypothesized that perceived involvement of AYA with SCD in shared decision making will be positively associated with better self-care management (self-care ability and self-care actions).

Aim 3. To investigate the association between perceived involvement of AYA with SCD in shared decision making and health outcomes.

Hypothesis 3.1. It is hypothesized that perceived involvement of AYA with SCD in shared decision making will be negatively associated with poor health outcomes.

The proposed study addresses the National Institute of Nursing Research's priorities: (1) To promote and improve the health of individuals, and (2) manage and eliminate symptoms caused by illness (National Institute of Nursing Research's, 2016). Study findings will contribute toward a better understanding of the interactions between AYA with SCD and healthcare providers, the decision-making literature, and the body of science that guides self-disease management.

Background and Significance

Shared Decision Making

Shared decision making (SDM) is a model of care with a potential to guide disease self-care management and promote optimal health outcomes in AYA with SCD. Mathias et al. (2016) defined SDM as an interpersonal, interdependent process in which healthcare providers, patients, and caregivers can relate to and influence each other as they collaborate in making decisions about the patients' care. Other researchers have defined SDM as an interactive process that involves opinions and information sharing; a discussion of patients' values; preferences, providers' responsibilities; and mutual agreement on a course of action (Montori et al., 2006; Deegan et al., 2006; Makoul & Clayman, 2006; Duncan et al., 2010).

The 2001 Institute of Medicine (IOM) report is often cited for bringing SDM to the forefront in US medicine. The IOM report pinpointed patient-centeredness as one of the aims for improving high-quality health care delivery where patient-centered care is (1) respectful; (2) caters to individual needs, preferences, and values; and (3) where patient values guide clinical decisions (IOM, 2001). What has ensued is a shift towards the SDM model of care and increased patient involvement in healthcare decision making (Scholl et al., 2011).

The Affordable Care Act of 2010 included SDM provisions to promote adoption of decision aids, establish standards for decision aid quality, and governmental support for their expansion (Braddock, 2010). Several years later, the National Quality Partners Shared Decision Making Action Team issued a national call to action for all persons and organizations that provide, receive pay for, and make policies for healthcare to embrace and incorporate SDM into clinical practice as a standard of person-centered care (National Quality Partners, 2017).

As an essential component of patient centered care (Mah et al., 2016) SDM builds upon clinical evidence, the providers' clinical expertise, and the unique attributes of the patient and their caregivers (Mathias et al., 2013). What hopefully follows is the patient's active involvement in their disease management and comprehension of the rationales for the care.

Légaré and Witteman (2013) noted that three essential elements must be present for healthcare providers to effectively implement SDM in the clinical setting. First, both the healthcare provider and the patient must recognize and acknowledge that a decision is needed; second, both must know and understand the best available evidence concerning the risks and benefits of each option; and third, decisions must consider both the provider's guidance and the patient's values and preferences.

Policy makers have widely advocated for and promoted SDM due to its potential to yield several benefits for patients, providers, and the healthcare system (Légaré et al., 2014). The benefits include: (1) increased patient knowledge; (2) increased use of beneficial treatment options; (3) decreased use of treatment options without clear benefits; (4) decreased variations in health care delivery; (5) promotion of patients' involvement in their own health; (6) decreased anxiety over the entire medical care process; (7) improved health outcomes; (8) reductions in unnecessary variations in care and costs; and (9) greater alignment of care with patient's values (Légaré et al., 2014; Hartley et al., 2012; Bot et al., 2014).

SDM is also advocated based on ethics (Young et al., 2008; Drake & Deegan, 2009), with patients' involvement in their care being deemed a fundamental right (Straub et al., 2008). Part of the ethical argument concerns patients' rights to be informed about and consent to treatments based on individual autonomy and bodily integrity (King & Mouton, 2006).

SDM includes patients' comprehension of their treatment goals and options, risks, and benefits (Katz, 1984). This inclusion is significant as patients live with the effects of treatment decisions daily. Thus, if patients are intimately involved in treatment decision making, they are more likely to implement and maintain the treatment, thereby increasing adherence and improving health outcomes (Montori et al., 2006; Karnieli-Miller & Salyers, 2011; Légaré & Witteman, 2013).

Additionally, SDM in clinical practice may not only benefit patients and improve their experience with the healthcare system, but also increase the use of relative evidence by healthcare providers (Légaré & Witteman, 2013). As such, it enables healthcare providers to accept decisions that are not necessarily what they perceive as the most appropriate course of action but are, at minimum, decisions to which the patient is prepared to commit to (Légaré & Witteman, 2013).

Literature Review

Despite improvements in SCD management, significant medical challenges persist. Documented challenges include increased hospitalizations (Cronin et al., 2019; Aljuburi et al., 2012; Yusuf et al., 2010; Brousseau et al., 2010); healthcare costs that exceed $900,000 by the age of 45 years (Kauf et al., 2009); and a heightened risk for premature mortality (Dampier et al., 2017; Crosby et al., 2015b). These challenges routinely worsen in AYA with SCD, when caregivers are beginning to or have transferred responsibility for disease management to adult services (Hamideh & Alvarez, 2013; Quinn et al., 2010). Specific examples of challenges include complications such as organ damage (Redding-Lallinger, 2006); neurocognitive deficits (Hood et al., 2019; Siciliano et al., 2019); acute/chronic pain (Siciliano et al., 2019; Field et al., 2019); depression and anxiety; delays in social functioning; and impairments in quality of life (Barakat et al., 2008., Palermo et al., 2008).

To control or prevent the illustrated challenges, it is important that AYA with SCD benefit from medical advances by being involved in the care that consists of both active self-care management at home, and SDM within the clinical setting (Crosby et al., 2015b).

SDM and Positive Patient Related Outcomes

A review of literature reveals an association of SDM with positive patient related outcomes that include affective-cognitive outcomes (Saheb et al., 2017; Alguera-Lara et al., 2017); behavior outcomes (Alguera-Lara et al., 2017; Wilson et al., 2010; Lerman et al., 1990); patient involvement in care (Alguera-Lara et al., 2017; Jabour et al., 2019; Lerman et al., 1990); and positive health outcomes (Alguera-Lara et al., 2017; Wilson et al., 2010; Lerman et al., 1990).

Affective-cognitive outcomes. Affective-cognitive outcomes include self-efficacy, knowledge, understanding, satisfaction, attitude, and anxiety (Lafata et al., 2017). After a review of SDM and treatments in psychiatry, Alguera-Lara et al. (2017) found SDM interventions to be associated with increased specific patient affective-cognitive outcomes. Particularly, the authors found participants improved self-esteem and increased patient satisfaction in care management. A second review by Stacey et al. (2017) evaluated the effects of decision aids in people facing treatment or screening decisions. Review results showed increased patient knowledge, increased patient decision satisfaction, and better patient risk perception in the care of numerous health conditions. A third review examined the association between treatment SDM and outcomes in diabetes. Results showed a correlation between SDM and decision quality, patient knowledge, and patient risk perception in type 2 diabetes (Saheb et al., 2017).

Behavioral outcomes. Behavioral outcomes include patients’ adherence to the plan of care as well as their engagement in other health-related behaviors such as diet and exercise (Latafa et al., 2017). There is compelling evidence supporting the relationship between SDM and adherence in chronic disease management (Bauer et al., 2014). Case in point, a randomized controlled trial by Wilson et al. (2010) compared controller medication adherence and clinical outcomes in adults with poorly managed asthma. Results showed patients who engaged in their treatment via SDM had significantly improved adherence to asthma controller medications and long-acting b-agonists, compared to those who were not. Due to their medication choices and better adherence, patients with SDM received a higher cumulative dose of anti-inflammatory medication over a year. Similarly, Alguera-Lara et al. (2017) reviewed the literature on SDM and psychiatry and found increased treatment adherence after the incorporation of SDM into mental health care.

Involvement in care. Involvement in care includes the engagement of patients in decision making (Vahdat et al., 2014; Targett, 2011) or expressing opinions about different treatment methods inclusive of information sharing, feelings/signs, and adherence to the plan of care (Rafii, et al., 2010). Several studies have demonstrated the association of SDM and increased patient involvement in their care. For example, a quantitative study of newly diagnosed patients with Multiple Sclerosis (D'Amico, et al., 2016) evaluated the willingness of newly diagnosed patients with Multiple Sclerosis to participate in the treatment decision-making process. Results showed patients with higher disability preferred to take a more active role in the decision-making process (D'Amico, et al., 2016). A qualitative study by Jabour et al. (2019) assessed the perspectives of patients with SCD on their process of deciding whether to take hydroxyurea. Hydroxyurea is the only effective drug demonstrated to reduce the frequency of SCD painful episodes (Agrawal et al., 2014*). Perceived SDM involvement* was one of the four themes that emerged from the study. Subjects expressed having discussions with their providers about hydroxyurea that led them to feel that the medication use decision was theirs to make. A quantitative study by Lerman et al. (1990) assessed patients' involvement in care by administering the Perceptions of Involvement in Care Scale (PICS) a 13-item questionnaire to patients in an adult outpatient primary care setting. Study results showed pre and post clinical encounter changes in patients' attitudes about their illnesses were related to their perceptions of physicians' efforts to encourage involvement, along with the levels of information sharing (Lerman et al., 1990).

Health outcomes. Physiological outcomes include measures of quality of life, self-rated health, and other biological measures of health (Latafa et al., 2017). In the review of studies on SDM and treatments in psychiatry, Alguera-Lara et al. (2017) reported findings of symptom reduction and decreased rates of hospitalization following the incorporation of SDM into mental health care. Additionally, in a randomized control trial Wilson et al. (2010) compared usual asthma care with SDM. Results showed that SDM was associated with significantly improved clinical outcomes: asthma-related quality of life, healthcare use, rescue medication use, asthma control, and lung function.

Although these findings can be generalized to patients with SCD within the context of chronic disease management, they are not specific to AYA with SCD. In fact, only one study (Jabour et al., 2019) targeted patients with SCD. Howbeit, this was a qualitative study limited to the outcome measure of treatment decision making. Similarly, majority of the reviewed studies focused only on specific outcome measures such as treatment decision making, adherence to the treatment plan, increased patient knowledge, increased patient decision satisfaction/care, and better patient risk perception. Because of the narrow focus, findings cannot be generalized to the entire clinical encounters of AYA with SCD. Moreover, data supporting the role of SDM in improving self-care management and health outcomes in AYA with SCD has not been evaluated. It is this critical gap in knowledge that the proposed study seeks to address.

The specific aim of this study therefore is to investigate SDM involvement during clinical encounters, from the perspective of AYA with SCD. Determining if collaboration in care occurs will enhance the understanding of SDM during clinical encounters and its role in self-care management and health outcomes in a vulnerable population like AYA with SCD.

Theoretical Model. A modified version of the *Transformation Model of Communication and Health Outcomes* (Figure 1) will guide this study (Shay & Latafa, 2015; Street et al., 2009; Kreps et al., 1994). In this model, Street et al. (2009) postulated that communication between healthcare providers and patients can lead to improved health outcomes directly and indirectly. The model categorizes patient outcomes according to their effect on the individual as follows: (1) *Affective-cognitive outcomes* - includes knowledge, attitudinal, and affective/ emotional effects; (2) *Behavioral outcomes* - includes adherence to recommended treatments and adoption of health behaviors*;* and (3) *Physiological outcomes* **-** includes measures of quality of life, self-rated health, and biological measures of health (Kreps et al., 1994). The proposed study will focus on both the relationship between the affective and behavioral outcomes as they relate to health outcomes of AYA with SCD. With the indirect pathway, perceived involvement in SDM could lead to self-care management and better health outcomes via the affective-cognitive outcomes. With the model's direct pathway, SDM could lead to improved self-care management (self-care ability & self-care actions) and better health outcomes if conversation between provider and patient, in this case AYA with SCD, help to identify the correct health problem, a suitable treatment plan, adherence to treatment or self-care plan, and/or affected patient's health beliefs (Street et al., 2009).

Innovation

The proposed study is innovative because it will engage a disadvantaged vulnerable population to investigate SDM beyond the restrictive discussions of treatment decisions to the entire clinical encounters. Further, since the ultimate issues underlying the study are disease self-care management and overall health outcomes, it is expected that the study will contribute toward a better understanding of the nature of interactions between AYA with SCD and healthcare providers; the decision-making literature; the body of science that guides disease management via SDM; and identification of elements of SDM that can be used as the stimulus for curriculum development in patient - provider SCD education programs.

Approach

Research Design and Setting

The study will be a cross-sectional descriptive design, conducted at the University of Texas (UT) Physicians Comprehensive Sickle Cell Center in Houston, Texas. Prior to conducting the study, permission and approval from the Institutional Review Board/Committee for the protection of Human Subjects from UT Physicians Comprehensive Sickle Cell Center and UT Health Cizik School of Nursing will be obtained.

Sample. Participants in the study will be (1) AYA ages 18 - 26 years old; (2) have a self-reported diagnosis of one of the following SCD genotypes: sickle cell anemia; sickle beta^0 thalassemia; sickle hemoglobin C disease; or sickle beta$^+$ thalassemia; (3) be enrolled at the center for routine health maintenance visits; (4) be able to read and write in English; and (5) be willing and able to consent and complete the questionnaires. The exclusion criteria will include AYA with SCD ages <18 and >26 years old and AYA with sickle cell trait (those who live normal lives without health problems related to SCD).

Sample size justification. A convenience sample of 67 is determined to be adequate and was calculated using G*Power 3.1. (Faul, et al., 2009). The parameters used are a one-tailed test decided based on directional hypotheses (Polit & Beck, 2017), alpha at 0.05, power at 0.80, and a medium effect size set to 0.3 for Pearson's correlation. This number fits well with the accessible sample of 100 AYA with SCD and allows for attrition, missing data due to misunderstanding of instructions, and the exclusion criteria (Suresh & Chandrashekara, 2012).

Measures

Demographic. *A Demographics and Health History Form* will be used to obtain data from participants about age, gender, race, ethnicity, SCD type, annual income, years of education, number of annual pain crises, number of crises managed at home, and daily pain rating. Data will be used to identify potential variables that may influence SDM, self-care management, and poor health outcomes (Jenerette & Murdaugh, 2008).

Perceived Involvement in SDM. The *Perceived Involvement in Care Scale* will be used to measure perceived involvement of AYA with SCD in SDM. The *Perceived Involvement in Care Scale* measures SDM scores on 3 subscales: (1) perceived provider facilitation of patient involvement (5 items); (2) perceived level of information sharing between patient and provider (4 items); and (3) perceived level of the patient's involvement in medical decision making (4 items) (Lerman et al., 1990). The response selections use an agree/disagree scale, where disagree = 0 points and agree = 1 point. The sum of the total score shows the degree of involvement, with high scores reflecting a higher degree of perceived SDM. The *Perceived Involvement in Care Scale* has reported reliability and validity across patient populations (Jonsdottir et al., 2013; Liang et al., 2002). Lerman and colleagues (1990) reported adequate evidence of internal consistency reliability (Cronbach's alpha = 0.73) and validity; and factor analysis (*N* = 131) supporting the *Perceived Involvement in Care Scale* three subscales.

Self-Care Ability. The *Appraisal of Self-Care Agency Scale* will be used to measure the outcome variable, perceived self-care ability. Self-care ability is defined as the ability to participate in therapeutic behaviors to improve or maintain health status and quality of life (Jenerette & Murdaugh, 2008). The scores range from 1 ("totally disagree") to 5 ("totally agree"). Responses on the scale are summed to obtain a total score, where higher scores correspond with higher levels of self-care ability. The *Appraisal of Self-Care Agency Scale* has established construct validity and a content validity index of 0.88 along with internal consistency reliabilities ranging from 0.80 to 0.86 (Jenerette & Murdaugh, 2008).

Self-Care Actions. The *Jenerette Self-Care Assessment Tool* (J-SAT*)* will be used to measure self-care actions. Self-care actions are defined as participation in therapeutic activities and using resources to enhance health status and quality of life. The instrument has eight items that measure self-care activities. A Likert scale ranging from "never" to "almost always" is used and items consist of statements such as "I understand (know why I am taking) my medications" and "I avoid stress whenever possible." Higher summed scores show greater frequency of self-care actions. The scale's construct validity was estimated by a significant negative correlation with the Centre for Epidemiological Studies Depression Scale (CESD; Radloff, 1977) and a significant positive correlation with the Functional Status Questionnaire (FSQ; Jette et al., 1986). The J-SAT had an internal consistency reliability of 0.80 in an initial test of the instrument (Jenerette & Murdaugh, 2008).

Health Outcomes. The Medical Outcomes Study (MOS) short form (SF-36) Questionnaire will be used to measure health outcomes of AYA with SCD. The SF-36 is a 36-item instrument for measuring health status and outcomes from patients' perceptions. The instrument has 36 items about eight health concepts: physical function (10 items); physical role health (4 items); emotional role functions (3 items); vitality (4 items); emotional wellbeing (5 items); social function (2 items); bodily pain (2 items); and general health perceptions (5 items) (Ware & Sherbourne, 1992). Data from SF-36 will be scored based on the scoring system reported by RAND Health. Accordingly, each item has a single summary variable ranging from 0 = poor health to 100 = good health (Ware & Sherbourne, 1992). The SF-36 has been shown to have high internal consistency (Cronbach's alpha 0.86–0.93) in the SCD population (Asnani et al., 2008). A second study (Ahmed et al., 2015) reported SF-36 to have high internal consistency (Cronbach's alpha > 0.6) for physical function (Cronbach's alpha = 0.81); physical role health (Cronbach's alpha = 0.84); emotional role functions (Cronbach's alpha = 0.86); vitality (Cronbach's alpha = 0.79); emotional wellbeing (Cronbach's alpha = 0.67); social function (Cronbach’s alpha = 0.67); bodily pain (Cronbach’s alpha = 0.84); and general health (Cronbach’s alpha = 0.60).

Protection of Human Subjects

After receiving approval from the Institutional Review Board (IRB) of the participating site and the University of Texas Committee for the Protection of Human Subjects (CPHS), participants will be provided with a written consent and demographic questionnaire. During the consenting process, the primary investigator (PI) will explain the purpose of the study to inform the decision to participate. Participants will be reminded that participation is voluntary, and confidentiality will be established by (1) keeping identifying information from the study data, and (2) not gathering names. Data will be kept secure by password protection and data encryption with the Research Electronic Data Capture (REDCap). The length of and estimated time to complete the questionnaires is approximately 40 minutes and will be shared with participants. The PI will also supply contact information, should participants have any questions about the study. Contact information for CPHS will also be provided, should participants have any questions about their rights as research subjects.

Data Collection Procedures and Management

After approval from the university’s Committee for The Protection of Human Subjects (CPHS) and the participating site’s Institutional Review Board (IRB), data collection will begin. The PI will reach out to the leadership team at the UT Sickle Cell Center to obtain email addresses of AYA with SCD who possibly meet the inclusion criteria. The PI will also reach out to the staff at the center to aid in referring AYA with SCD during their clinic appointments. The center’s staff will be asked to aid with distributing study recruitment flyers and participant invitation letters. For AYA with SCD expressing interest in the study, they will receive a REDCap study link via email, or the invitation letter handed to them by the center's staff. For AYA with SCD who wish to participate in the study after reading recruitment flyers and personally contacting the PI via email or text message, the PI will email or text the REDCap study link to them. Participants will be able to access the study via their personal electronic devices. Before the participants can begin the survey, they PI will explain to them the purpose of the study and the length of time necessary to complete the surveys and questions. Thereafter, they will be asked to complete an electronic consent (sample Table 8), which will have a stated assurance of data confidentiality for all willing participants. After completing the informed consent, participants will have to meet the study's inclusion criteria before advancing to the questionnaires. If they select answers that exclude them from the study, the survey will end and thank them for their time. Participants who meet the study's inclusion criteria will be asked to provide the following socio-demographic data and health history: age, gender, race, ethnicity, SCD type, annual income, years of education, number of annual pain crises, number of crises managed at home, and daily pain rating. At the end of the survey, participants will click on a Qualtrics link asking only for their email address to send them the electronic $25 dollar gift card. The separate Qualtrics link to send the gift cards ensures the participants responses to the REDCap study survey do not link them to their email addresses. The PI will fund the $25 dollar gift cards.

The estimated timeline for the IRB/CPHS approval for the study will begin May 2022. Data collection and participant recruitment will occur concurrently throughout the months with final data analyses at the end of August/September 2022. If the PI requires more time to conduct the study and to recruit more participants, the IRB/CPHS will be notified.

Data Analysis

The Statistical Package for Social Sciences (SPSS) version 27.0 for Windows (SPSS Inc., Chicago, IL) will be used for data analysis. The shape of data distribution will be described via skewness and kurtosis. Data will also be displayed in graphs or tables, and histograms. Following a test of statistical normality, data will be summarized using descriptive statistics: mean and standard deviation, as well as median and range will be reported for numeric variables; frequency distributions will be used to examine age, gender, level of education, employment status, and living situation using. Internal consistency (Cronbach's alpha) will be calculated for the multi-item instruments.

Aim 1. To identify perceived level of involvement of AYA with SCD in shared decision making during clinical encounters. Data will be analyzed using descriptive statistics.

Aim 2. To investigate the association between perceived involvement of AYA with SCD in shared decision making and self-care management (self-care ability and self-care actions). The Pearson correlation coefficient will be used to assess the strength and direction of SDM association with self-care ability and self-care actions. Multiple logistic regression will be conducted to control for confounding variables.

Aim 3. To investigate the association between perceived involvement of AYA with SCD in shared decision making and health outcomes. The Pearson correlation coefficient will be used to assess the strength and the direction of SDM association with AYA health outcomes. Multiple logistic regression will be conducted to control for confounding variables.

Methodological Issues and Limitations

The proposed study has foreseeable limitations. First, the primary limitation of the cross-sectional study design is that although the investigator may determine that there is an association between an exposure and an outcome, there is typically no evidence that the exposure caused the outcome (Carlson & Morrison, 2009). To eliminate this limitation, multiple logistic regression will be conducted to control for confounding variables (Pourhoseingholi et al., 2012).

A second limitation is that convenience sampling is prone to researcher bias, thereby challenging the representativeness of the sample. A large sample size will increase the statistical power of the convenience sample. Additionally, the use of a clear eligibility criteria for sampling and a theoretical model to guide the study should control for this limitation (Sharma, 2017). A third limitation is that the administration of a battery of multiple measurements may be discouraging due to the time needed to complete the questionnaires. Illustrating the purpose and significance of the study and compensating participants for their time will foster commitment to completing the questionnaires.

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May 1, 2023

Lanetta Bronté-Hall, MD, MPH, MSPH

Editor-in-Chief

The Journal for Sickle Cell and Hemoglobinopathies

Dear Dr. Bronté-Hall,

I am submitting our manuscript, "Shared Decision Making in Self-Care Management and Health Outcomes of Adolescents and Young Adults with Sickle Cell Disease" for the board's consideration of publication into your journal, *The Journal for Sickle Cell and Hemoglobinopathies*. The role of shared decision making in self-care management and health outcomes of adolescents and young adults with sickle cell disease has not been explored. We believe the findings from this study will be of interest to your readers and will provide information for future implications in nursing research and practice.

The final manuscript has been read and approved by all the authors. We look forward to your review and response.

Sincerely,

Judith Odityo, PhD(c), MBA, RN, CPN

The University of Texas Health Science Center – Cizik School of Nursing

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Shared Decision Making in Self-Care Management and Health Outcomes of Adolescents and Young adults with Sickle Cell Disease Introduction

Approximately 100,000 individuals in the United States (US) live with sickle cell disease (SCD), an inherited hemoglobin disorder known to have a significant impact on quality of life, increased morbidity, and premature mortality (Center for Disease Control [CDC], 2020). According to CDC (2020) nearly 1 in 13 African American babies are born with sickle cell trait; 1 out of 365 African American births results in SCD; and 1 out of every 16,300 Hispanic-American births results in SCD. Today however, most children with sickle cell anemia (93.9%) a severe form of SCD and approximately all children with milder forms (98.4%) survive into adulthood (Quin et al., 2010). Survivorship is attributed to the introduction of newborn screening, pneumococcal prophylaxis, comprehensive care, and disease modifying therapies such as hydroxyurea, bone marrow transplantation, and chronic blood transfusion (Quinn, 2013; Bakshi et al., 2017). Despite these preventive measures and disease-modifying therapies, patients, particularly young adults with SCD ages 20-24 years continue to experience severe disease-related complications and premature mortality (Peek et al., 2014). The Dallas Newborn Cohort study (Quinn et al., 2010) found an elevated risk of mortality in young adults during the transition period between pediatric and adult healthcare. This finding was substantiated by a second study which reported a marked increase in deaths from 0.6/100,000 for age 15–19 years to 1.4/100,000 for age 20-24 years during 1999–2009 (Hamideh & Alvarez, 2013). Other studies have highlighted a rise in acute care utilization, hospitalizations, readmissions, and poor health outcomes for adolescents and young adults (AYA) ages 18-30 with SCD (Guarino et al., 2022).

Management of SCD requires the use of problem solving and positive disease management skills (Treadwell et al., 2011), yet data suggest that AYA with SCD routinely lack the skills and confidence needed to effectively manage their disease (McPherson et al., 2009; Stollon et al., 2015). Inadequate self-care management is manifested by ignoring symptoms such as fevers, missing clinic appointments, and poor adherence to medications, which precipitate further health complications requiring urgent and costly treatments (Brousseau et al., 2010). Data supporting perceived involvement in self-care management in this group is lacking.

The aim of this study is to identify from the perspective of AYA with SCD, their involvement in the shared decision making (SDM) process and the role of SDM in (1) self-care management, defined as self-care ability and self-care actions; and (2) health outcomes defined as disease severity. To achieve this aim, the study will (1) identify from the perspective of AYA with SCD, how healthcare providers involve them in the SDM process during clinical encounters, and (2) examine the association of perceived SDM with self-care management (self-ability and self-care actions) and health outcomes (disease severity).

Background

Shared Decision Making

Shared decision making (SDM) is a model of care with a potential to guide disease self-care management and promote optimal health outcomes in AYA with SCD. Mathias et al. (2016) defined SDM as an interpersonal, interdependent process in which healthcare providers, patients, and caregivers can relate to and influence each other as they collaborate in making decisions about the patients’ care. Other researchers have defined SDM as an interactive process that involves opinions and information sharing; a discussion of patients' values; preferences, providers' responsibilities; and mutual agreement on a course of action (Montori et al., 2006; Deegan et al., 2006; Makoul & Clayman, 2006; Duncan et al., 2010).

The 2001 Institute of Medicine (IOM) report is often cited for bringing SDM to the forefront in US medicine. The IOM report pinpointed patient-centeredness as one of the aims for improving high-quality health care delivery where patient-centered care is (1) respectful; (2) caters to individual needs, preferences, and values; and (3) where patient values guide clinical decisions (IOM, 2001). What has ensued is a shift towards the SDM model of care and increased patient involvement in healthcare decision making (Scholl et al., 2011).

The Affordable Care Act of 2010 included SDM provisions to promote adoption of decision aids, establish standards for decision aid quality, and governmental support for their expansion (Braddock, 2010). Several years later, the National Quality Partners Shared Decision Making Action Team issued a national call to action for all persons and organizations that provide, receive pay for, and make policies for healthcare to embrace and incorporate SDM into clinical practice as a standard of person-centered care (National Quality Partners, 2017).

As an essential component of patient centered care (Mah et al., 2016) SDM builds upon clinical evidence, the providers' clinical expertise, and the unique attributes of the patient and their caregivers (Mathias et al., 2013). What hopefully follows is the patient's active involvement in their disease management and comprehension of the rationales for the care.

Légaré and Witteman (2013) noted that three essential elements must be present for healthcare providers to effectively implement SDM in the clinical setting. First, both the healthcare provider and the patient must recognize and acknowledge that a decision is needed; second, both must know and understand the best available evidence concerning the risks and benefits of each option; and third, decisions must consider both the provider's guidance and the patient's values and preferences.

Policy makers have widely advocated for and promoted SDM due to its potential to yield several benefits for patients, providers, and the healthcare system (Légaré et al., 2014). The benefits include: (1) increased patient knowledge; (2) increased use of beneficial treatment options; (3) decreased use of treatment options without clear benefits; (4) decreased variations in health care delivery; (5) promotion of patients' involvement in their own health; (6) decreased anxiety over the entire medical care process; (7) improved health outcomes; (8) reductions in unnecessary variations in care and costs; and (9) greater alignment of care with patient's values (Légaré et al., 2014; Hartley et al., 2012; Bot et al., 2014).

SDM is also advocated based on ethics (Young et al., 2008; Drake & Deegan, 2009), with patients' involvement in their care being deemed a fundamental right (Straub et al., 2008). Part of the ethical argument concerns patients' rights to be informed about and consent to treatments based on individual autonomy and bodily integrity (King & Mouton, 2006).

SDM includes patients' comprehension of their treatment goals and options, risks, and benefits (Katz, 1984). This inclusion is significant as patients live with the effects of treatment decisions daily. Thus, if patients are intimately involved in treatment decision making, they are more likely to implement and maintain the treatment, thereby increasing adherence and improving health outcomes (Montori et al., 2006; Karnieli-Miller & Salyers, 2011; Légaré & Witteman, 2013).

Additionally, SDM in clinical practice may not only benefit patients and improve their experience with the healthcare system, but also increase the use of relative evidence by healthcare providers (Légaré & Witteman, 2013). As such, it enables healthcare providers to accept decisions that are not necessarily what they perceive as the most appropriate course of action but are, at minimum, decisions to which the patient is prepared to commit to (Légaré & Witteman, 2013).

Literature Review

Despite improvements in SCD management, significant medical challenges persist. Documented challenges include increased hospitalizations (Cronin et al., 2019; Aljuburi et al., 2012; Yusuf et al., 2010; Brousseau et al., 2010); healthcare costs that exceed $900,000 by the age of 45 years (Kauf et al., 2009); and a heightened risk for premature mortality (Dampier et al., 2017; Crosby et al., 2015b). These challenges routinely worsen in AYA with SCD, when caregivers are beginning to or have transferred responsibility for disease management to adult services (Hamideh & Alvarez, 2013; Quinn et al., 2010). Specific examples of challenges include complications such as organ damage (Redding-Lallinger, 2006); neurocognitive deficits (Hood et al., 2019; Siciliano et al., 2019); acute/chronic pain (Siciliano et al., 2019; Field et al., 2019); depression and anxiety; delays in social functioning; and impairments in quality of life (Barakat et al., 2008., Palermo et al., 2008).

To control or prevent the illustrated challenges, it is important that AYA with SCD benefit from medical advances by being involved in the care that consists of both active self-care management at home, and SDM within the clinical setting (Crosby et al., 2015b).

SDM and Positive Patient Related Outcomes

A review of literature reveals an association of SDM with positive patient related outcomes that include affective-cognitive outcomes (Saheb et al., 2017; Alguera-Lara et al., 2017); behavior outcomes (Alguera-Lara et al., 2017; Wilson et al., 2010; Lerman et al., 1990); patient involvement in care (Alguera-Lara et al., 2017; Jabour et al., 2019; Lerman et al., 1990); and positive health outcomes (Alguera-Lara et al., 2017; Wilson et al., 2010; Lerman et al., 1990).

Affective-cognitive outcomes. Affective-cognitive outcomes include self-efficacy, knowledge, understanding, satisfaction, attitude, and anxiety (Lafata et al., 2017). After a review of SDM and treatments in psychiatry, Alguera-Lara et al. (2017) found SDM interventions to be associated with increased specific patient affective-cognitive outcomes. Particularly, the authors found participant improved self-esteem and increased patient satisfaction in care management. A second review by Stacey et al. (2017) evaluated the effects of decision aids in people facing treatment or screening decisions. Review results showed increased patient knowledge, increased patient decision satisfaction, and better patient risk perception in the care of numerous health conditions. A third review examined the association between treatment SDM and outcomes in diabetes. Results showed a correlation between SDM and decision quality, patient knowledge, and patient risk perception in type 2 diabetes (Saheb et al., 2017).

Behavioral outcomes. Behavioral outcomes include patients' adherence to the plan of care as well as their engagement in other health-related behaviors such as diet and exercise (Latafa et al., 2017). There is compelling evidence supporting the relationship between SDM and adherence in chronic disease management (Bauer et al., 2014). Case in point, a randomized controlled trial by Wilson et al. (2010) compared controller medication adherence and clinical outcomes in adults with poorly managed asthma. Results showed patients who engaged in their treatment via SDM had significantly improved adherence to asthma controller medications and long-acting b-agonists, compared to those who were not. Due to their medication choices and better adherence, patients with SDM received a higher cumulative dose of anti-inflammatory medication over a year. Similarly, Alguera-Lara et al. (2017) reviewed the literature on SDM and psychiatry and found increased treatment adherence after the incorporation of SDM into mental health care.

Involvement in care. Involvement in care includes the engagement of patients in decision making (Vahdat et al., 2014; Targett, 2011) or expressing opinions about different treatment methods inclusive of information sharing, feelings/signs, and adherence to the plan of care (Rafii, et al., 2010). Several studies have demonstrated the association of SDM and increased patient involvement in their care. For example, a quantitative study of newly diagnosed patients with Multiple Sclerosis (D'Amico, et al., 2016) evaluated the willingness of newly diagnosed patients with Multiple Sclerosis to participate in the treatment decision-making process. Results showed patients with higher disability preferred to take a more active role in the decision-making process (D'Amico, et al., 2016). A qualitative study by Jabour et al. (2019) assessed the perspectives of patients with SCD on their process of deciding whether to take hydroxyurea. Hydroxyurea is the only effective drug demonstrated to reduce the frequency of SCD painful episodes (Agrawal et al., 2014*). Perceived SDM involvement* was one of the four themes that emerged from the study. Subjects expressed having discussions with their providers about hydroxyurea that led them to feel that the medication use decision was theirs to make. A quantitative study by Lerman et al. (1990) assessed patients' involvement in care by administering the Perceptions of Involvement in Care Scale (PICS) a 25-item questionnaire to patients in an adult outpatient primary care setting. Study results showed pre and post clinical encounter changes in patients' attitudes about their illnesses were related to their perceptions of physicians' efforts to encourage involvement, along with the levels of information sharing (Lerman et al., 1990).

Health outcomes. Physiological outcomes include measures of quality of life, self-rated health, and other biological measures of health (Latafa et al., 2017). In the review of studies on SDM and treatments in psychiatry, Alguera-Lara et al. (2017) reported findings of symptom reduction and decreased rates of hospitalization following the incorporation of SDM into mental health care. Additionally, in a randomized control trial Wilson et al. (2010) compared usual asthma care with SDM. Results showed that SDM was associated with significantly improved clinical outcomes: asthma-related quality of life, healthcare use, rescue medication use, asthma control, and lung function.

Although these findings can be generalized to patients with SCD within the context of chronic disease management, they are not specific to AYA with SCD. In fact, only one study (Jabour et al., 2019) targeted patients with SCD. Howbeit, this was a qualitative study limited to the outcome measure of treatment decision making. Similarly, majority of the reviewed studies focused only on specific outcome measures such as treatment decision making, adherence to the treatment plan, increased patient knowledge, increased patient decision satisfaction/care, and better patient risk perception. Because of the narrow focus, findings cannot be generalized to the entire clinical encounters of AYA with SCD. Moreover, data supporting the role of SDM in improving self-care management and health outcomes in AYA with SCD has not been evaluated. It is this critical gap in knowledge that the proposed study seeks to address.

Theoretical Model. A modified version of the *Transformation Model of Communication and Health Outcomes* (Figure 1) guided this study (Shay & Latafa, 2015; Street et al., 2009; Kreps et al., 1994). In this model, Street et al. (2009) postulated that communication between healthcare providers and patients can lead to improved health outcomes directly and indirectly. The model categorizes patient outcomes according to their effect on the individual as follows: (1) *Affective-cognitive outcomes* - includes knowledge, attitudinal, and affective/ emotional effects; (2) *Behavioral outcomes* - includes adherence to recommended treatments and adoption of health behaviors*;* and (3) *Physiological outcomes* **-** includes measures of quality of life, self-rated health, and biological measures of health (Kreps et al., 1994). This study focused on both the relationship between the affective and behavioral outcomes as they relate to health outcomes of AYA with SCD. With the indirect pathway, perceived involvement in SDM could lead to self-care management and better health outcomes via the affective-cognitive outcomes. With the model’s direct pathway, SDM could lead to improved self-care management (self-care ability & self-care actions) and better health outcomes if conversation between provider and patient, in this case AYA with SCD, help to identify the correct health problem, a suitable treatment plan, adherence to treatment or self-care plan, and/or affected patient's health beliefs (Street et al., 2009).

Aims

The aim of this study was to identify from the perspective of AYA with SCD, their involvement in the shared decision making (SDM) process and the role of SDM in (1) self-care management, defined as self-care ability and self-care actions; and (2) health outcomes defined as disease severity. To achieve this aim, the study (1) identified from the perspective of AYA with SCD, how healthcare providers involve them in the SDM process during clinical encounters, and (2) investigated the association of perceived SDM with self-care management (self-ability and self-care actions) and health outcomes (disease severity). The specific aims of the study were:

Aim 1. To identify perceived level of involvement of AYA with SCD in shared decision making during clinical encounters.

Aim 2. To investigate the association between perceived level of involvement of AYA with SCD in shared decision making and self-care management (self-care ability and self-care actions). **Hypothesis:** It was hypothesized that perceived involvement of AYA with SCD in shared decision making would be positively associated with better self-care management (self-care ability and self-care actions).

Aim 3. To investigate the association between perceived involvement of AYA with SCD in shared decision making and health outcomes. **Hypothesis:** It was hypothesized that perceived involvement of AYA with SCD in shared decision making would be negatively associated with poor health outcomes.

Method

Design

This study was a descriptive, cross-sectional design.

Sample

A convenience sampling of AYA with SCD was recruited. The inclusion criteria were: (1) AYA ages 18 to 26 years old; (2) a self-reported diagnosis of one of the following SCD genotypes: sickle cell anemia; sickle beta^0 thalassemia; sickle hemoglobin C disease; or sickle beta$^+$ thalassemia; (3) enrollment at the sickle cell center for routine health maintenance visits; (4) ability to read and write in English; and (5) ability to consent and complete the questionnaires. The exclusion criteria were AYA with SCD ages <18 and >26 years old and AYA with sickle cell trait (those who live normal lives without health problems related to SCD).

Instruments and Variables

Demographic. *A Demographics and Health History Form* was used to obtain data from participants about age, gender, years of education, first SCD crisis, first SCD hospitalization, marital status, living conditions, and the most frequently experienced SCD related ailments. Demographic data were used to identify potential variables that may influence SDM, self-care management, and poor health outcomes (See Appendix F and Appendix G).

Perceived Involvement in SDM. The *Perceived Involvement in Care Scale* was used to measure perceived involvement of AYA with SCD in SDM. The *Perceived Involvement in Care Scale* measures SDM scores on 3 subscales: (1) *Perceived Provider Facilitation of Patient Involvement* (5 items); (2) *Perceived Level of Information Sharing between Patient and Provider* (4 items); and (3) *Perceived Level of Patient Involvement* *in Medical Decision* (4 items) (Lerman et al., 1990). The response selection uses an agree/disagree scale, where disagree = 0 points and agree = 1 point. The sum of the total score indicates the degree of involvement, with high scores reflecting a higher degree of perceived SDM (see Appendix H and Appendix I). Reliability for the overall PICS in this study showed evidence of adequate internal consistency (α = .83). The PICS subscales of *Perceived Level of Patient Involvement in Medical Decision Making and Perceived Level of Information Exchange between Patient and Provider* had adequate internal consistency of (α =.81) and (α = .78), respectively. The subscale of *Perceived Provider Facilitation of Patient Involvement* had a marginal internal consistency of (α = .65). Table 3 shows the internal consistency results of all scales used in this study.

Self-Care Ability. The *Appraisal of Self-Care Agency (ASA)* scale was used to measure the outcome variable, perceived self-care ability. Self-care ability is defined as the ability to participate in therapeutic behaviors to improve or maintain health status and quality of life (Jenerette & Murdaugh, 2008). The scores range from 1 (“totally disagree”) to 5 (“totally agree”). Higher scores indicate higher self-care ability (See Appendix J and Appendix K). The ASA scale in this study showed evidence of adequate internal consistency, α = .79. Table 3 shows the internal consistency results of all scales used in this study.

Self-Care Actions. The *Jenerette Self-Care Assessment Tool* (JSAT*)* was used to measure self-care actions. Self-care actions are defined as participation in therapeutic activities and using resources to enhance health status and quality of life (Jenerette & Murdaugh, 2008). The instrument has eight items that measure self-care activities. A Likert scale ranging from “never” to “almost always” is used and items consist of statements such as “I understand (know why I am taking) my medications” and “I avoid stress whenever possible.” Higher summed scores indicate greater frequency of self-care actions (See Appendix L and Appendix M). The JSAT scale showed a marginal internal consistency, α = .66. Table 3 shows the internal consistency results of all scales used in this study.

Health Outcomes. The Medical Outcomes Study (MOS) short form (SF-36) Questionnaire was used to measure health outcomes of AYA with SCD. The SF-36 is a 36-item instrument for measuring health status and outcomes from patients’ perceptions. The instrument’s 36 items focus on eight health concepts: *Physical Function* (10 items); *Role Limitation due to Physical Health* (4 items); *Emotional Role Functions* (3 items); *Vitality* (4 items); *Emotional Wellbeing* (5 items); *Social Function* (2 items); *Bodily Pain* (2 items); and *General Health Perceptions* (5 items). Data from SF-36 were scored based on the scoring system reported by RAND Health Care (Ware & Sherbourne, 1992) (See Appendices N, O, and P). Accordingly, each item has a single summary variable ranging from 0 = poor health to 100 = good health (Ware & Sherbourne, 1992). Reliability for four SF-36 health outcome scale showed adequate internal consistency as follows: *Physical Functioning*, α = .89; *Role Functioning*, α = .75; *Emotional Wellbeing*, α = .76; *Pain*, α = .92. The SF-36 subscales of *Energy/Fatigue* and *General Health* had inadequate marginal consistency of α = .61 and α = .62 respectively. The SF-36 subscale of *Social Functioning* was not analyzed because only one question was included. Table 3 shows the internal consistency results of all scales used in this study.

Data Collection

Flyers describing the study with the primary investigator's contact information were distributed to potential participants at the study site (See Appendix C). Staff at the study site also referred potential participants who were visiting the center and met the study's inclusion criteria. Surveys were sent to potential participants who met the inclusion via email, with up to six reminders for those who had not responded. Upon completion of the survey, Participants received a $25 gift card. Data collection and participant recruitment occurred between September 17, 2022, and January 31, 2023.

Ethical Considerations

Permission and approval from the University of Texas Health Science Center at Houston Institutional Review Board (IRB), Committee for the Protection of Human Subjects (CPHS) was granted to conduct the study at UT Physician Comprehensive Sickle Cell Center (Appendix D).

Data Analysis

Data were exported from REDCap to Microsoft Excel for validation and analyzed using IBM SPSS version 29. Labeling, coding, recoding, and scoring of instruments were completed in SPSS. Data were summarized using descriptive statistics: mean and standard deviation were reported for numeric variables, and frequencies for categorical variables. Histogram and box plots as well as skewness and kurtosis tests were applied to check for normality of data. Scatter plots were used to show the distribution and linearity of an outcome variable and a predictor variable, e.g., ASA and PICS. Pearson's Correlation Coefficient was used to evaluate the strength of the correlations among variables. Reliability of each instrument was estimated using Cronbach's alpha.

Aim 1 - Identify perceived level of involvement of AYA with SCD in SDM during clinical encounters. Descriptive statistics were performed to determine the extent of Perceived Level of Involvement in SDM (PICS).

Aim 2 - Investigate if perceived involvement of AYA with SCD in SDM would be positively associated with improved self-care management defined as *self-care ability* and *self-care actions.* The Pearson's *r* was used to determine the strength and direction of the associations between the variables (Polit & Beck, 2017). The criterion for strength and direction of the correlations between the dependent variables were interpreted as positively or negatively weak (0 to 0.3/ 0 to – 0.3), moderate (0.3 to 0.7/ - 0.3 to – 0.7), or strong (0.7 to 1/ -0.7 to -1) (Ratner, 2009). The P-values were reported for associations with a two-sided level of significance of 0.05 set as the prior.

Aim 3 - Investigate the association between perceived involvement of AYA with SCD in SDM and health outcomes. The Pearson's *r* was used to determine the strength and direction of the associations between variables (Polit & Beck, 2017).

Results

Demographics and General Characteristics

One hundred and sixty-two adolescents and young adults (AYA) met the inclusion criteria and were invited to participate in the study. Of the 162 AYA with SCD, 27 consented to participate. The remainder either declined, did not respond to letters of invitation, or had undeliverable email addresses. Of those consenting to participate in the study, 96% (N=26) advanced to the study questionnaires and one opted out. The completion rate for each questionnaire was as follows: The demographic questionnaire had a 92.5% completion rate (1 participant missed an item on marital status and one opted out of the study); the PICS questionnaire had a 96% completion rate (1 participant opted out of the study); the ASA and JSAT questionnaires had a 96% completion rate (1participant opted out of the study and a second responded only to the demographic and PICS questionnaires); and the SF-36 Health Outcome questionnaire had a 89% completion rate (1 participant opted out of the study and 2 omitted the survey). Participants were able to complete the survey without questions or assistance. Data from 25 participants were included in the final analysis.

Table 1 shows the socio-demographic data of the participants. More than half of the participants (56%) were female (N=14) and 44% were male (N=11). The mean age was M=22.72, SD=0.46 and ranged from 18 to 26. The reported mean ages for first sickle cell crisis and first hospitalization were M=4.51, SD=0.99 and M=2.84, SD=0.64, respectively. Two individuals reporting their first hospitalization at 12 years old were found to be extreme outliers and were omitted from the analysis to bring the skewness and Kurtosis values within tolerance. The most commonly experienced SCD-related conditions were painful crises (25, 100.0%) and anemia (22, 88%). Table 2 shows the distribution of the surveyed SCD-related conditions. Education level ranged from high school diploma to graduate degree. Specifically, > 1/3 of the participants (N=9, 36%) reported having some college credits; 28% (N=7) reported having high school diplomas; 20% (N=5) reported having bachelor's degrees; 8% (N=2) reported having associate degrees; and 8% (N=2) reported having master's degrees.

Perceived Involvement in Shared Decision Making

The overall mean score on PICS was M=9.0, SD=0.64 with a possible range of 0-13. The mean score for the *Perceived Provider Facilitation of Patient Involvement* subscale was M=3.83, SD= 0.27 with a possible range of 0-5. The mean score for the *Perceived Level of Information Sharing between Patient and Provider* subscale was

M= 3.25, SD=0.25 with a possible range of 0-4. The mean score for the *Perceived Level of Patient Involvement in Medical Decision Making* subscale was M=1.92, SD=0.31 with a possible range of 0-4. Table 3 shows descriptive statistics for the studied variables.

Perceived Level of Involvement in Shared Decision Making and Self-Care Management

Aim 2 hypothesized that perceived involvement of AYA with SCD in SDM would be positively associated with better self-care management defined as *self-care ability* and *self-care actions.* The findings were as follows:

- Perceived Involvement in SDM (Overall PICS) showed a significant, positive moderate association with a higher *self-care ability* (*r* = .515**, *p* = .008), but no evidence of association with greater frequency in *self-care actions* (*r* = .383, *p* = .059)
- *Perceived Provider Facilitation of Patient Involvement* (PICS subscale) showed no evidence of association with a higher *self-care ability* (*r* = .364, *p* = .073) and greater frequency in *self-care actions* (*r* = .0.68, *p* = .747)
- *Perceived Level of Information Sharing between Patient and Provider* (PICS subscale) showed a significant moderate positive association with a higher *self-care ability* (*r* = .433*, *p* = .031) and greater frequency in *self-care actions* (*r* = .524*, *p* = .007)
- *Perceived Level of Patient Involvement in Medical Decision Making* (PICS subscale) showed a significant positive moderate association with a higher *self-care ability* (*r* = .407*, *p* = .044) but no evidence of association with greater frequency *self-care actions* (*r* = .318, *p* = .121)

Table 4 shows the association between perceived involvement in SDM and self-care management.

Perceived Level of Involvement in Shared Decision Making and Health Outcomes

Aim 3 hypothesized that the perceived involvement of AYA with SCD in SDM would be negatively associated with poor health outcomes. Table 4 shows associations between perceived involvement in SDM and health outcome variables. *Pain* had a significant negative, moderate association with Perceived Involvement in SDM (r = -.0.423*, p = .040). There was no evidence of an association between Perceived Involvement in SDM and the health outcome variables of *Social Functioning* (r = -.382, p = .065); *Physical Functioning* (r= -.211, p = .322); *Role Limitation* (r =.170, p = .426); *Emotional Wellbeing* (r = .143, p = .504); *Energy/Fatigue* (r = .135, p = .528); *and General Health* (r = .061, p = .775).

Discussion

The results of this study underscore the role of SDM in self-care management and the health outcomes of AYA with SCD and adds to the literature because there is support for the involvement of AYA with SCD in SDM.

AYA Perceived Level of Involvement in Shared Decision Making

The findings reveal a moderate to high agreement toward (1) Perceived Involvement in SDM (overall PICS); (2) *Perceived Provider Facilitation of Patient Involvement* (PICS subscale)*;* and (3) *Perceived Level of Information Sharing between Patient and Provider* (PICS subscale). Moderate to high agreement may indicate patients preference for a collaborative-passive role in SDM during clinical encounters (E Lindsay et al., 2020; Yamauchi et al., 2017; De Las Cuevas & Peñate, 2016; Degner et al., 1997). Participants' *Perceived Level of Patient Involvement in Medical Decision Making* (PICS subscale) revealed a positive but low mean value. Involvement in decision making as a component of SDM is supported by literature (Vahdat et al., 2014; Targett, 2011; Rafii, et al., 2010). According to the authors, involvement in care includes the engagement of patients in decision making or expressing opinions about different treatment methods. The low mean value may however indicate a partial practice of SDM by providers. Specifically, Bakshi and colleagues (2017) reported that while studying physician perspectives on SDM, they found various approaches that ranged from physicians who were committed to SDM, to those who distinctly promoted a specific therapeutic plan based on their understanding of patient adherence, socioeconomic status, and the severity of the clinical condition. The low mean value may also indicate participants preference for a passive role in medical decision making. Previous studies have demonstrated that majority of patients prefer a perceive role in decision making (Rodriguez et al., 2008; Gregório et al., 2020). Another study reported that in decision-making roles, 44% of the respondents preferred a passive role, while only 1.9% preferred an active role (Mah et al., 2016). The study by E Lindsay et al. (2020) found that overall, participants preferred a semi-passive role in the decision making process.

Shared Decision Making and Self-Care Management

In this study, self-care management was defined as self-care ability and self-care actions (Jenerette & Murdaugh, 2008). The two attributes seemingly function in tandem to promote complete involvement in self-care management.

Self-care ability. Perceived Involvement in SDM showed a significant positive association with higher *self-care ability*. This finding indicates that involvement in SDM likely influenced *self-care ability* and is consistent with studies that have demonstrated an association of SDM with increased patient involvement in their care (D'Amico, et al., 2016; Jabour et al., 2019). Specifically, Pearson’s *r* results for the association of Perceived Involvement in SDM and *self-care ability* indicated a significant moderate positive association for (1) overall PICS; (2) *Perceived Level of Information Sharing between Patient and Provider* (PICS subscale); and (3) *Provider* and *Perceived Level of Patient Involvement in Medical Decision Making* (PICS subscale).

Self-care actions. Findings for perceived involvement in SDM and *self-care actions* varied. The association of Perceived Involvement in SDM (overall PICS) and greater frequency in *self-care actions* was found to be negligible. The association of *Perceived Provider Facilitation of Patient Involvement* (PICS subscale) and *self-care actions* was also found to be negligible. Conversely, the association of *Perceived Level of Information Sharing between Patient and Provider* (PICS subscale) showed a significant moderate positive association with greater frequency in *self-care actions*. These mixed results may indicate (1) participants preference for a passive role (Rodriguez et al., 2008; Gregório et al., 2020; Mah et al., 2016); (2) participant preference for a semi-passive role (E Lindsay et al. (2020); or (3) limited provider facilitation of patient involvement in SDM (Bakshi et al., 2017). Responses to the questionnaires in this regard showed when there was a provider–patient partnership with the patients taking the lead in asking questions about their condition (*Perceived Level of Information Sharing between Patient and Provider*) or suggesting treatment for their condition/symptoms (*Perceived Level of Patient Involvement in Medical Decision Making*), a level of agreement toward Perceived Involvement in SDM emerged. Yet, when the provider took the lead by asking patients whether they agreed with his/her opinion or encouraged them to discuss concerns about their condition/treatment (*Perceived Provider Facilitation of Patient Involvement*), a level of agreement toward Perceived Involvement in SDM weakened.

Shared Decision Making and Health Outcomes

Findings showed that perceived involvement in SDM had (1) a significant negative moderate association with *Pain*. The finding may indicate that a higher level of Perceived Involvement in SDM resulted in improved pain management. This finding is consistent with previous studies which have shown an association of SDM with positive health outcomes (Alguera-Lara et al., 2017; Wilson et al., 2010; Lerman et al., 1990). Particularly, Alguera-Lara et al. (2017) reported findings of symptom reduction and decreased rates of hospitalization following the incorporation of SDM into mental health care. Wilson et al. (2010) found that SDM was associated with significantly improved clinical outcomes of asthma-related quality of life, healthcare use, rescue medication use, asthma control, and lung function.

Findings of the health outcome of *Pain* are particularly important because in the present study, 100% (N=25) of the participants reported pain as the most frequently experienced condition. Notably, painful acute vaso-occlusive crisis is the insignia of SCD and the leading cause of hospitalization or acute care utilization (Siciliano et al., 2019; Field et al., 2019; Brandow et al., 2010; McClish et al., 2005). Moreover, pain crises increase in frequency, duration, and intensity as patients age (Panepinto et al., 2005). It is also important to note that the subjective nature of reporting pain (Gladwin et al., 2011) posits it as an intriguing topic for SDM and would likely impact scores on the PICS subscale of *Perceived Level of Patient Involvement in Medical Decision Making*. Case in point, Matthias and colleagues (2020) found that although providers desire patient involvement in treatment decisions, they are hesitant where opioids are concerned. Yet patients with SCD largely depend on opioids for acute and chronic pain management (Sinha et al., 2019).

Study Strengths and Limitations

This study addressed the gap in knowledge on the role of SDM in self-care management and the health outcomes of AYA with SCD. The contribution of the study should however be considered in the light of limitations. The study sample size was small and homogenous, hence limiting the generalizability of results to other populations. The study also investigated the associations of the variables hence causality could not be established (Hulley et al., 2013). It cannot be determined if associations among variables are bi-directional. The generalizability of any significant findings in the study would be limited to convenient sampling. Variables or likely mediating and moderating variables not addressed in the study to the hypothesized associations merit attention. They include SCD severity and different genotypes that may influence the associations. Supporting this notation is a study of newly diagnosed patients with Multiple Sclerosis which found that patients with higher disability preferred to take a more active role in the decision-making process (D'Amico, et al., 2016). The use of a general and narrow measure of SDM in this study is likely limiting. Future research that develops or uses an SDM scale specific to SCD would enhance understanding of the concept within the context of self-care management and the health outcomes of AYA with SCD. Lastly, the administration of multiple instruments likely discouraged potential participants due to the time needed to complete the questionnaires.

Implications for Nursing Practice

Nurses are in a position to facilitate and involve patients in the SDM process. Nurses are the largest health care workforce (Chung et al., 2021) and essential members of the medical team (Friesen-Storms et al., 2015; Ervin et al., 2017). According to Chung and colleagues (2021), the promotion of SDM can aid nurses in exploring the views and expectations of patients and caregivers, as well as determine the direction of care. Therefore, it is incumbent upon nurse educators and leaders to consider including SDM information in curriculums and training manuals. Plans for continuing education to stay abreast with likely policy and practice changes should also be considered.

Implications for Nursing Research

The present study focused on AYA with SCD ages 18-26 years. Future research should include health care providers who share the responsibilities of SDM, to capture their perceptions as they pertain to the hypothesized aims of the study. Future research should also target a representative sample to support an analysis that could determine mediating or moderating variables that the present study did not address (SCD severity, Hb SS, Hb SC, Hb Sβ+-thalassemia and Hb Sβ0-thalassemia). Lastly, this study will likely contribute toward a better understanding of the nature of interactions between AYA with SCD and healthcare providers; the decision-making literature; and the body of science that guides disease management via SDM.

Conclusion

While particular attributes of the modified version of the Transformation Model of Communication and Health Outcomes prevailed in determining factors influencing Perceived Involvement in SDM and its associations with self-care management and health outcomes, the model as a whole was not supported. Future research should consider more appropriate theoretical models to understand how patient perceived involvement in SDM influences self-care management and the health outcomes of AYA with SCD. Notwithstanding, the present study findings advance AYA Perceived Involvement in SDM during entire clinical encounters, the association of perceived involvement in SDM with self-care management, and the association of SDM with the health outcome of pain. The present study also highlights the likely practice of negating certain aspects of SDM and the patients preference for a collaborative-passive role in SDM. In the light of these findings, we recommend that for SDM to thrive, providers should remain guided by the patients’ values while ensuring that patients understand all relevant information (Kon, 2010).

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Table 1

Demographic Variables
N=25

Variable	Mean	SD
Age	22.72	0.46
First SCD Crisis	4.51	0.99
First Hospitalization	2.84	0.64

Note. N = Sample size; SD = Standard deviation

Table 2

Distribution of Participant Responses to SCD Related Ailments
N=25

Ailment	Number of Participants	Percentage
Anemia	22	88
Depression	12	46.2
Drug Dependency	2	7.7
Heart Failure	0	0.0
Impotence/Priapism	0	0.0
Kidney Problems	1	3.8
Leg Ulcers	0	0.0
Osteosclerosis (Hip/Joint replacement problems)	4	15.4
Painful crises	25	100
Vison problems	8	30.8
Other	0	0.0

Note. N = Sample size

Table 3

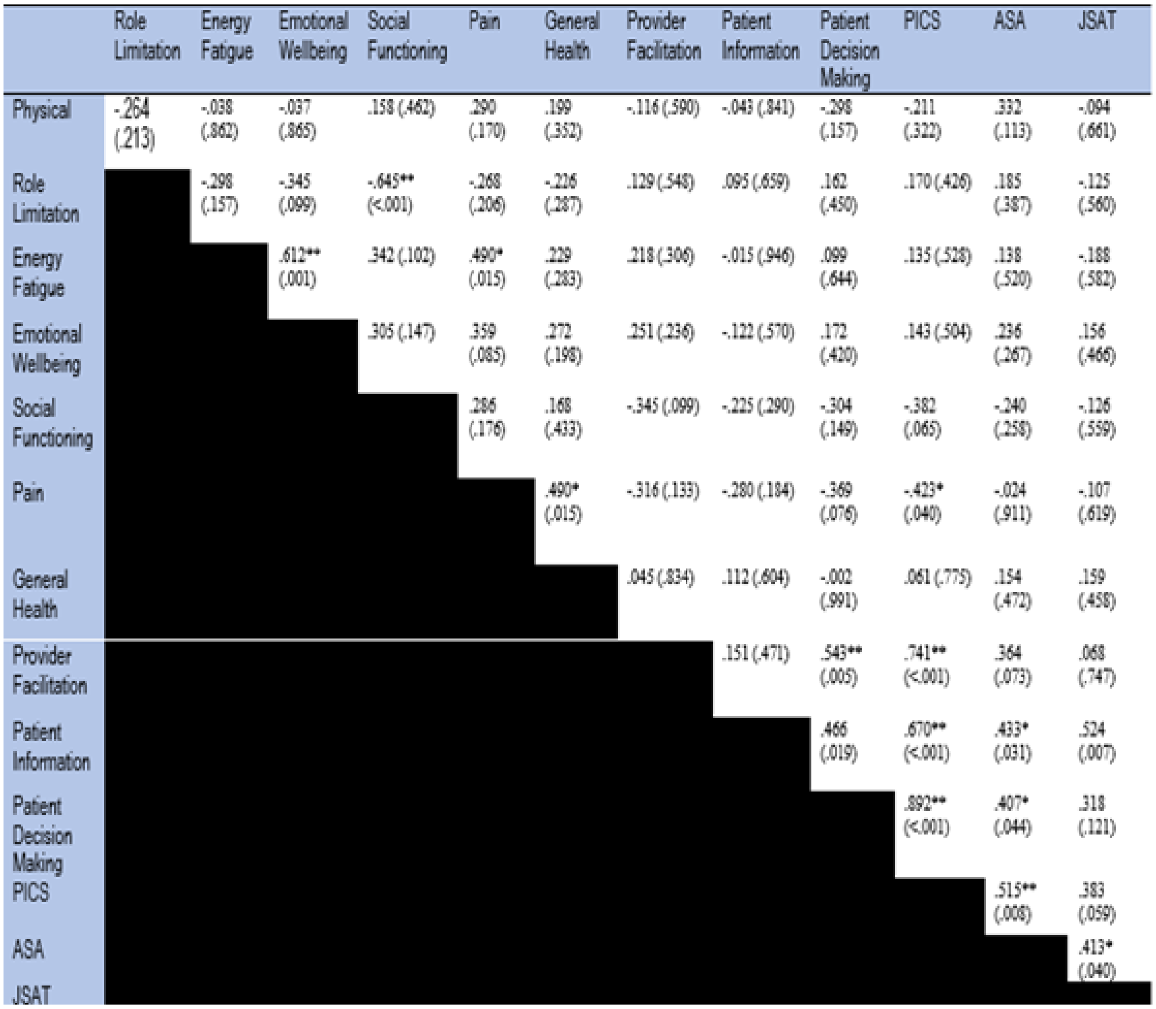
Descriptive Statistics
N=24 for SF- 36; N=25 for PICS, ASA, & J-SAT

SCALE	MEAN	SD	CRONBACH'S ALPHA	POSSIBLE RAGE
Physical	73.96	4.81	0.892	0 - 1000
Role Limitation	48.61	8.27	0.751	0 - 300
Energy/Fatigue	2.08	3.75	0.614	0 - 400
Emotional Well being	60.83	4.09	0.760	0 - 500
Social Functioning	51.04	6.64	NA	0 - 100
Pain	53.13	5.72	0.915	0 - 200
General Health	49.17	3.90	0.624	0 - 400
Provider Facilitation	3.83	0.27	0.650	0 - 5
Provider Information	3.25	0.25	0.780	0 - 4
Patient Decision Making	1.92	0.31	0.807	0 - 4
PICS	9.00	0.64	0.828	0 - 13
ASA	91.83	2.01	0.788	24 - 120
J-SAT	28.63	0.58	0.663	8 - 32

Note. N = Sample size; SD = Standard deviation; SF-36 = Short Form Health Outcome Survey; PICS = Perceived Involvement in Care Scale; ASA = Appraisal of Self-Care Agency Scale; Jenerette Self-Care Assessment Too

Table 4

Correlations

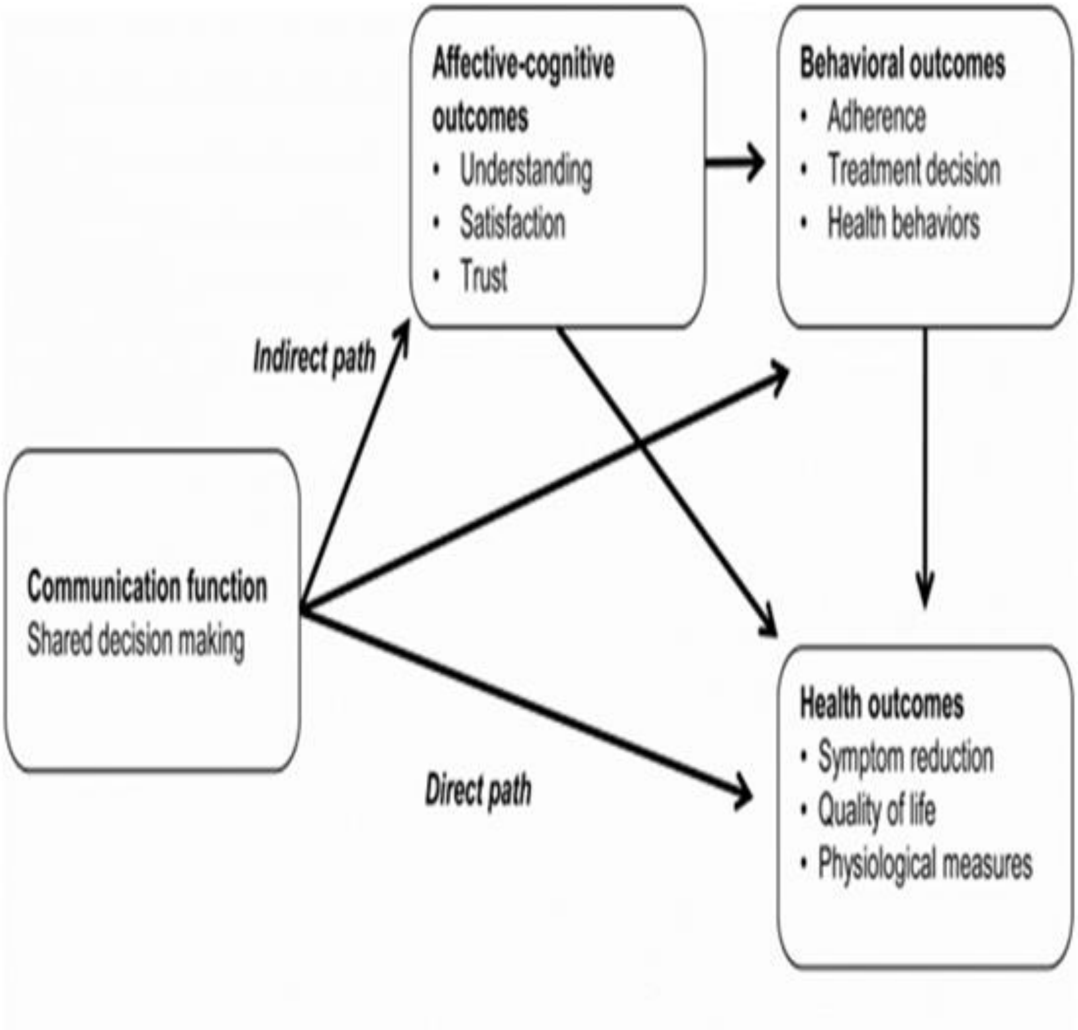


	Role Limitation	Energy Fatigue	Emotional Wellbeing	Social Functioning	Pain	General Health	Provider Facilitation	Patient Information	Patient Decision Making	PICS	ASA	JSAT
Physical	-.264 (.213)	-.038 (.862)	-.037 (.865)	.158 (.462)	.290 (.170)	.199 (.352)	-.116 (.590)	-.043 (.841)	-.298 (.157)	-.211 (.322)	.332 (.113)	-.094 (.661)
Role Limitation		-.298 (.157)	-.345 (.099)	-.645** (<.001)	-.268 (.206)	-.226 (.287)	.129 (.548)	.095 (.659)	.162 (.450)	.170 (.426)	.185 (.387)	-.125 (.560)
Energy Fatigue			.612** (.001)	.342 (.102)	.490* (.015)	.229 (.283)	.218 (.306)	-.015 (.946)	.099 (.644)	.135 (.528)	.138 (.520)	-.188 (.582)
Emotional Wellbeing				.305 (.147)	.359 (.085)	.272 (.198)	.251 (.236)	-.122 (.570)	.172 (.420)	.143 (.504)	.236 (.267)	.156 (.466)
Social Functioning					.286 (.176)	.168 (.433)	-.345 (.099)	-.225 (.290)	-.304 (.149)	-.382 (.065)	-.240 (.258)	-.126 (.559)
Pain						.490* (.015)	-.316 (.133)	-.280 (.184)	-.369 (.076)	-.423* (.040)	-.024 (.911)	-.107 (.619)
General Health							.045 (.834)	.112 (.604)	-.002 (.991)	.061 (.775)	.154 (.472)	.159 (.458)
Provider Facilitation								.151 (.471)	.543** (.005)	.741** (<.001)	.364 (.073)	.068 (.747)
Patient Information									.466 (.019)	.670** (<.001)	.433* (.031)	.524 (.007)
Patient Decision Making										.892** (<.001)	.407* (.044)	.318 (.121)
PICS											.515** (.008)	.383 (.059)
ASA												.413* (.040)
JSAT												

Note. **Correlation is significant at the 0.01 level (2-tailed)
*Correlation is significant at the 0.05 level (2-tailed)

Figure 1

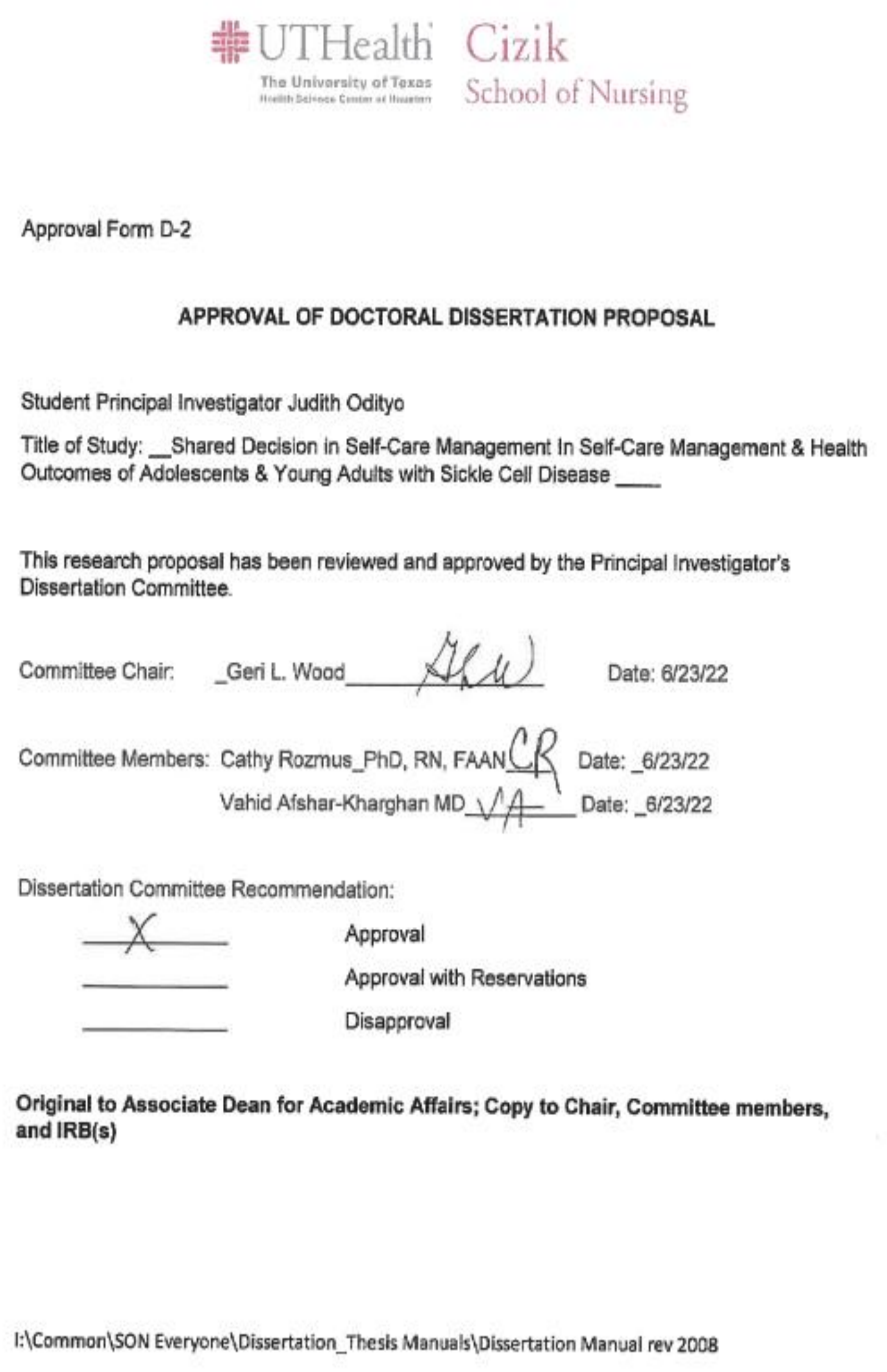
Conceptual Framework Linking SDM to Patient Outcomes



(Street et al., 2009).

Appendix A

Approval of Proposal by Dissertation Committee (D2 Form)



UTHealth Cizik
The University of Texas Health Science Center at Houston School of Nursing

Approval Form D-2

APPROVAL OF DOCTORAL DISSERTATION PROPOSAL

Student Principal Investigator Judith Odityo

Title of Study: __Shared Decision in Self-Care Management In Self-Care Management & Health Outcomes of Adolescents & Young Adults with Sickle Cell Disease ____

This research proposal has been reviewed and approved by the Principal Investigator's Dissertation Committee.

Committee Chair: _Geri L. Wood_ GLW _ Date: 6/23/22

Committee Members: Cathy Rozmus_PhD, RN, FAAN CR Date: _6/23/22
Vahid Afshar-Kharghan MD_ VA _ Date: _6/23/22

Dissertation Committee Recommendation:

_X_ Approval
____ Approval with Reservations
____ Disapproval

Original to Associate Dean for Academic Affairs; Copy to Chair, Committee members, and IRB(s)

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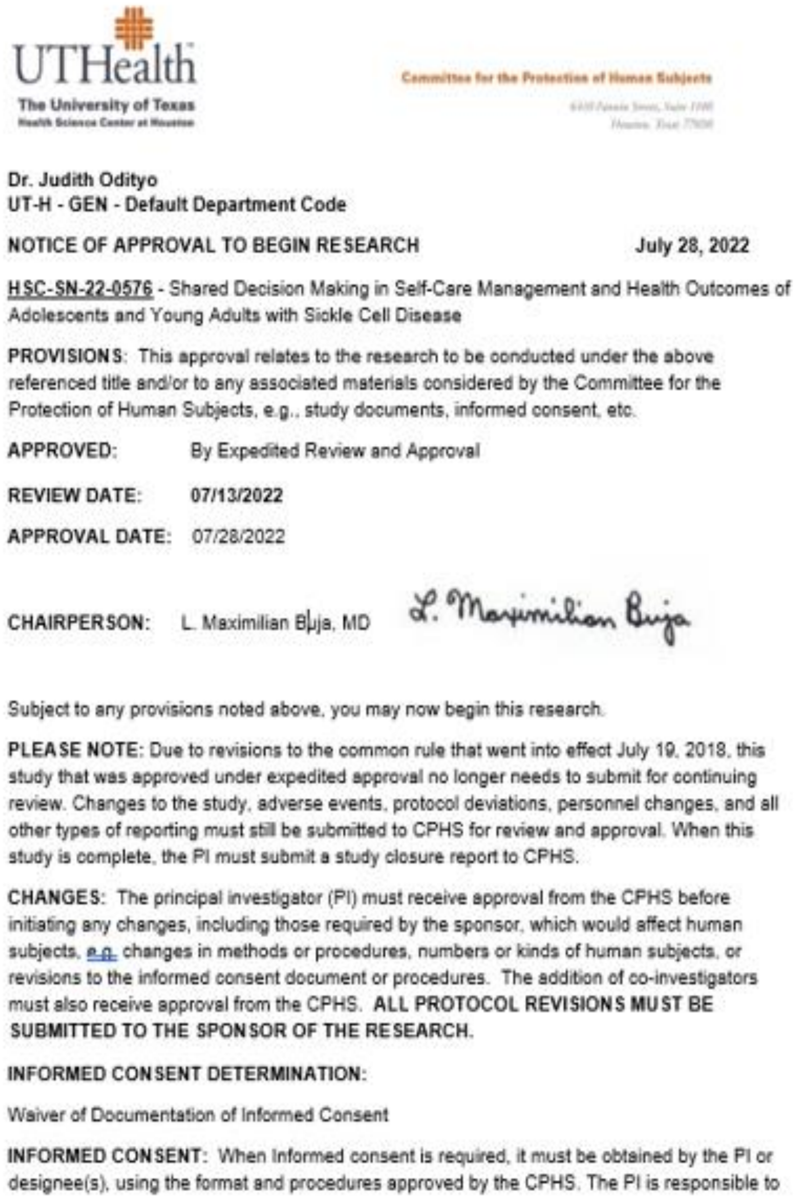
Appendix B

UT Health Science Center at Houston CPHS Approval of Proposal



UTHealth
The University of Texas
Health Science Center at Houston

Committee for the Protection of Human Subjects

Dr. Judith Odityo
UT-H - GEN - Default Department Code

NOTICE OF APPROVAL TO BEGIN RESEARCH **July 28, 2022**

HSC-SN-22-0576 - Shared Decision Making in Self-Care Management and Health Outcomes of Adolescents and Young Adults with Sickle Cell Disease

PROVISIONS: This approval relates to the research to be conducted under the above referenced title and/or to any associated materials considered by the Committee for the Protection of Human Subjects, e.g., study documents, informed consent, etc.

APPROVED: By Expedited Review and Approval

REVIEW DATE: **07/13/2022**

APPROVAL DATE: 07/28/2022

CHAIRPERSON: L. Maximilian Buja, MD L. Maximilian Buja

Subject to any provisions noted above, you may now begin this research.

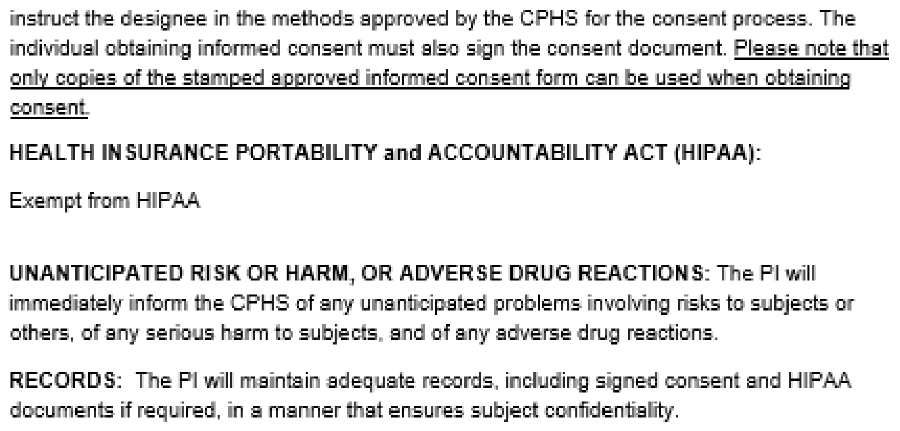
PLEASE NOTE: Due to revisions to the common rule that went into effect July 19, 2018, this study that was approved under expedited approval no longer needs to submit for continuing review. Changes to the study, adverse events, protocol deviations, personnel changes, and all other types of reporting must still be submitted to CPHS for review and approval. When this study is complete, the PI must submit a study closure report to CPHS.

CHANGES: The principal investigator (PI) must receive approval from the CPHS before initiating any changes, including those required by the sponsor, which would affect human subjects, e.g. changes in methods or procedures, numbers or kinds of human subjects, or revisions to the informed consent document or procedures. The addition of co-investigators must also receive approval from the CPHS. **ALL PROTOCOL REVISIONS MUST BE SUBMITTED TO THE SPONSOR OF THE RESEARCH.**

INFORMED CONSENT DETERMINATION:

Waiver of Documentation of Informed Consent

INFORMED CONSENT: When Informed consent is required, it must be obtained by the PI or designee(s), using the format and procedures approved by the CPHS. The PI is responsible to



instruct the designee in the methods approved by the CPHS for the consent process. The individual obtaining informed consent must also sign the consent document. Please note that only copies of the stamped approved informed consent form can be used when obtaining consent.

HEALTH INSURANCE PORTABILITY and ACCOUNTABILITY ACT (HIPAA):

Exempt from HIPAA

UNANTICIPATED RISK OR HARM, OR ADVERSE DRUG REACTIONS: The PI will immediately inform the CPHS of any unanticipated problems involving risks to subjects or others, of any serious harm to subjects, and of any adverse drug reactions.

RECORDS: The PI will maintain adequate records, including signed consent and HIPAA documents if required, in a manner that ensures subject confidentiality.

Appendix C

IRB Approved Flyer for Study

UTHealth Houston
Cizik School of Nursing

RECRUITIING PARTICIPANTS FOR A RESEARCH STUDY

What is this Study about?

- Identifying the perceived involvement of adolescents and young adults with sickle cell disease in the shared decision making process
- Examining the role of shared decision making in selfcare management and health outcomes of adolescents and young adults with sickle cell disease

Why Participate?

- You will contribute toward a better understanding of the nature of interactions between adolescents and young adults with sickle cell disease and their healthcare providers
- You will contribute to the decision-making literature and the body of science that guides disease management via shared decision making
- You will contribute to the identification of elements of the shared decision making process that can be used as the basis for curriculum development in patient-provider sickle cell education programs
- You will be compensated for participating

Who can Participate?

- Adolescents and young adults with sickle cell disease, ages 18 to 26 years old
- Currently enrolled at the UT Physician Comprehensive Sickle Cell Center for routine health maintenance visits

IF YOU WISH TO PARTICPATE, PLEASE SCAN THE QR CODE BELOW TO FIND OUT IF YOU QUALIFY.

SCAN ME

FOR MORE INFORMATION OR QUESTIONS ABOUT THIS RESEARCH PLEASE CONTACT:

Judith odityo at: XXX-XXX-XXXX or
JUDITH.M.ODITYO@UTH.TMC.EDU

UTHealth The University of Texas

IRB NUMBER: HSC-SN-22-0576
IRB APPROVAL DATE: 07/28/2022

Appendix D

Approved Letter of Invitation for Study

UTHealth
The University of Texas
Health Science Center at Houston

LETTER OF INFORMATION TO TAKE PART IN RESEARCH

Study Title: Shared Decision Making in Self-Care Management and Health Outcomes of Adolescents and Young Adults with Sickle Cell Disease.

Principal Investigator: Judith Odityo, MSN, MBA, RN, CPN; UT Health Houston - Cizik School of Nursing.

IRB Number: HSC-SN-22-0576

The purpose of this study is to survey adolescents and young adults with sickle cell disease to understand their interaction with healthcare providers. The study will also examine the association of these interactions with self-care management and health outcomes of adolescents and young adults with sickle cell disease.

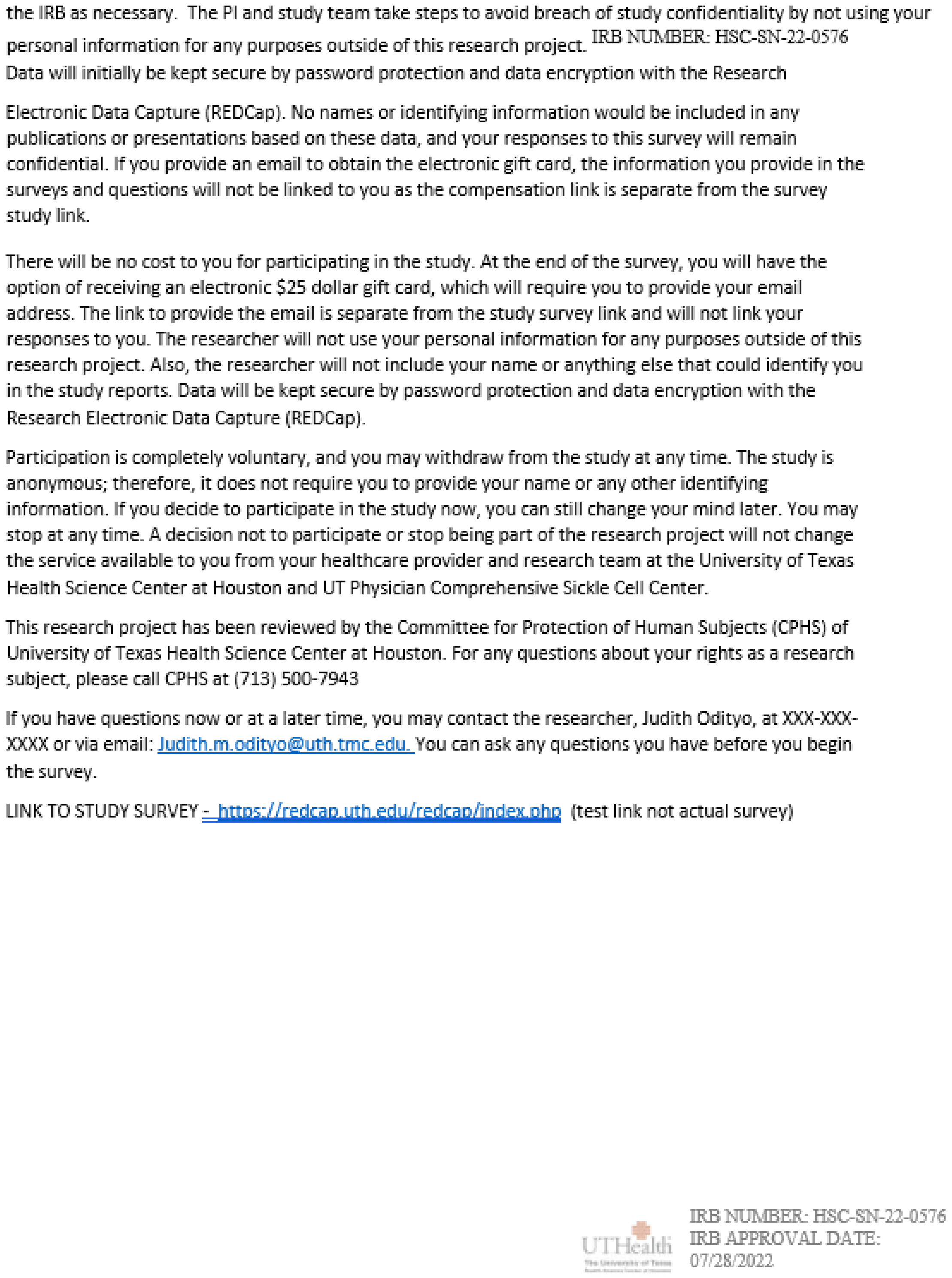
You are invited to participate in the study because you are either an adolescent or young adult with a diagnosis of sickle cell disease. To be eligible for the study you must also be (1) 18 to 26 years old; (2) have a diagnosis of one of the four sickle cell disease genotypes; (3) be enrolled at the UT Physician comprehensive sickle cell center for routine health maintenance visits; (4) be able to read and write in English; and (5) be willing and able to consent and complete the questionnaires.

This study will help us to better understand the nature of interactions between adolescent or young adult with sickle cell disease and healthcare providers; the decision-making literature; the body of science that guides disease management via shared decision making; and identification of elements of the shared decision making process that can be used as the basis for curriculum development in both patient-provider sickle cell education programs.

If you agree to participate in the study, you will be asked to complete a brief questionnaire about your age; gender; years of school completed by you; years of schooling completed by your father; employment status; marital status; housing status; living situation; and a health history form. You will also complete four, one time surveys: (1) The Perceived Involvement in Care Scale; (2) The Appraisal of Self-Care Agency Scale; (3) The Jenerette Self-Care Assessment Tool; and (4) The Medical Outcomes Study (MOS) short form (SF-36) Questionnaire. The estimated time to complete the survey is 40 minutes.

There are no foreseeable risks involved in participating in this study other than those encountered in daily life such as stress, discomfort, fatigue, and concerns. Specifically, some of the survey questions that ask about self-care and disease management may be distressing to you as you think about your experiences. Questions asking how your healthcare provider involves you in your care may cause concerns about your relationship with your healthcare providers. Being in this study will not pose risk to your safety or wellbeing.

It is anticipated there will be a very small chance of a breach of confidentiality and names and identities might be accidentally disclosed. Identified confidentiality breaches will be reviewed by the research team and reported to



the IRB as necessary. The PI and study team take steps to avoid breach of study confidentiality by not using your personal information for any purposes outside of this research project. IRB NUMBER: HSC-SN-22-0576
Data will initially be kept secure by password protection and data encryption with the Research

Electronic Data Capture (REDCap). No names or identifying information would be included in any publications or presentations based on these data, and your responses to this survey will remain confidential. If you provide an email to obtain the electronic gift card, the information you provide in the surveys and questions will not be linked to you as the compensation link is separate from the survey study link.

There will be no cost to you for participating in the study. At the end of the survey, you will have the option of receiving an electronic $25 dollar gift card, which will require you to provide your email address. The link to provide the email is separate from the study survey link and will not link your responses to you. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure by password protection and data encryption with the Research Electronic Data Capture (REDCap).

Participation is completely voluntary, and you may withdraw from the study at any time. The study is anonymous; therefore, it does not require you to provide your name or any other identifying information. If you decide to participate in the study now, you can still change your mind later. You may stop at any time. A decision not to participate or stop being part of the research project will not change the service available to you from your healthcare provider and research team at the University of Texas Health Science Center at Houston and UT Physician Comprehensive Sickle Cell Center.

This research project has been reviewed by the Committee for Protection of Human Subjects (CPHS) of University of Texas Health Science Center at Houston. For any questions about your rights as a research subject, please call CPHS at (713) 500-7943

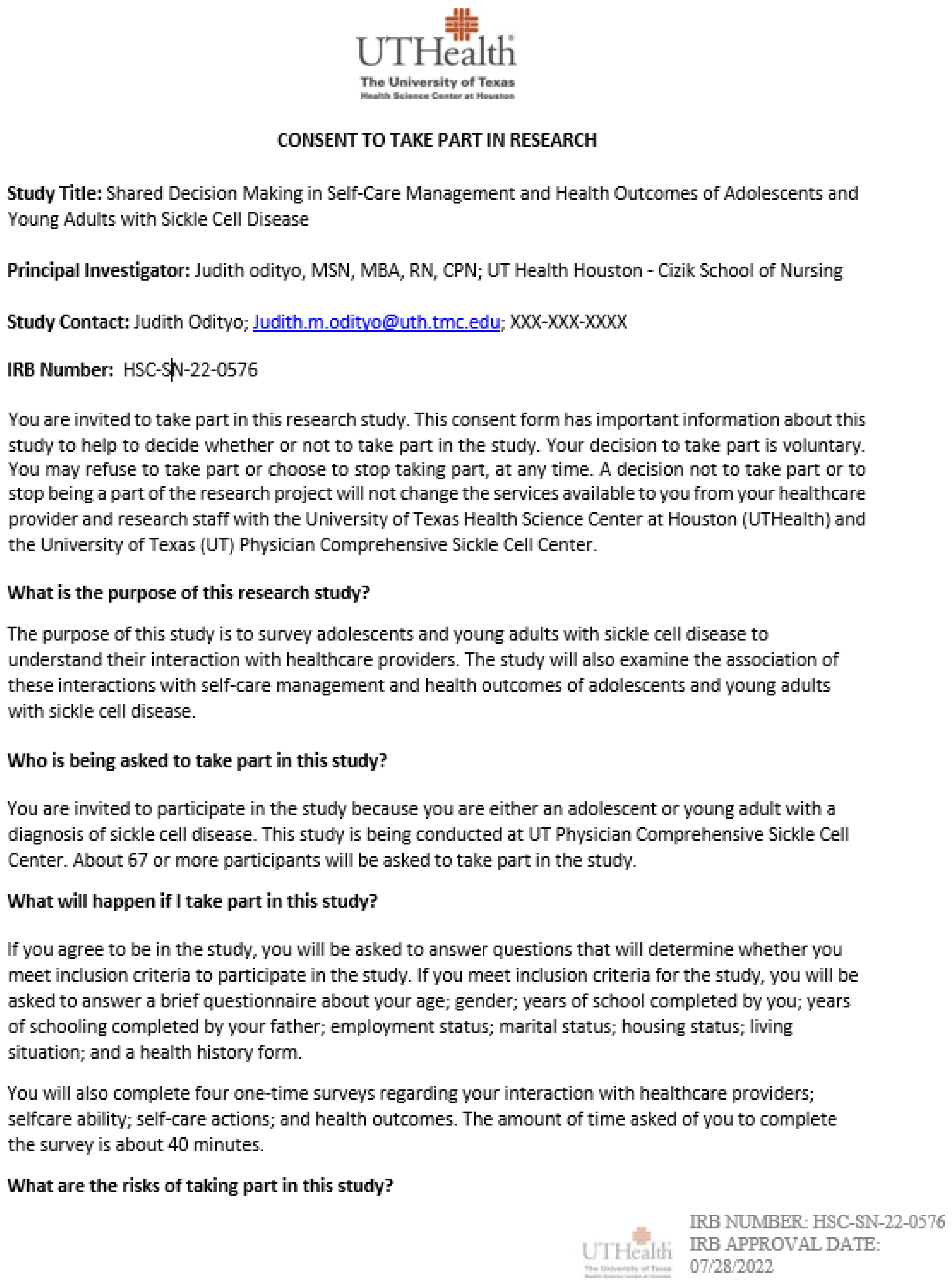
If you have questions now or at a later time, you may contact the researcher, Judith Odityo, at XXX-XXX-XXXX or via email: Judith.m.odityo@uth.tmc.edu. You can ask any questions you have before you begin the survey.

LINK TO STUDY SURVEY - https://redcap.uth.edu/redcap/index.php (test link not actual survey)

IRB NUMBER: HSC-SN-22-0576
IRB APPROVAL DATE: 07/28/2022

Appendix E

Consent Form



UTHealth
The University of Texas
Health Science Center at Houston

CONSENT TO TAKE PART IN RESEARCH

Study Title: Shared Decision Making in Self-Care Management and Health Outcomes of Adolescents and Young Adults with Sickle Cell Disease

Principal Investigator: Judith odityo, MSN, MBA, RN, CPN; UT Health Houston - Cizik School of Nursing

Study Contact: Judith Odityo; Judith.m.odityo@uth.tmc.edu; XXX-XXX-XXXX

IRB Number: HSC-SN-22-0576

You are invited to take part in this research study. This consent form has important information about this study to help to decide whether or not to take part in the study. Your decision to take part is voluntary. You may refuse to take part or choose to stop taking part, at any time. A decision not to take part or to stop being a part of the research project will not change the services available to you from your healthcare provider and research staff with the University of Texas Health Science Center at Houston (UTHealth) and the University of Texas (UT) Physician Comprehensive Sickle Cell Center.

What is the purpose of this research study?

The purpose of this study is to survey adolescents and young adults with sickle cell disease to understand their interaction with healthcare providers. The study will also examine the association of these interactions with self-care management and health outcomes of adolescents and young adults with sickle cell disease.

Who is being asked to take part in this study?

You are invited to participate in the study because you are either an adolescent or young adult with a diagnosis of sickle cell disease. This study is being conducted at UT Physician Comprehensive Sickle Cell Center. About 67 or more participants will be asked to take part in the study.

What will happen if I take part in this study?

If you agree to be in the study, you will be asked to answer questions that will determine whether you meet inclusion criteria to participate in the study. If you meet inclusion criteria for the study, you will be asked to answer a brief questionnaire about your age; gender; years of school completed by you; years of schooling completed by your father; employment status; marital status; housing status; living situation; and a health history form.

You will also complete four one-time surveys regarding your interaction with healthcare providers; selfcare ability; self-care actions; and health outcomes. The amount of time asked of you to complete the survey is about 40 minutes.

What are the risks of taking part in this study?

IRB NUMBER: HSC-SN-22-0576
IRB APPROVAL DATE: 07/28/2022

There are no foreseeable risks involved in participating in this study other than those encountered in daily life such as stress, discomfort, and fatigue. Specifically, some of the survey questions that ask about self-care and disease management may be distressing to you as you think about your experiences.

Questions asking how your healthcare provider involves you in your care may cause concerns about your relationship with your healthcare providers. Being in this study will not pose risk to your safety or wellbeing.

It is anticipated there will be a very small chance of a breach of confidentiality and names and identities might be accidentally disclosed. Identified confidentiality breaches will be reviewed by the research team and reported to the IRB as necessary. The PI and study team take steps to avoid breach of study confidentiality by not using your personal information for any purposes outside of this research project. Data will initially be kept secure by password protection and data encryption with the Research Electronic Data Capture (REDCap). No names or identifying information would be included in any publications or presentations based on these data, and your responses to this survey will remain confidential. If you provide an email to obtain the electronic gift card, the information you provide in the surveys and questions will not be linked to you as the compensation link is separate from the survey study link.

What are the benefits to taking part in this study?

There are no direct benefits to taking part in the study. However, your participation in the research will contribute toward a better understanding of the nature of interactions between adolescents and young adults with sickle cell disease and healthcare providers; the decision-making literature; the body of science that guides disease management via shared decision making; and identification of elements of the shared decision making process that can be used as the basis for curriculum development in patient provider sickle cell education programs.

Subject compensation

You will be compensated a $25 electronic gift card for completion of all the surveys and questions.

Can you stop taking part in this study?

You may decide to stop taking part in the study at any time. To withdraw from the study, you may either discontinue completing the online survey or please contact the primary investigator, Judith Odityo, at

XXX-XXX-XXXX.

If you stop participating in this study after submitting the survey, the information already collected about you will still be used in the data analysis. However, no further information will be collected without your permission.

What are the costs of taking part in this study?

There are no costs in taking part in the study.

How will privacy and confidentiality be protected?

Your privacy is important and your participation in this study will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Data will initially be kept secure by password protection and data encryption with the Research Electronic Data Capture (REDCap). No names or identifying information would be included in any publications or presentations based on these data, and your responses to this survey will remain confidential. If you provide your email to obtain the electronic gift card, the information you provide in the surveys and questions will not be linked to you as the compensation link is separate from the survey study link.

Who can I contact if I have questions about the study?

If you have questions at any time about this research study, please feel free to contact the primary investigator, Judith Odityo at 281-460-2284; as they will be glad to answer your questions. You can contact the primary investigator to discuss problems, voice concerns, obtain information in addition to asking questions about the research.

The Committee for Protection of Human Subjects at the University of Texas Health Science Center has reviewed this research study. You may contact them for any questions about your rights as a research subject, and to discuss any concerns, comments or complaints about taking part in a research study at (713) 500-7943.

Please select your choice below.

☐ Agree to participate in the study

☐ Disagree to participate in the study

Contact Name: Judith Odityo
Telephone: XXX-XXX-XXXX

Appendix F

Demographic Questionnaire – Original

Demographic Questionnaire

1. Age: ____________
2. Gender (Select your response): **1. Female** **2. Male**
3. What is the number of years of schooling completed? (Select your response)

   Elementary/Intermediate: **01 02 03 04 05 06 07 08 09**

   High School: **09 10 11 12**

   Technical College (Associate Degree): **13 14**

   4-Year College (Bachelor's Degree): 13 **14 15 16**

   Graduate School (Master's Degree): 17 **18**

   Doctorate: **19 20 21**
4. What is the number of years of schooling completed by <u>your father</u>? (Select your response):

   Elementary/Intermediate: **01 02 03 04 05 06 07 08 09**

   High School: **09 10 11 12**

   Technical College (Associate Degree): **13 14**

   4-Year College (Bachelor's Degree): **13 14 15 16**

   Graduate School (Master's Degree): **17 18**

   Doctorate: **19 20 21**
5. Are you currently working a paying job? (Select your response):

1. Yes, full-time
2. Yes, part-time
3. No, not employed
4. No, not employed (disabled)

6. What is your current marital status? (Select your response):

1. Single/never married
2. Married
3. Divorced
4. Widowed
5. Separated

7. Which best describes your current housing situation? (Select your response):

1. Rent
2. Own

8. Which best describes your living situation? (Select your response):

1. I live alone
2. I share housing with my family.
3. I share housing with friends

9. What is your zip code? __________________________

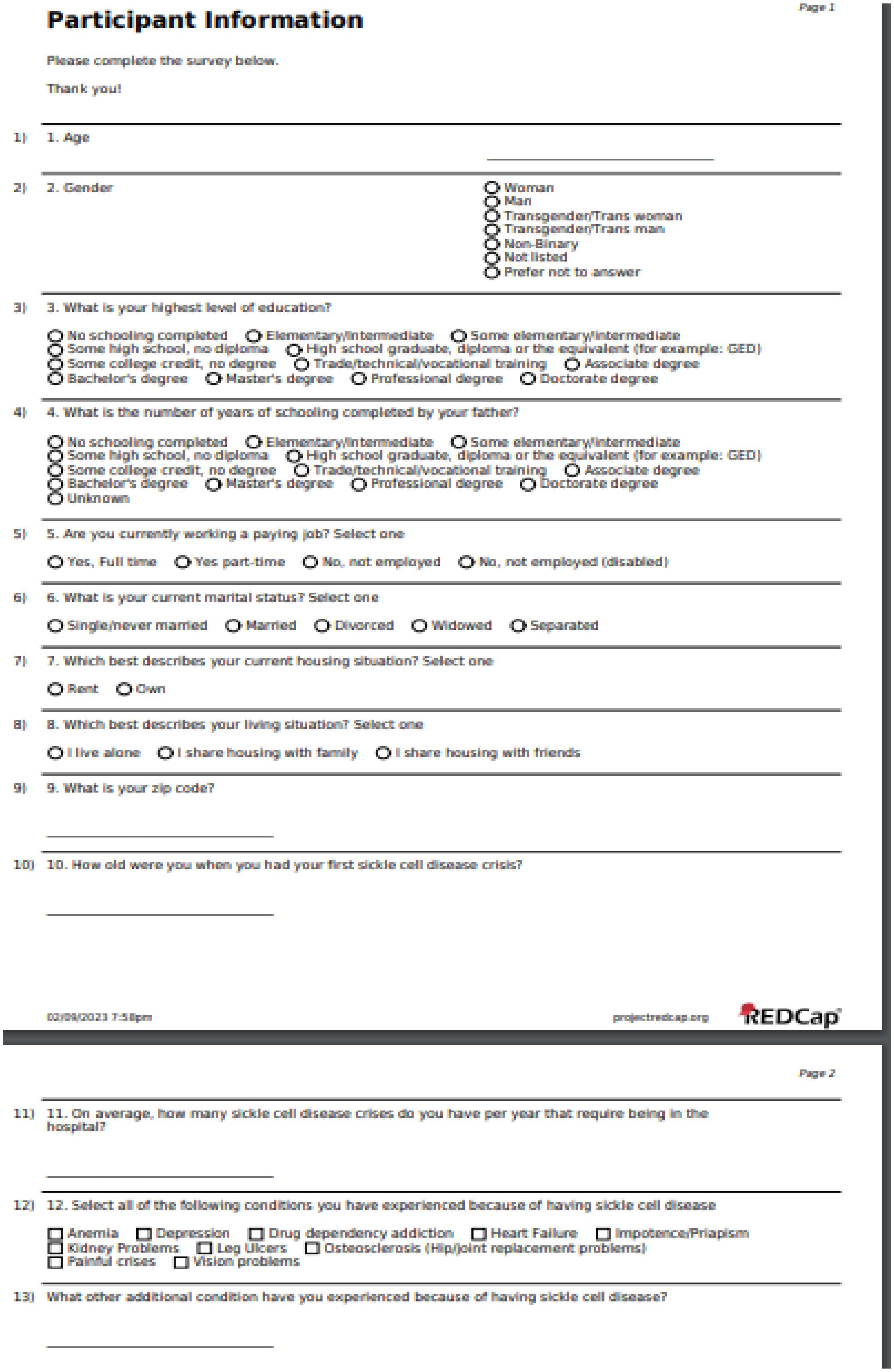
10. How old were you when you had your first sickle cell disease crisis? _________Years Old
11. On average, how many sickle cell disease crises do you have per year that require being in the hospital? __________________________________
12. Select all of the following conditions you have experienced because of having sickle cell disease

1. Anemia
2. Depression
3. Drug dependency addiction
4. Heart Failure
5. Impotence/Priapism
6. Kidney Problems
7. Leg Ulcers
8. Osteosclerosis (Hip/joint replacement problems)
9. Painful crises
10. Vision problems
11. Other ____

Jenerette & Murdaugh (2008)

Appendix G

Demographic Questionnaire - REDCap



Page 1

Participant Information

Please complete the survey below.

Thank you!

1) 1. Age

2) 2. Gender

○ Woman
○ Man
○ Transgender/Trans woman
○ Transgender/Trans man
○ Non-Binary
○ Not listed
○ Prefer not to answer

3) 3. What is your highest level of education?

○ No schooling completed ○ Elementary/Intermediate ○ Some elementary/intermediate
○ Some high school, no diploma ○ High school graduate, diploma or the equivalent (for example: GED)
○ Some college credit, no degree ○ Trade/technical/vocational training ○ Associate degree
○ Bachelor's degree ○ Master's degree ○ Professional degree ○ Doctorate degree

4) 4. What is the number of years of schooling completed by your father?

○ No schooling completed ○ Elementary/Intermediate ○ Some elementary/intermediate
○ Some high school, no diploma ○ High school graduate, diploma or the equivalent (for example: GED)
○ Some college credit, no degree ○ Trade/technical/vocational training ○ Associate degree
○ Bachelor's degree ○ Master's degree ○ Professional degree ○ Doctorate degree
○ Unknown

5) 5. Are you currently working a paying job? Select one

○ Yes, Full time ○ Yes part-time ○ No, not employed ○ No, not employed (disabled)

6) 6. What is your current marital status? Select one

○ Single/never married ○ Married ○ Divorced ○ Widowed ○ Separated

7) 7. Which best describes your current housing situation? Select one

○ Rent ○ Own

8) 8. Which best describes your living situation? Select one

○ I live alone ○ I share housing with family ○ I share housing with friends

9) 9. What is your zip code?

10) 10. How old were you when you had your first sickle cell disease crisis?

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11) 11. On average, how many sickle cell disease crises do you have per year that require being in the hospital?

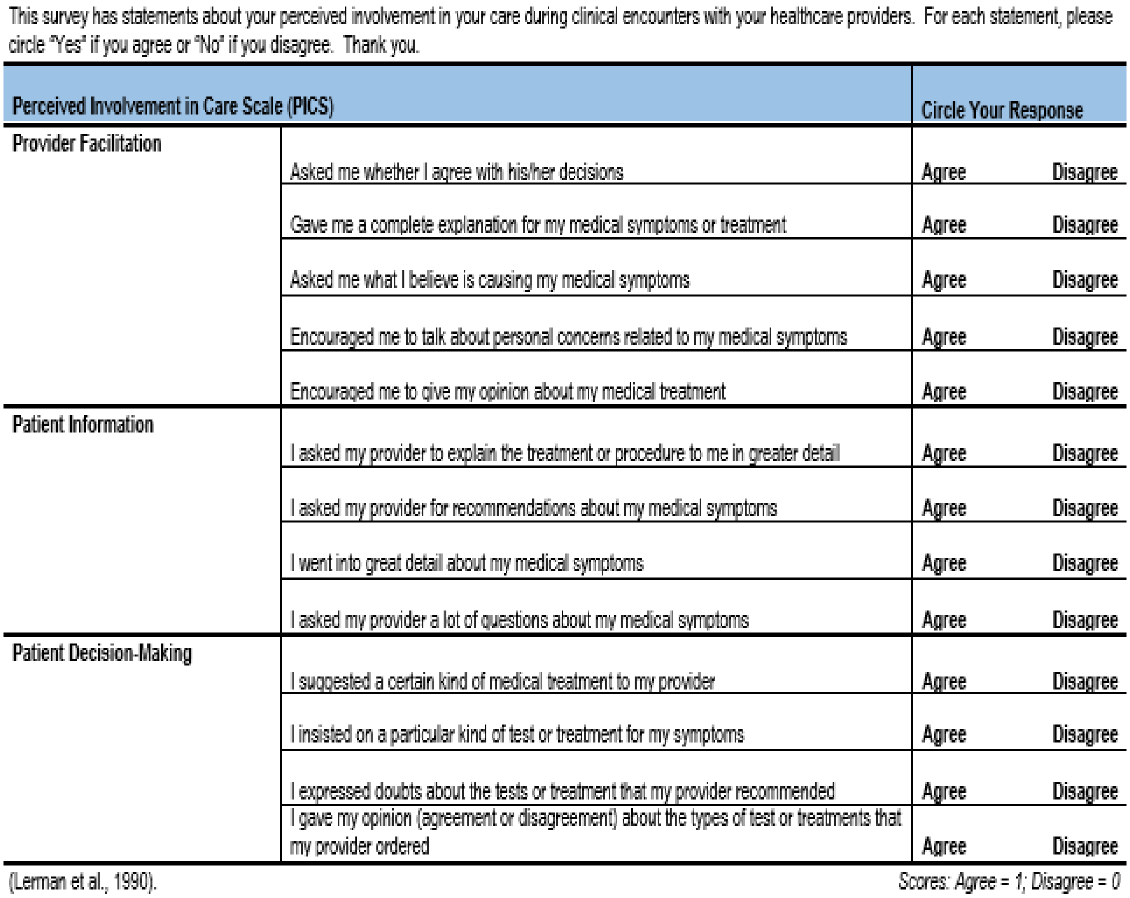
12) 12. Select all of the following conditions you have experienced because of having sickle cell disease

☐ Anemia ☐ Depression ☐ Drug dependency addiction ☐ Heart Failure ☐ Impotence/Priapism
☐ Kidney Problems ☐ Leg Ulcers ☐ Osteosclerosis (Hip/joint replacement problems)
☐ Painful crises ☐ Vision problems

13) What other additional condition have you experienced because of having sickle cell disease?

Appendix H

Perceived Involvement in Care Scale (PICS) - Original



This survey has statements about your perceived involvement in your care during clinical encounters with your healthcare providers. For each statement, please circle "Yes" if you agree or "No" if you disagree. Thank you.

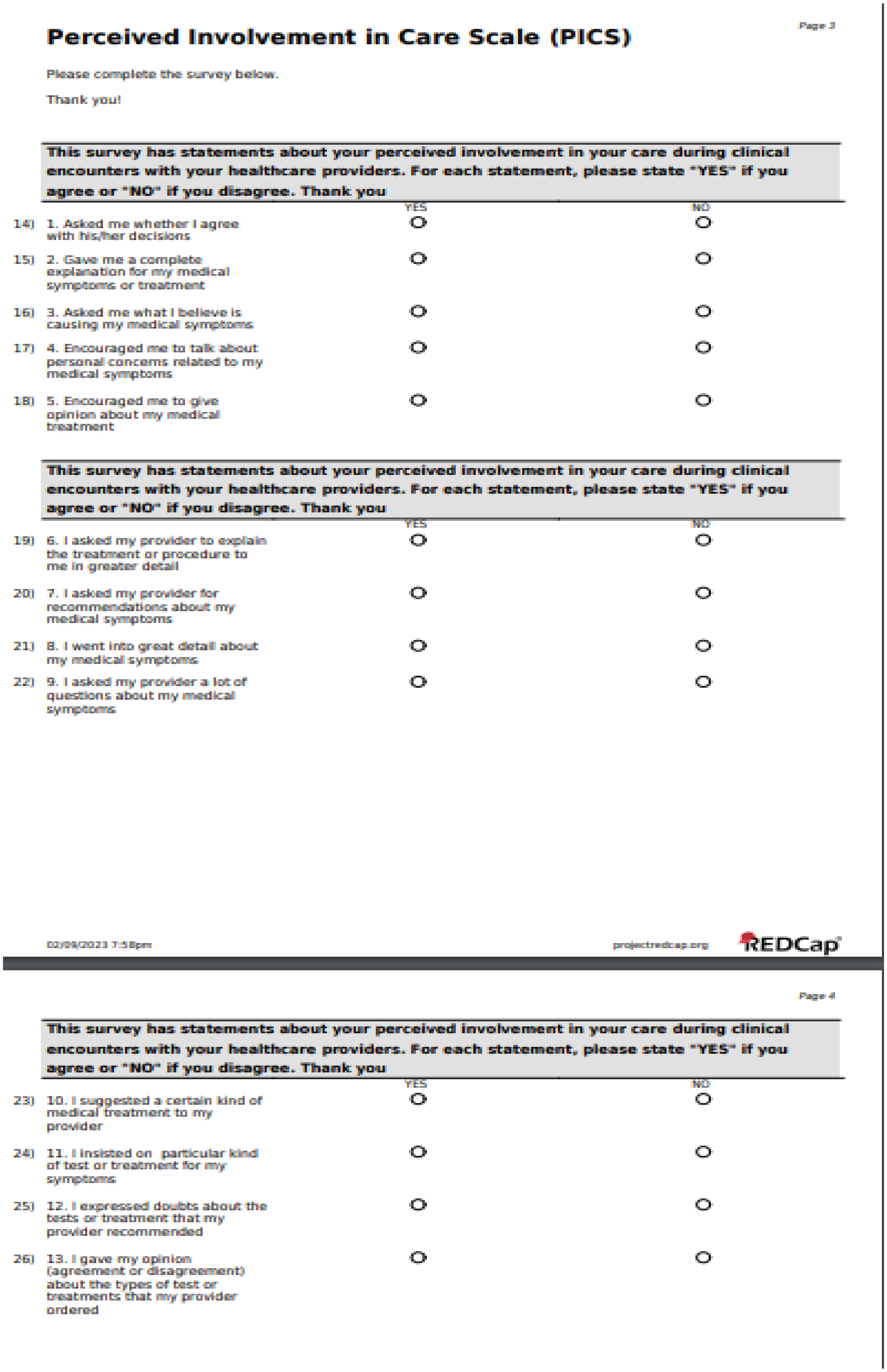
Perceived Involvement in Care Scale (PICS)		**Circle Your Response**	
Provider Facilitation	Asked me whether I agree with his/her decisions	**Agree**	**Disagree**
	Gave me a complete explanation for my medical symptoms or treatment	**Agree**	**Disagree**
	Asked me what I believe is causing my medical symptoms	**Agree**	**Disagree**
	Encouraged me to talk about personal concerns related to my medical symptoms	**Agree**	**Disagree**
	Encouraged me to give my opinion about my medical treatment	**Agree**	**Disagree**
Patient Information	I asked my provider to explain the treatment or procedure to me in greater detail	**Agree**	**Disagree**
	I asked my provider for recommendations about my medical symptoms	**Agree**	**Disagree**
	I went into great detail about my medical symptoms	**Agree**	**Disagree**
	I asked my provider a lot of questions about my medical symptoms	**Agree**	**Disagree**
Patient Decision-Making	I suggested a certain kind of medical treatment to my provider	**Agree**	**Disagree**
	I insisted on a particular kind of test or treatment for my symptoms	**Agree**	**Disagree**
	I expressed doubts about the tests or treatment that my provider recommended	**Agree**	**Disagree**
	I gave my opinion (agreement or disagreement) about the types of test or treatments that my provider ordered	**Agree**	**Disagree**

(Lerman et al., 1990).

Scores: Agree = 1; Disagree = 0

Appendix I

Perceived Involvement in Care Scale (PICS) - REDCap



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Perceived Involvement in Care Scale (PICS)

Please complete the survey below.

Thank you!

This survey has statements about your perceived involvement in your care during clinical encounters with your healthcare providers. For each statement, please state "YES" if you agree or "NO" if you disagree. Thank you

		YES	NO
14)	1. Asked me whether I agree with his/her decisions	○	○
15)	2. Gave me a complete explanation for my medical symptoms or treatment	○	○
16)	3. Asked me what I believe is causing my medical symptoms	○	○
17)	4. Encouraged me to talk about personal concerns related to my medical symptoms	○	○
18)	5. Encouraged me to give opinion about my medical treatment	○	○

This survey has statements about your perceived involvement in your care during clinical encounters with your healthcare providers. For each statement, please state "YES" if you agree or "NO" if you disagree. Thank you

		YES	NO
19)	6. I asked my provider to explain the treatment or procedure to me in greater detail	○	○
20)	7. I asked my provider for recommendations about my medical symptoms	○	○
21)	8. I went into great detail about my medical symptoms	○	○
22)	9. I asked my provider a lot of questions about my medical symptoms	○	○

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This survey has statements about your perceived involvement in your care during clinical encounters with your healthcare providers. For each statement, please state "YES" if you agree or "NO" if you disagree. Thank you

		YES	NO
23)	10. I suggested a certain kind of medical treatment to my provider	○	○
24)	11. I insisted on particular kind of test or treatment for my symptoms	○	○
25)	12. I expressed doubts about the tests or treatment that my provider recommended	○	○
26)	13. I gave my opinion (agreement or disagreement) about the types of test or treatments that my provider ordered	○	○

Appendix J

Appraisal of Self-Care Agency (ASA) Scale - Original

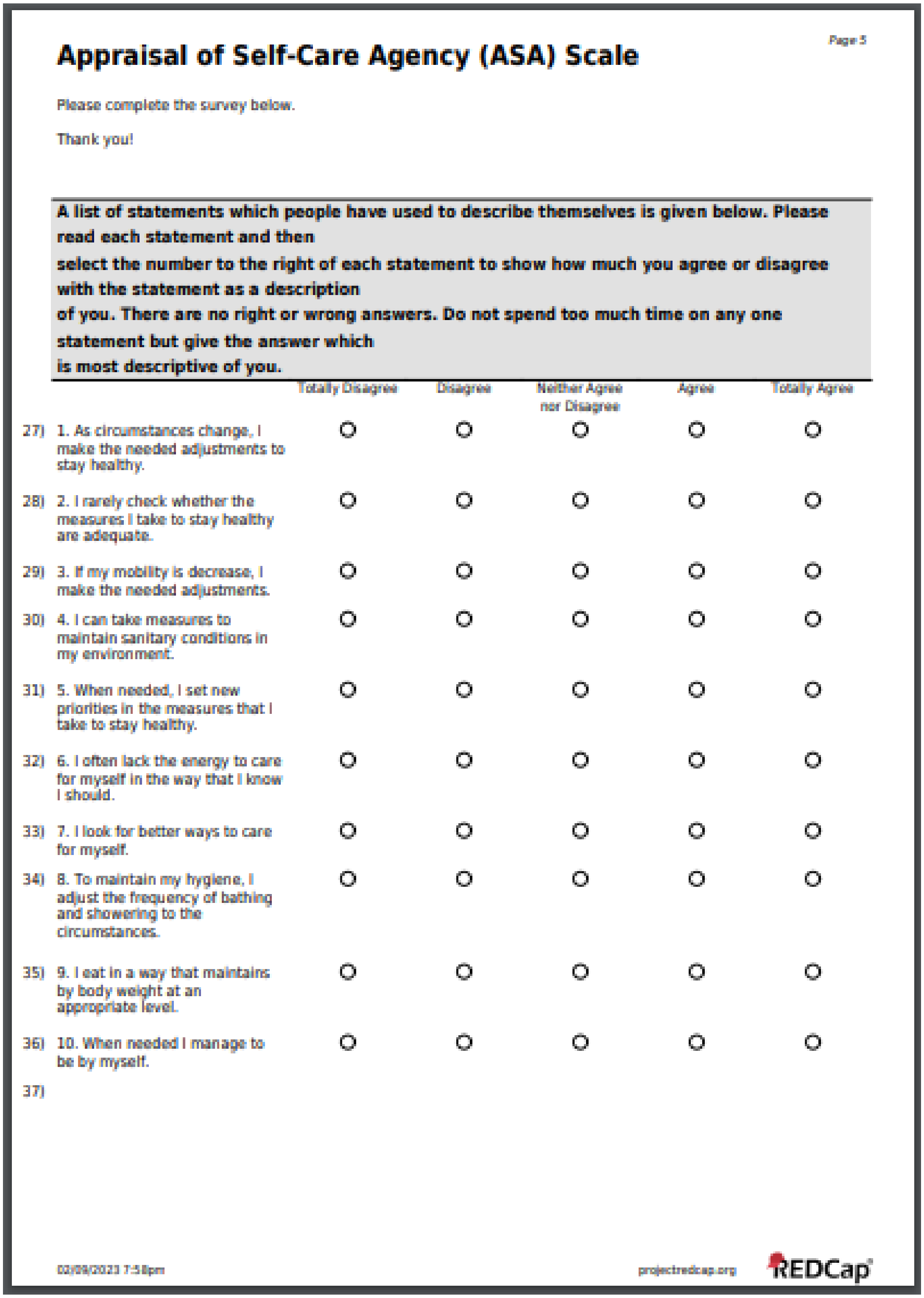
A list of statements which people have used to describe themselves is given below. Please read each statement and then select the number to the right of each statement to show how much you agree or disagree with the statement as a description of you. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which is most descriptive of you.

Statement	**Totally disagree**	**Disagree**	**Neither Agree nor disagree**	**Agree**	**Totally Agree**
1. As circumstances change, I make the needed adjustments to stay healthy.	1	2	3	4	5
2. I rarely check whether the measures I take to stay healthy are adequate.	1	2	3	4	5
3. If my mobility is decrease, I make the needed adjustments.	1	2	3	4	5
4. I can take measures to maintain sanitary conditions in my environment.	1	2	3	4	5
5. When needed, I set new priorities in the measures that I take to stay healthy.	1	2	3	4	5
6. I often lack the energy to care for myself in the way that I know I should.	1	2	3	4	5
7. I look for better ways to care for myself.	1	2	3	4	5
8. To maintain my hygiene, I adjust the frequency of bathing and showering to the circumstances.	1	2	3	4	5
9. I eat in a way that maintains by body weight at an appropriate level.	1	2	3	4	5
10. When needed I manage to be by myself.	1	2	3	4	5
11. I always think about including a program of exercise and rest in my daily routine but never get around to doing it.	1	2	3	4	5
12. Over the years I have developed a circle of friends that I can call upon when I need help.	1	2	3	4	5
13. I rarely get enough sleep to feel rested.	1	2	3	4	5
14. When receiving information about my health, I rarely ask for clarification of language that I do not understand.	1	2	3	4	5
15. I rarely examine my body to determine the presence of any changes.	1	2	3	4	5
16. If I take a new medication, I obtain information about the side effects.	1	2	3	4	5
17. In the past, I have changed some of my old habits in order to improve my health.	1	2	3	4	5
18. I routinely take measures to ensure the safety of myself and my family.	1	2	3	4	5
19. I regularly evaluate the effectiveness of the things that I do stay healthy.	1	2	3	4	5
20. In my daily activities, I rarely take time to care for myself.	1	2	3	4	5
21. I am able to get the information I need, when my health is threatened.	1	2	3	4	5
22. I seek help when unable to care for myself.	1	2	3	4	5
23. I rarely have time for myself.	1	2	3	4	5
24. Due to limited mobility, I am not always able to care for myself in a way I would like to.	1	2	3	4	5

Jenerette & Murdaugh, 2008.

Appendix K

Appraisal of Self-Care Agency (ASA) Scale - REDCap



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Appraisal of Self-Care Agency (ASA) Scale

Please complete the survey below.

Thank you!

A list of statements which people have used to describe themselves is given below. Please read each statement and then
select the number to the right of each statement to show how much you agree or disagree with the statement as a description
of you. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which
is most descriptive of you.

		Totally Disagree	Disagree	Neither Agree nor Disagree	Agree	Totally Agree
27)	1. As circumstances change, I make the needed adjustments to stay healthy.	○	○	○	○	○
28)	2. I rarely check whether the measures I take to stay healthy are adequate.	○	○	○	○	○
29)	3. If my mobility is decrease, I make the needed adjustments.	○	○	○	○	○
30)	4. I can take measures to maintain sanitary conditions in my environment.	○	○	○	○	○
31)	5. When needed, I set new priorities in the measures that I take to stay healthy.	○	○	○	○	○
32)	6. I often lack the energy to care for myself in the way that I know I should.	○	○	○	○	○
33)	7. I look for better ways to care for myself.	○	○	○	○	○
34)	8. To maintain my hygiene, I adjust the frequency of bathing and showering to the circumstances.	○	○	○	○	○
35)	9. I eat in a way that maintains by body weight at an appropriate level.	○	○	○	○	○
36)	10. When needed I manage to be by myself.	○	○	○	○	○
37)						

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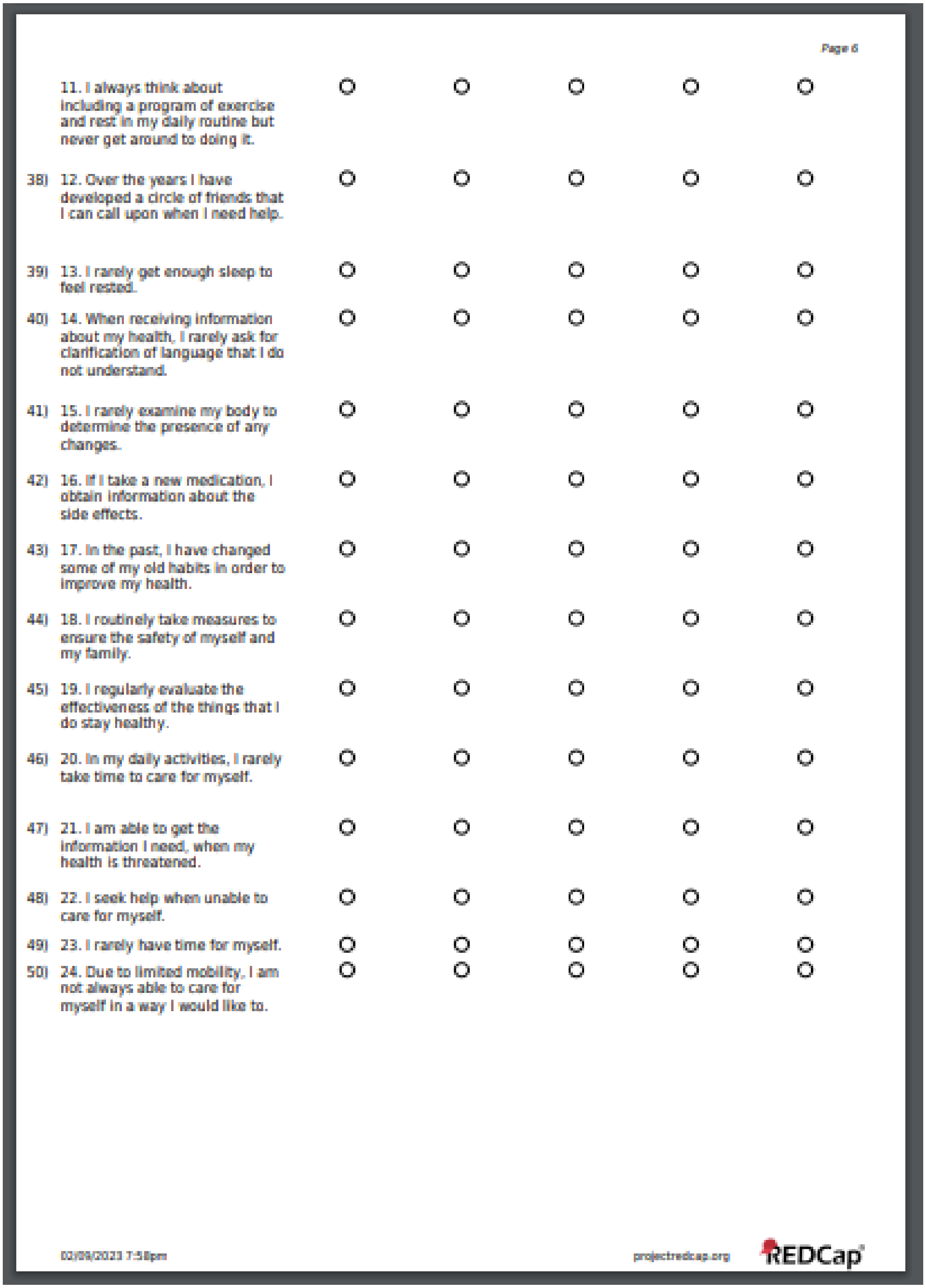

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	11. I always think about including a program of exercise and rest in my daily routine but never get around to doing it.	○	○	○	○	○
38)	12. Over the years I have developed a circle of friends that I can call upon when I need help.	○	○	○	○	○
39)	13. I rarely get enough sleep to feel rested.	○	○	○	○	○
40)	14. When receiving information about my health, I rarely ask for clarification of language that I do not understand.	○	○	○	○	○
41)	15. I rarely examine my body to determine the presence of any changes.	○	○	○	○	○
42)	16. If I take a new medication, I obtain information about the side effects.	○	○	○	○	○
43)	17. In the past, I have changed some of my old habits in order to improve my health.	○	○	○	○	○
44)	18. I routinely take measures to ensure the safety of myself and my family.	○	○	○	○	○
45)	19. I regularly evaluate the effectiveness of the things that I do stay healthy.	○	○	○	○	○
46)	20. In my daily activities, I rarely take time to care for myself.	○	○	○	○	○
47)	21. I am able to get the information I need, when my health is threatened.	○	○	○	○	○
48)	22. I seek help when unable to care for myself.	○	○	○	○	○
49)	23. I rarely have time for myself.	○	○	○	○	○
50)	24. Due to limited mobility, I am not always able to care for myself in a way I would like to.	○	○	○	○	○

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Appendix L

Jenerette Self-Care Assessment Tool (J-SAT) - Original

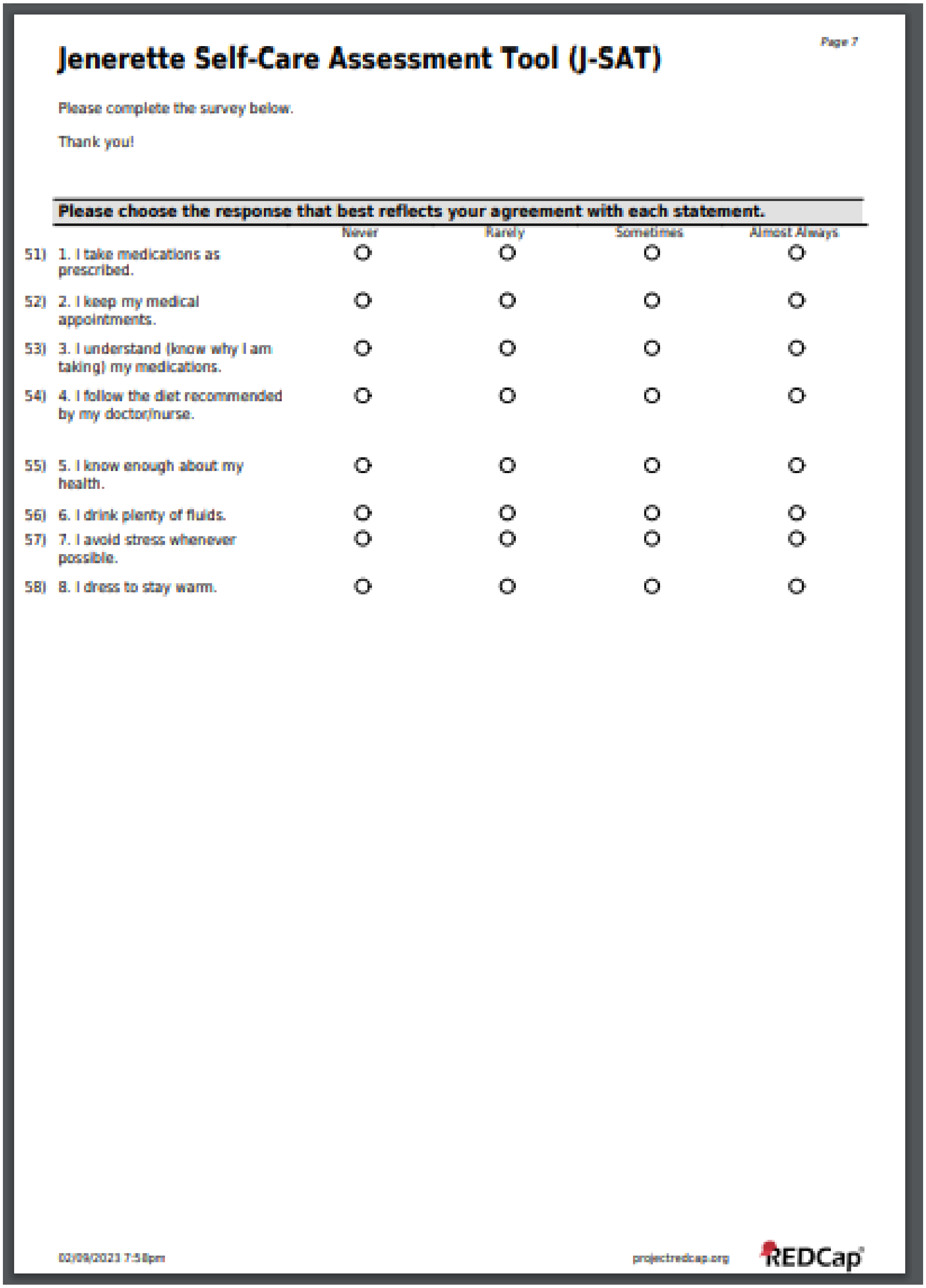
Please choose the response that best reflects your agreement with each statement.

Statement	**Never**	**Rarely**	**Sometimes**	**Almost Always**
I take medications as prescribed.				
I keep my medical appointments.				
I understand (know why I am taking) my medications.				
I follow the diet recommended by my doctor/nurse.				
I know enough about my health.				
I drink plenty of fluids.				
I avoid stress whenever possible.				
I dress to stay warm.				

Jenerette & Murdaugh, 2008.

Appendix M

Jenerette Self-Care Assessment Tool (J-SAT) -REDCap



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Jenerette Self-Care Assessment Tool (J-SAT)

Please complete the survey below.

Thank you!

Please choose the response that best reflects your agreement with each statement.

		Never	Rarely	Sometimes	Almost Always
51)	1. I take medications as prescribed.	○	○	○	○
52)	2. I keep my medical appointments.	○	○	○	○
53)	3. I understand (know why I am taking) my medications.	○	○	○	○
54)	4. I follow the diet recommended by my doctor/nurse.	○	○	○	○
55)	5. I know enough about my health.	○	○	○	○
56)	6. I drink plenty of fluids.	○	○	○	○
57)	7. I avoid stress whenever possible.	○	○	○	○
58)	8. I dress to stay warm.	○	○	○	○

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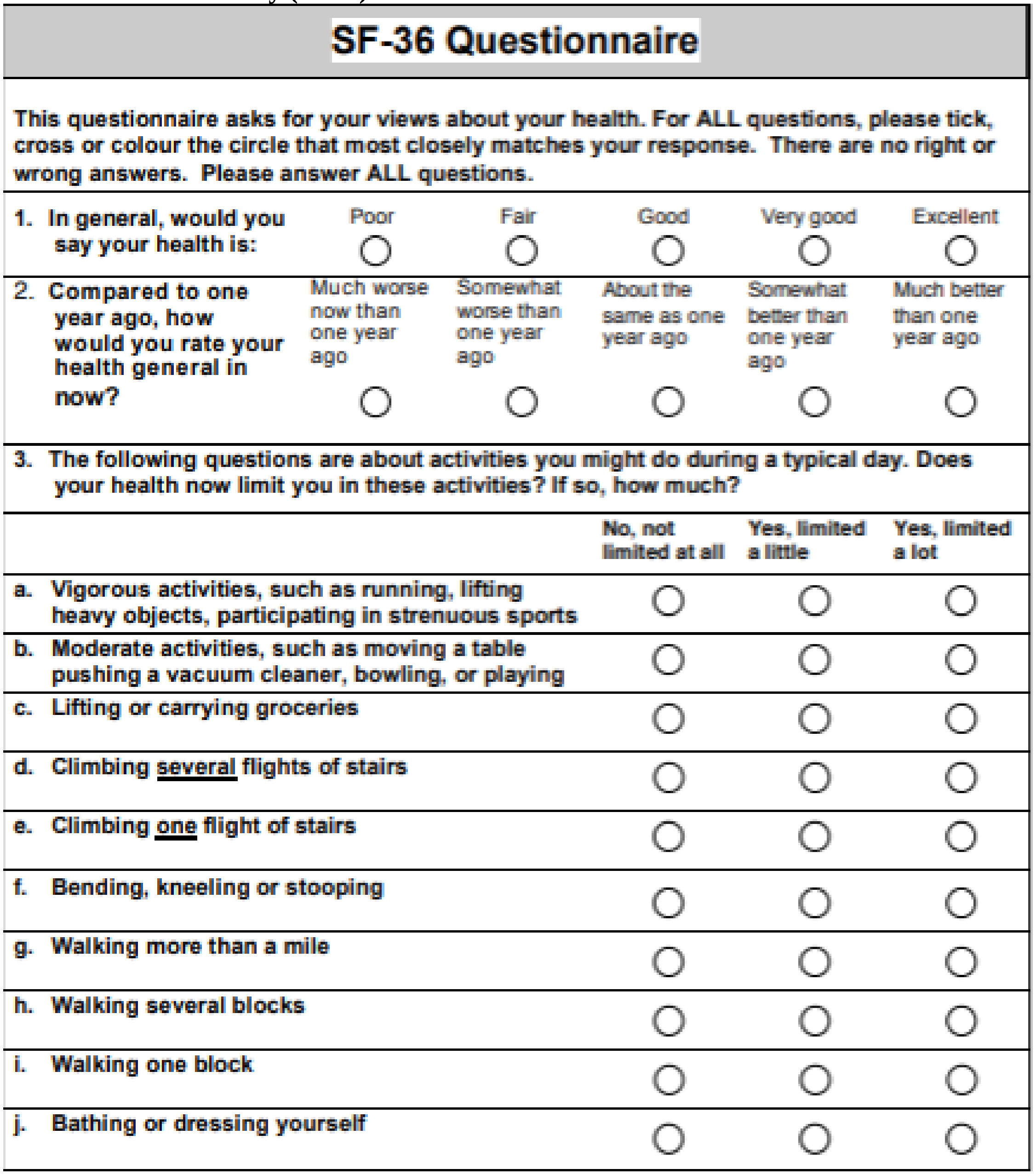
Appendix N

Medical Outcome Study Short Form SF-36 – Original

Medical Outcome Study (MOS) Short



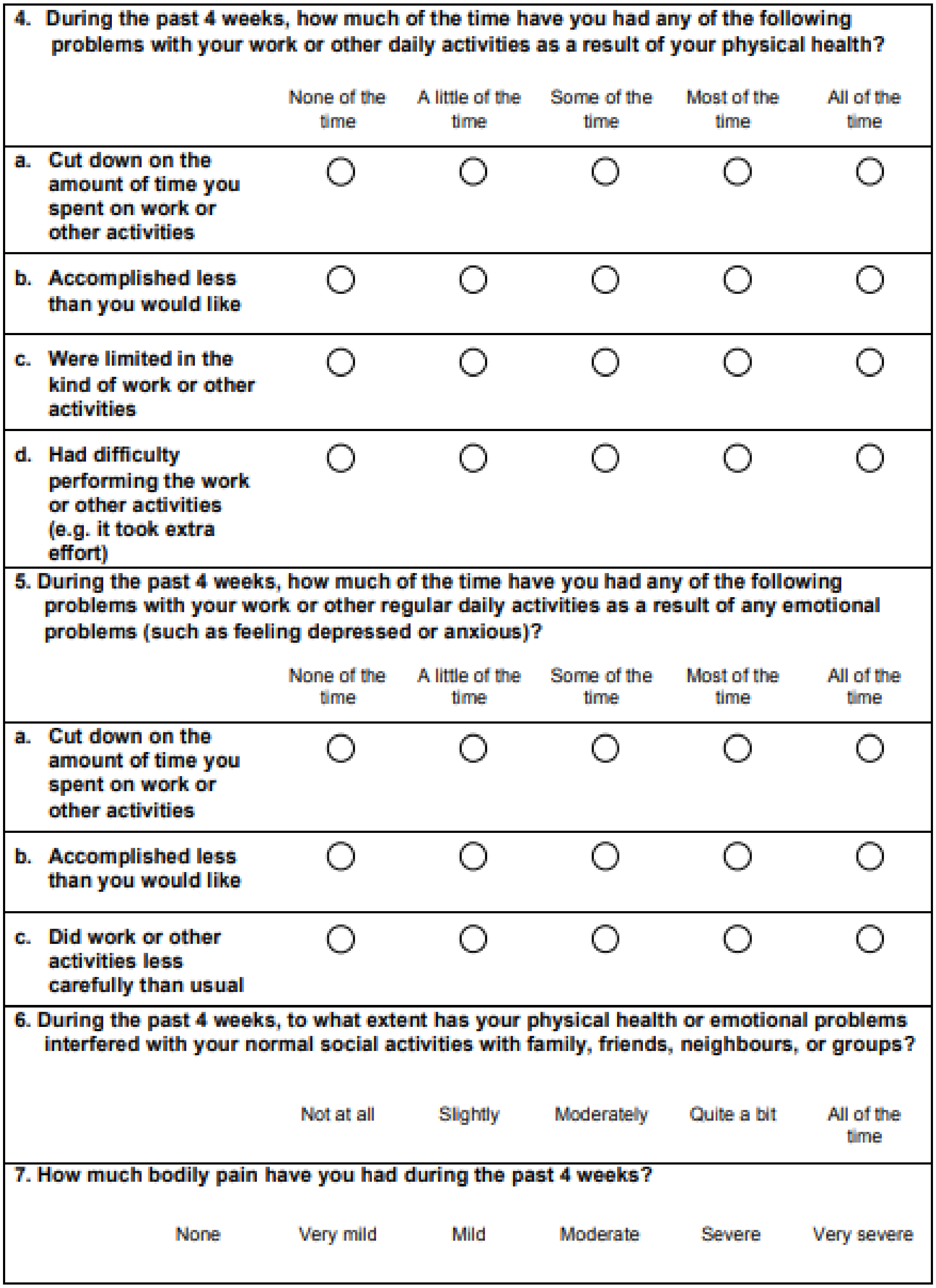
SF-36 Questionnaire

This questionnaire asks for your views about your health. For ALL questions, please tick, cross or colour the circle that most closely matches your response. There are no right or wrong answers. Please answer ALL questions.

1. In general, would you say your health is:	Poor ○	Fair ○	Good ○	Very good ○	Excellent ○
2. Compared to one year ago, how would you rate your health general in now?	Much worse now than one year ago ○	Somewhat worse than one year ago ○	About the same as one year ago ○	Somewhat better than one year ago ○	Much better than one year ago ○

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	No, not limited at all	Yes, limited a little	Yes, limited a lot
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
b. Moderate activities, such as moving a table pushing a vacuum cleaner, bowling, or playing	○	○	○
c. Lifting or carrying groceries	○	○	○
d. Climbing several flights of stairs	○	○	○
e. Climbing one flight of stairs	○	○	○
f. Bending, kneeling or stooping	○	○	○
g. Walking more than a mile	○	○	○
h. Walking several blocks	○	○	○
i. Walking one block	○	○	○
j. Bathing or dressing yourself	○	○	○



4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other daily activities as a result of your physical health?

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Cut down on the amount of time you spent on work or other activities	○	○	○	○	○
b. Accomplished less than you would like	○	○	○	○	○
c. Were limited in the kind of work or other activities	○	○	○	○	○
d. Had difficulty performing the work or other activities (e.g. it took extra effort)	○	○	○	○	○

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Cut down on the amount of time you spent on work or other activities	○	○	○	○	○
b. Accomplished less than you would like	○	○	○	○	○
c. Did work or other activities less carefully than usual	○	○	○	○	○

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

Not at all	Slightly	Moderately	Quite a bit	All of the time

7. How much bodily pain have you had during the past 4 weeks?

None	Very mild	Mild	Moderate	Severe	Very severe

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. did you feel full of life?	○	○	○	○	○
b. have you been very nervous?	○	○	○	○	○
c. have you felt so down in the dumps that nothing could cheer you up?	○	○	○	○	○
d. have you felt calm and peaceful?	○	○	○	○	○
e. did you have a lot of energy?	○	○	○	○	○
f. have you felt downhearted and depressed?	○	○	○	○	○
g. did you feel worn out?	○	○	○	○	○
h. have you been happy?	○	○	○	○	○
i. did you feel tired?	○	○	○	○	○

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

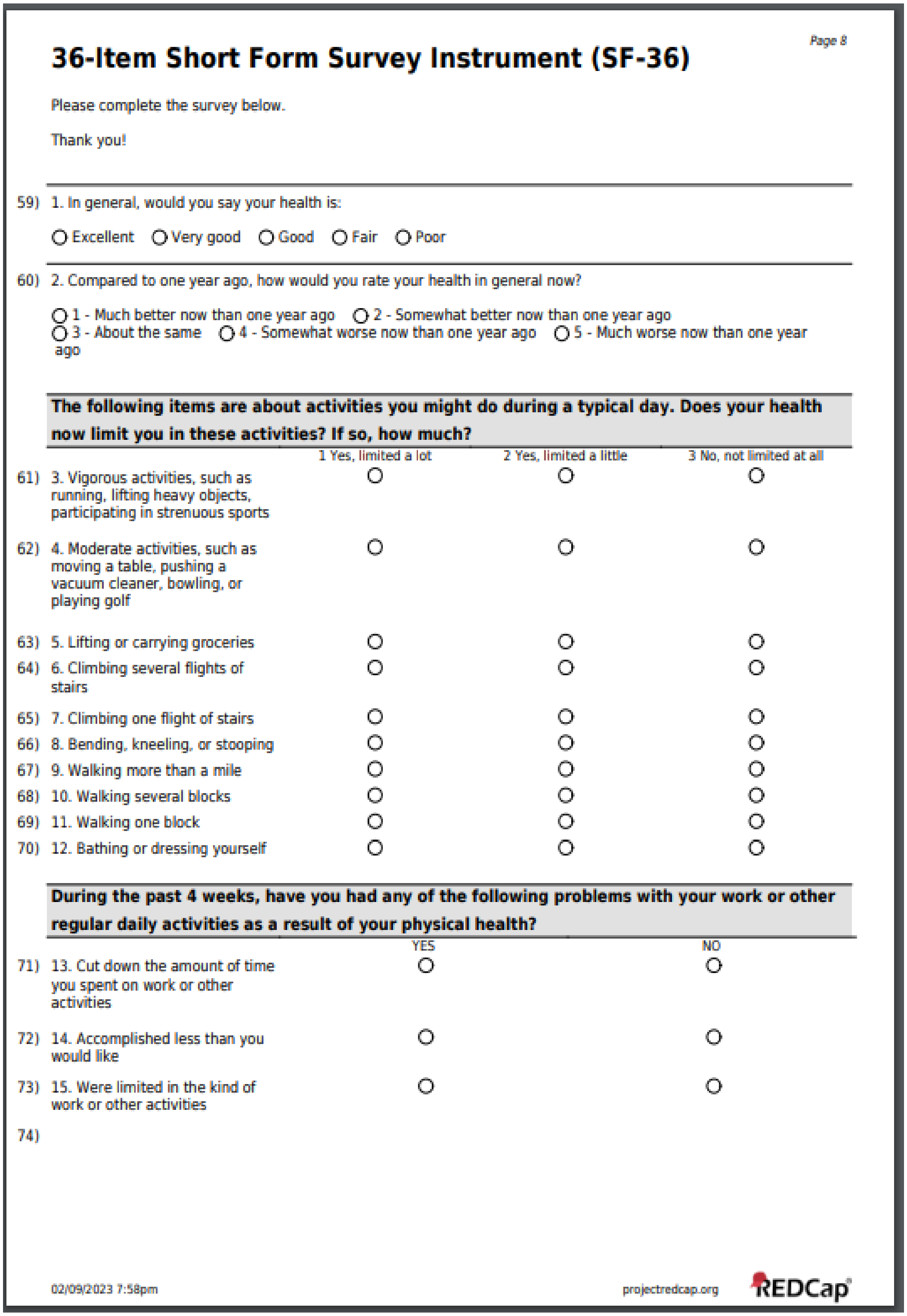
None of the time	A little of the time	Some of the time	Most of the time	All of the time

11. How TRUE or FALSE is each of the following statements for you?

	Defintely false	Mostly false	Don't know	Mostly true	Definitely true
a. I seem to get sick a little easier than other people	○	○	○	○	○
b. I am as healthy as anybody I know	○	○	○	○	○
c. I expect my health to get worse	○	○	○	○	○
d. My health is excellent	○	○	○	○	○

Appendix O

Medical Outcome Study Short Form SF-36 – REDCap



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36-Item Short Form Survey Instrument (SF-36)

Please complete the survey below.

Thank you!

59) 1. In general, would you say your health is:

○ Excellent ○ Very good ○ Good ○ Fair ○ Poor

60) 2. Compared to one year ago, how would you rate your health in general now?

○ 1 - Much better now than one year ago ○ 2 - Somewhat better now than one year ago
○ 3 - About the same ○ 4 - Somewhat worse now than one year ago ○ 5 - Much worse now than one year ago

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	1 Yes, limited a lot	2 Yes, limited a little	3 No, not limited at all
61) 3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
62) 4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
63) 5. Lifting or carrying groceries	○	○	○
64) 6. Climbing several flights of stairs	○	○	○
65) 7. Climbing one flight of stairs	○	○	○
66) 8. Bending, kneeling, or stooping	○	○	○
67) 9. Walking more than a mile	○	○	○
68) 10. Walking several blocks	○	○	○
69) 11. Walking one block	○	○	○
70) 12. Bathing or dressing yourself	○	○	○

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	YES	NO
71) 13. Cut down the amount of time you spent on work or other activities	○	○
72) 14. Accomplished less than you would like	○	○
73) 15. Were limited in the kind of work or other activities	○	○

74)

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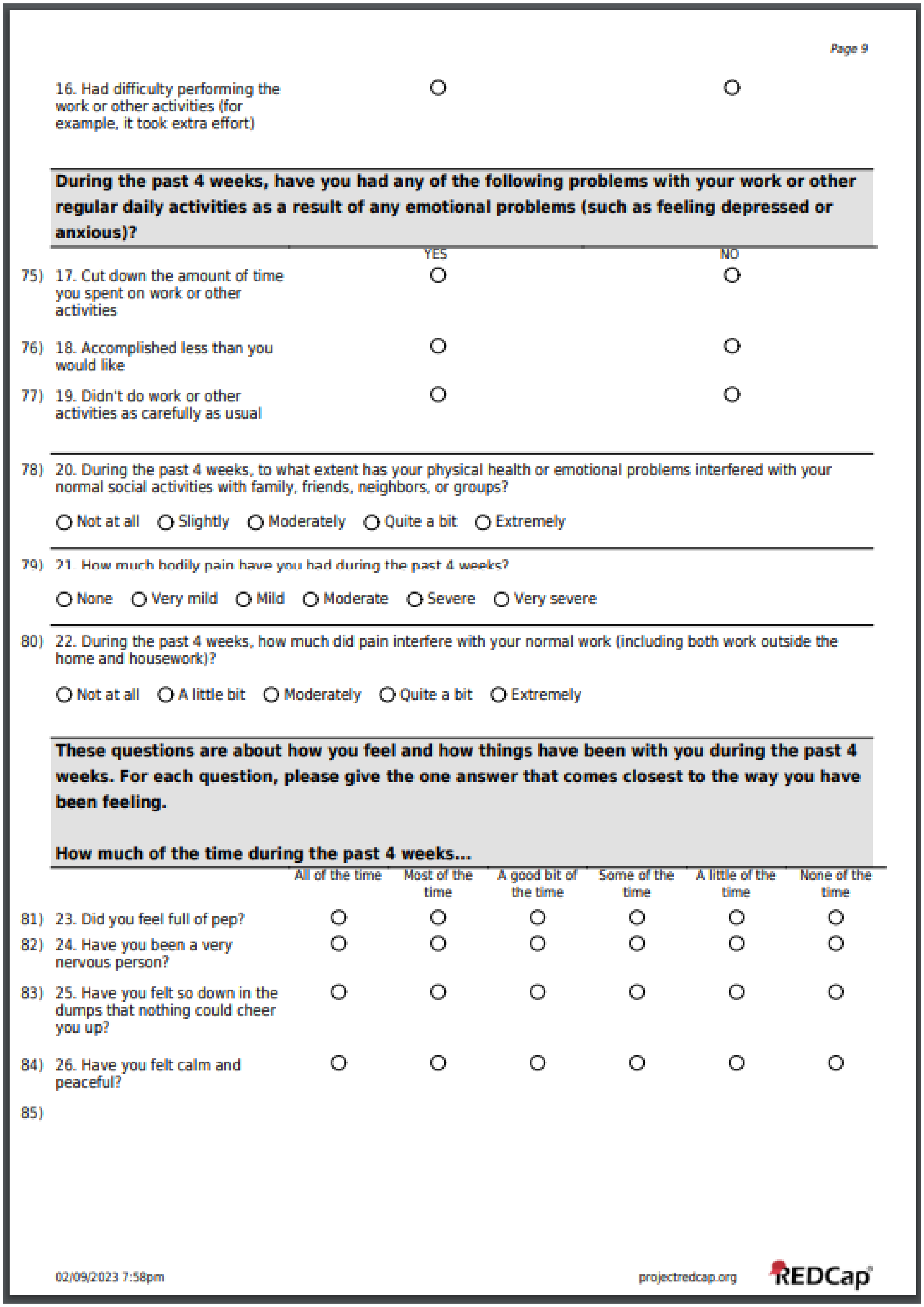


16. Had difficulty performing the work or other activities (for example, it took extra effort)	○	○

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

		YES	NO
75)	17. Cut down the amount of time you spent on work or other activities	○	○
76)	18. Accomplished less than you would like	○	○
77)	19. Didn't do work or other activities as carefully as usual	○	○

78) 20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

○ Not at all ○ Slightly ○ Moderately ○ Quite a bit ○ Extremely

79) 21. How much bodily pain have you had during the past 4 weeks?

○ None ○ Very mild ○ Mild ○ Moderate ○ Severe ○ Very severe

80) 22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

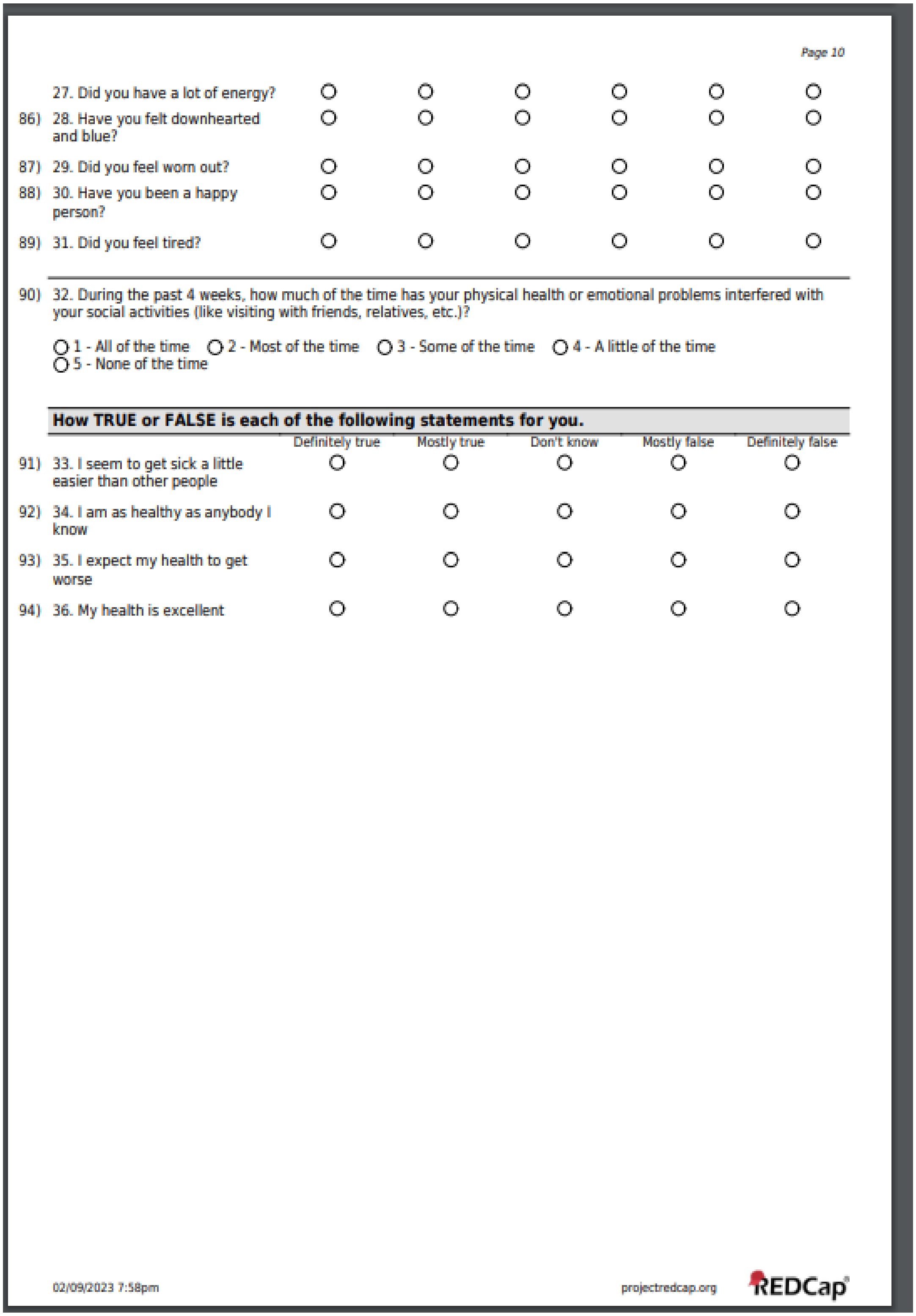
○ Not at all ○ A little bit ○ Moderately ○ Quite a bit ○ Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks...

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
81)	23. Did you feel full of pep?	○	○	○	○	○	○
82)	24. Have you been a very nervous person?	○	○	○	○	○	○
83)	25. Have you felt so down in the dumps that nothing could cheer you up?	○	○	○	○	○	○
84)	26. Have you felt calm and peaceful?	○	○	○	○	○	○

85)



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	27. Did you have a lot of energy?	○	○	○	○	○	○
86)	28. Have you felt downhearted and blue?	○	○	○	○	○	○
87)	29. Did you feel worn out?	○	○	○	○	○	○
88)	30. Have you been a happy person?	○	○	○	○	○	○
89)	31. Did you feel tired?	○	○	○	○	○	○

90) 32. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

○ 1 - All of the time ○ 2 - Most of the time ○ 3 - Some of the time ○ 4 - A little of the time
○ 5 - None of the time

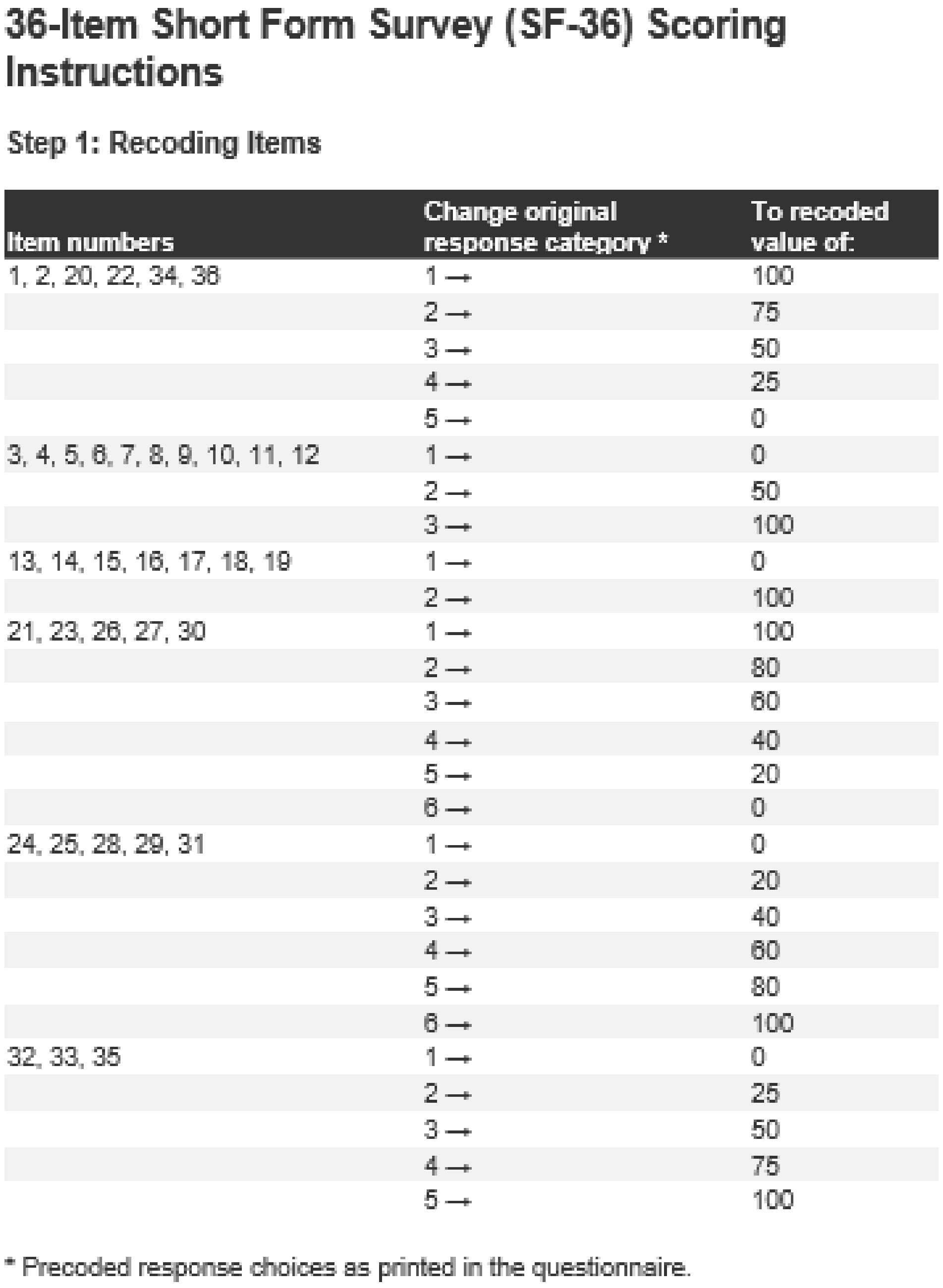
How TRUE or FALSE is each of the following statements for you.

		Definitely true	Mostly true	Don't know	Mostly false	Definitely false
91)	33. I seem to get sick a little easier than other people	○	○	○	○	○
92)	34. I am as healthy as anybody I know	○	○	○	○	○
93)	35. I expect my health to get worse	○	○	○	○	○
94)	36. My health is excellent	○	○	○	○	○

02/09/2023 7:58pm projectredcap.org REDCap

Appendix P

Medical Outcome Study Short Form SF-36 – Scoring Guideline

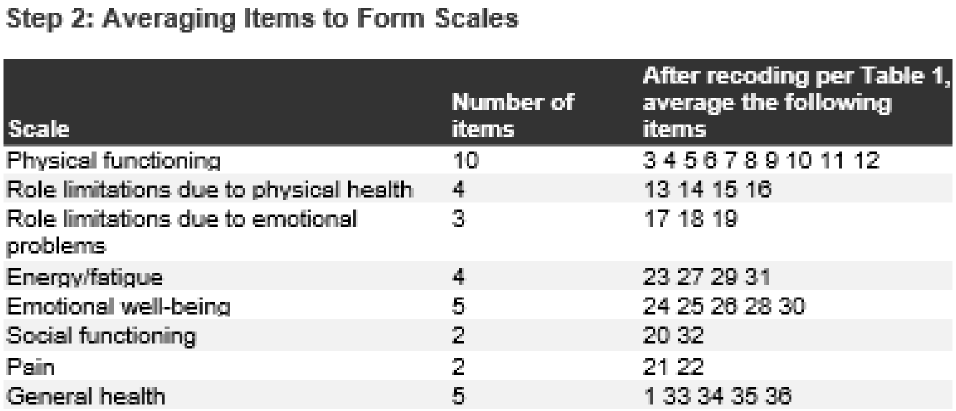


36-Item Short Form Survey (SF-36) Scoring Instructions

Step 1: Recoding Items

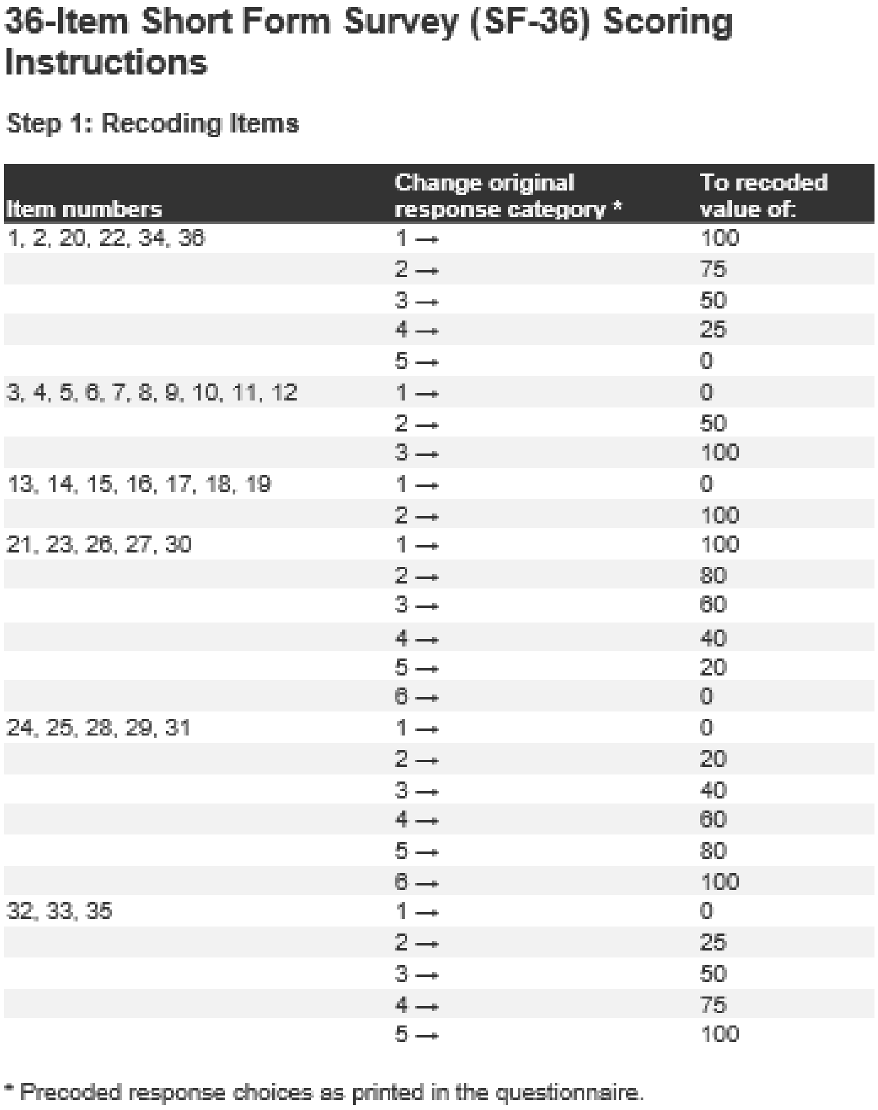
Item numbers	Change original response category *	To recoded value of:
1, 2, 20, 22, 34, 36	1 →	100
	2 →	75
	3 →	50
	4 →	25
	5 →	0
3, 4, 5, 6, 7, 8, 9, 10, 11, 12	1 →	0
	2 →	50
	3 →	100
13, 14, 15, 16, 17, 18, 19	1 →	0
	2 →	100
21, 23, 26, 27, 30	1 →	100
	2 →	80
	3 →	60
	4 →	40
	5 →	20
	6 →	0
24, 25, 28, 29, 31	1 →	0
	2 →	20
	3 →	40
	4 →	60
	5 →	80
	6 →	100
32, 33, 35	1 →	0
	2 →	25
	3 →	50
	4 →	75
	5 →	100

* Precoded response choices as printed in the questionnaire.



Step 2: Averaging Items to Form Scales

Scale	Number of items	After recoding per Table 1, average the following items
Physical functioning	10	3 4 5 6 7 8 9 10 11 12
Role limitations due to physical health	4	13 14 15 16
Role limitations due to emotional problems	3	17 18 19
Energy/fatigue	4	23 27 29 31
Emotional well-being	5	24 25 26 28 30
Social functioning	2	20 32
Pain	2	21 22
General health	5	1 33 34 35 36

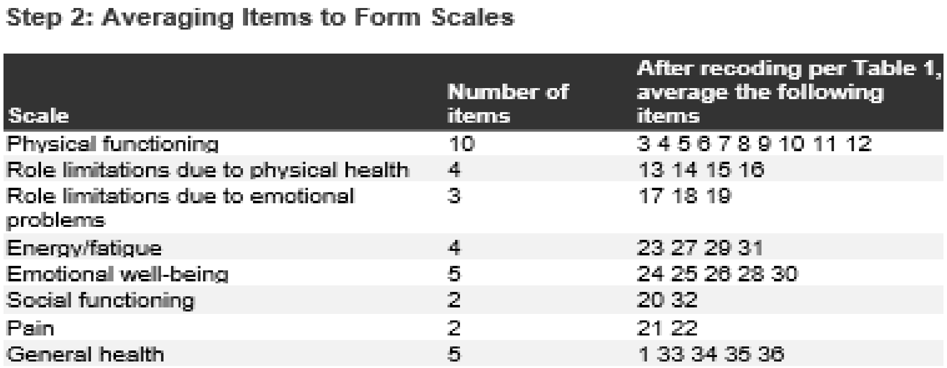


36-Item Short Form Survey (SF-36) Scoring Instructions

Step 1: Recoding Items

Item numbers	Change original response category *	To recoded value of:
1, 2, 20, 22, 34, 36	1 →	100
	2 →	75
	3 →	50
	4 →	25
	5 →	0
3, 4, 5, 6, 7, 8, 9, 10, 11, 12	1 →	0
	2 →	50
	3 →	100
13, 14, 15, 16, 17, 18, 19	1 →	0
	2 →	100
21, 23, 26, 27, 30	1 →	100
	2 →	80
	3 →	60
	4 →	40
	5 →	20
	6 →	0
24, 25, 28, 29, 31	1 →	0
	2 →	20
	3 →	40
	4 →	60
	5 →	80
	6 →	100
32, 33, 35	1 →	0
	2 →	25
	3 →	50
	4 →	75
	5 →	100

* Precoded response choices as printed in the questionnaire.

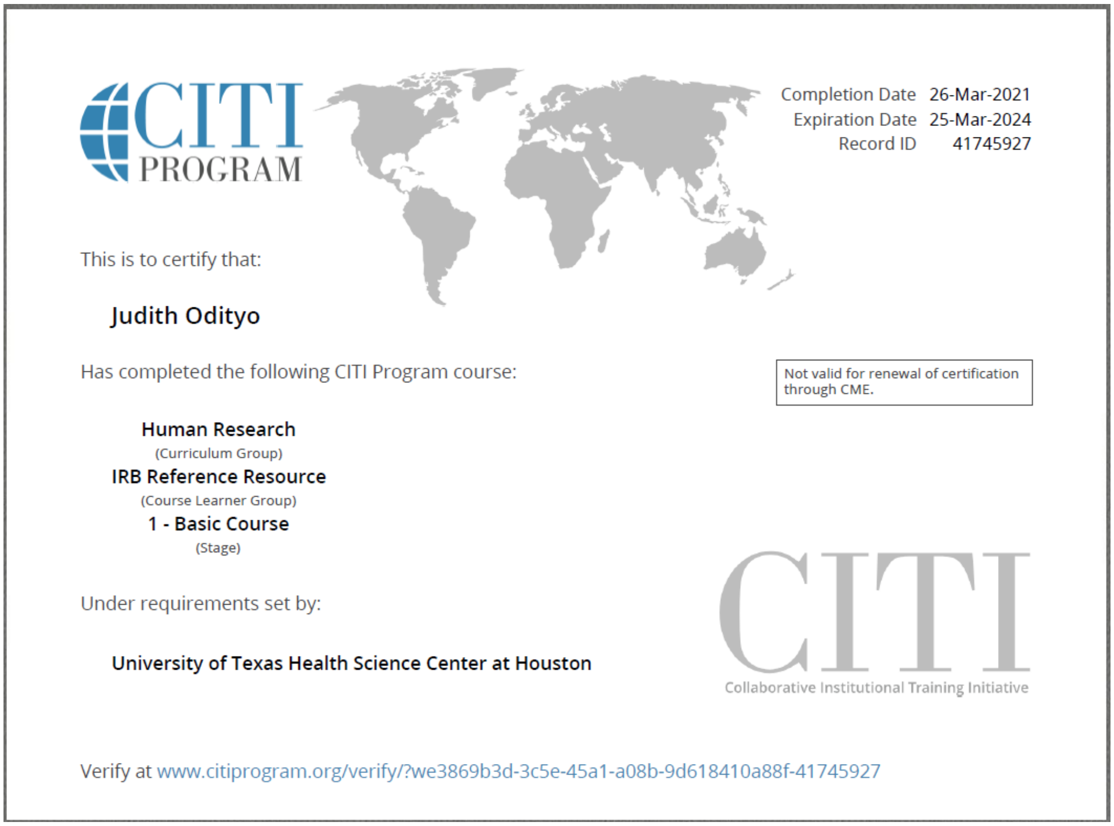


Step 2: Averaging Items to Form Scales

Scale	Number of items	After recoding per Table 1, average the following items
Physical functioning	10	3 4 5 6 7 8 9 10 11 12
Role limitations due to physical health	4	13 14 15 16
Role limitations due to emotional problems	3	17 18 19
Energy/fatigue	4	23 27 29 31
Emotional well-being	5	24 25 26 28 30
Social functioning	2	20 32
Pain	2	21 22
General health	5	1 33 34 35 36

Appendix Q

Human Subjects Research Training Certificate (CITI)



CITI PROGRAM

Completion Date 26-Mar-2021
Expiration Date 25-Mar-2024
Record ID 41745927

This is to certify that:

Judith Odityo

Has completed the following CITI Program course:

Not valid for renewal of certification through CME.

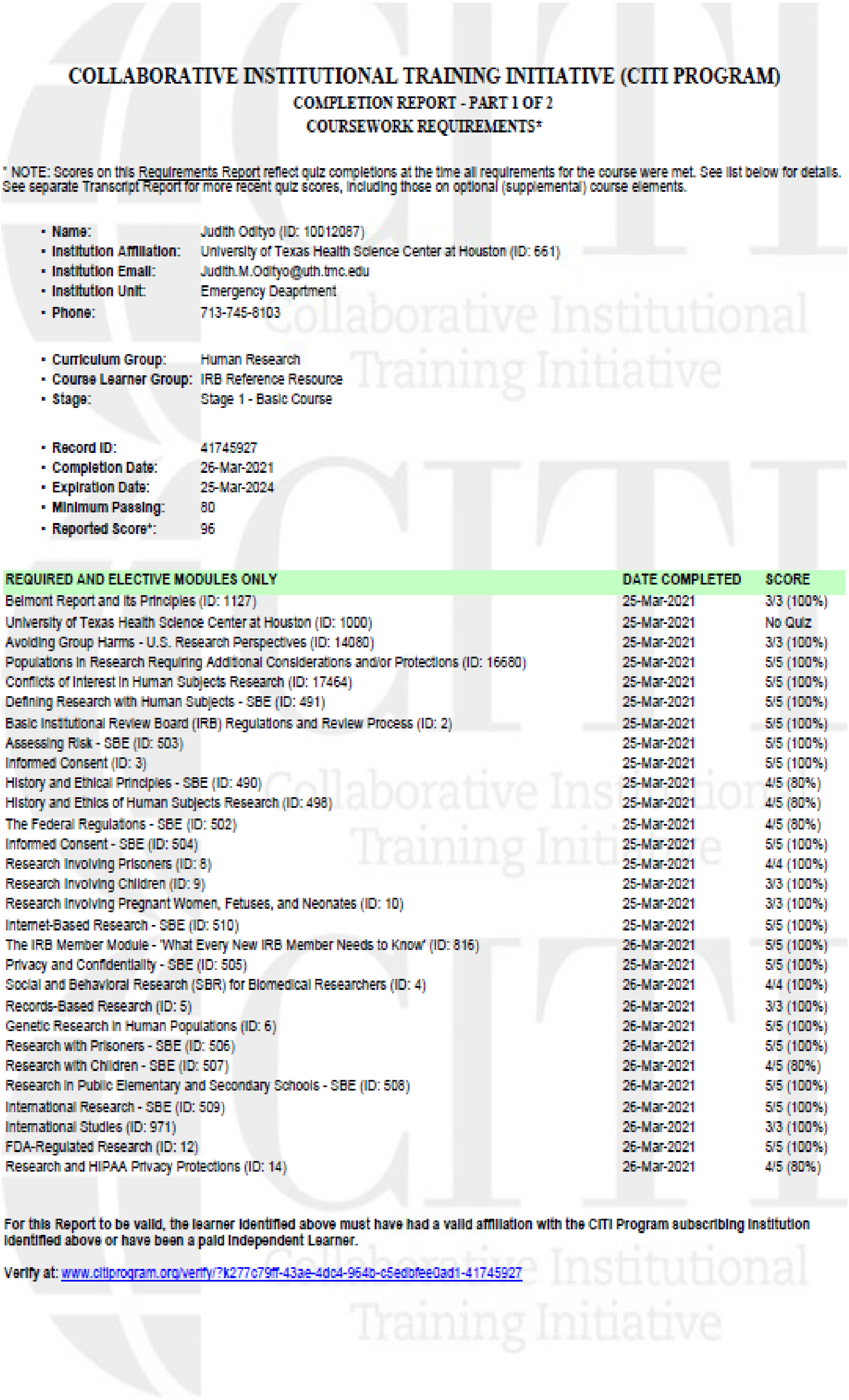
Human Research
(Curriculum Group)
IRB Reference Resource
(Course Learner Group)
1 - Basic Course
(Stage)

Under requirements set by:

University of Texas Health Science Center at Houston

CITI
Collaborative Institutional Training Initiative

Verify at www.citiprogram.org/verify/?we3869b3d-3c5e-45a1-a08b-9d618410a88f-41745927



COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COMPLETION REPORT - PART 1 OF 2

COURSEWORK REQUIREMENTS*

* NOTE: Scores on this Requirements Report reflect quiz completions at the time all requirements for the course were met. See list below for details. See separate Transcript Report for more recent quiz scores, including those on optional (supplemental) course elements.

- **Name:** Judith Odityo (ID: 10012087)
- **Institution Affiliation:** University of Texas Health Science Center at Houston (ID: 661)
- **Institution Email:** Judith.M.Odityo@uth.tmc.edu
- **Institution Unit:** Emergency Deaprtment
- **Phone:** 713-745-8103

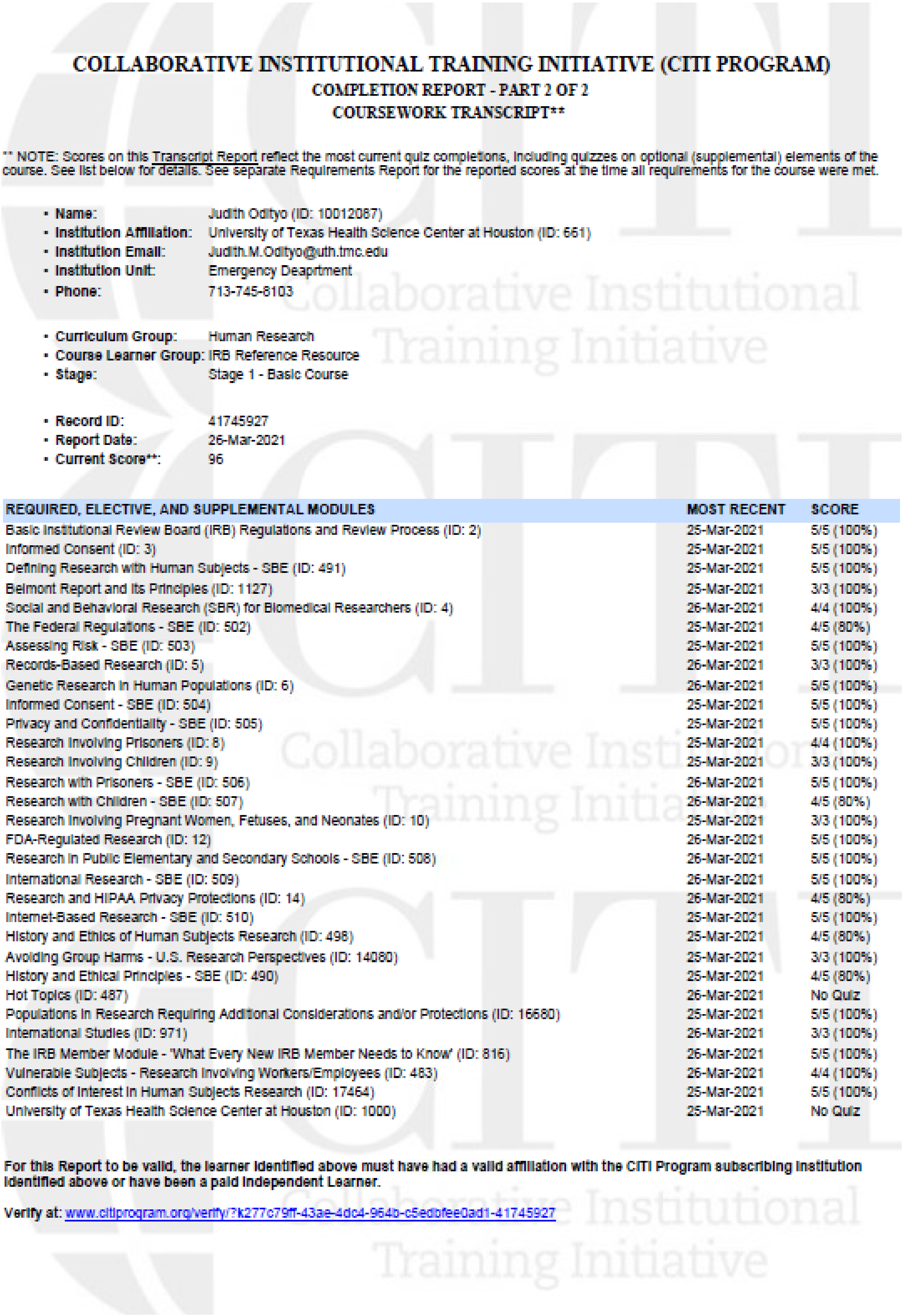
- **Curriculum Group:** Human Research
- **Course Learner Group:** IRB Reference Resource
- **Stage:** Stage 1 - Basic Course

- **Record ID:** 41745927
- **Completion Date:** 26-Mar-2021
- **Expiration Date:** 25-Mar-2024
- **Minimum Passing:** 80
- **Reported Score*:** 96

REQUIRED AND ELECTIVE MODULES ONLY	DATE COMPLETED	SCORE
Belmont Report and Its Principles (ID: 1127)	25-Mar-2021	3/3 (100%)
University of Texas Health Science Center at Houston (ID: 1000)	25-Mar-2021	No Quiz
Avoiding Group Harms - U.S. Research Perspectives (ID: 14080)	25-Mar-2021	3/3 (100%)
Populations in Research Requiring Additional Considerations and/or Protections (ID: 16680)	25-Mar-2021	5/5 (100%)
Conflicts of Interest in Human Subjects Research (ID: 17464)	25-Mar-2021	5/5 (100%)
Defining Research with Human Subjects - SBE (ID: 491)	25-Mar-2021	5/5 (100%)
Basic Institutional Review Board (IRB) Regulations and Review Process (ID: 2)	25-Mar-2021	5/5 (100%)
Assessing Risk - SBE (ID: 503)	25-Mar-2021	5/5 (100%)
Informed Consent (ID: 3)	25-Mar-2021	5/5 (100%)
History and Ethical Principles - SBE (ID: 490)	25-Mar-2021	4/5 (80%)
History and Ethics of Human Subjects Research (ID: 498)	25-Mar-2021	4/5 (80%)
The Federal Regulations - SBE (ID: 502)	25-Mar-2021	4/5 (80%)
Informed Consent - SBE (ID: 504)	25-Mar-2021	5/5 (100%)
Research Involving Prisoners (ID: 8)	25-Mar-2021	4/4 (100%)
Research Involving Children (ID: 9)	25-Mar-2021	3/3 (100%)
Research Involving Pregnant Women, Fetuses, and Neonates (ID: 10)	25-Mar-2021	3/3 (100%)
Internet-Based Research - SBE (ID: 510)	25-Mar-2021	5/5 (100%)
The IRB Member Module - 'What Every New IRB Member Needs to Know' (ID: 816)	26-Mar-2021	5/5 (100%)
Privacy and Confidentiality - SBE (ID: 505)	25-Mar-2021	5/5 (100%)
Social and Behavioral Research (SBR) for Biomedical Researchers (ID: 4)	26-Mar-2021	4/4 (100%)
Records-Based Research (ID: 5)	26-Mar-2021	3/3 (100%)
Genetic Research in Human Populations (ID: 6)	26-Mar-2021	5/5 (100%)
Research with Prisoners - SBE (ID: 506)	26-Mar-2021	5/5 (100%)
Research with Children - SBE (ID: 507)	26-Mar-2021	4/5 (80%)
Research in Public Elementary and Secondary Schools - SBE (ID: 508)	26-Mar-2021	5/5 (100%)
International Research - SBE (ID: 509)	26-Mar-2021	5/5 (100%)
International Studies (ID: 971)	26-Mar-2021	3/3 (100%)
FDA-Regulated Research (ID: 12)	26-Mar-2021	5/5 (100%)
Research and HIPAA Privacy Protections (ID: 14)	26-Mar-2021	4/5 (80%)

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

Verify at: www.citiprogram.org/verify/?k277c79ff-43ae-4dc4-964b-c5edbfee0ad1-41745927



COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)

COMPLETION REPORT - PART 2 OF 2

COURSEWORK TRANSCRIPT**

** NOTE: Scores on this Transcript Report reflect the most current quiz completions, including quizzes on optional (supplemental) elements of the course. See list below for details. See separate Requirements Report for the reported scores at the time all requirements for the course were met.

- **Name:** Judith Odityo (ID: 10012087)
- **Institution Affiliation:** University of Texas Health Science Center at Houston (ID: 661)
- **Institution Email:** Judith.M.Odityo@uth.tmc.edu
- **Institution Unit:** Emergency Deaprtment
- **Phone:** 713-745-8103

- **Curriculum Group:** Human Research
- **Course Learner Group:** IRB Reference Resource
- **Stage:** Stage 1 - Basic Course

- **Record ID:** 41745927
- **Report Date:** 26-Mar-2021
- **Current Score**:** 96

REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES	MOST RECENT	SCORE
Basic Institutional Review Board (IRB) Regulations and Review Process (ID: 2)	25-Mar-2021	5/5 (100%)
Informed Consent (ID: 3)	25-Mar-2021	5/5 (100%)
Defining Research with Human Subjects - SBE (ID: 491)	25-Mar-2021	5/5 (100%)
Belmont Report and Its Principles (ID: 1127)	25-Mar-2021	3/3 (100%)
Social and Behavioral Research (SBR) for Biomedical Researchers (ID: 4)	26-Mar-2021	4/4 (100%)
The Federal Regulations - SBE (ID: 502)	25-Mar-2021	4/5 (80%)
Assessing Risk - SBE (ID: 503)	25-Mar-2021	5/5 (100%)
Records-Based Research (ID: 5)	26-Mar-2021	3/3 (100%)
Genetic Research in Human Populations (ID: 6)	26-Mar-2021	5/5 (100%)
Informed Consent - SBE (ID: 504)	25-Mar-2021	5/5 (100%)
Privacy and Confidentiality - SBE (ID: 505)	25-Mar-2021	5/5 (100%)
Research Involving Prisoners (ID: 8)	25-Mar-2021	4/4 (100%)
Research Involving Children (ID: 9)	25-Mar-2021	3/3 (100%)
Research with Prisoners - SBE (ID: 506)	26-Mar-2021	5/5 (100%)
Research with Children - SBE (ID: 507)	26-Mar-2021	4/5 (80%)
Research Involving Pregnant Women, Fetuses, and Neonates (ID: 10)	25-Mar-2021	3/3 (100%)
FDA-Regulated Research (ID: 12)	26-Mar-2021	5/5 (100%)
Research in Public Elementary and Secondary Schools - SBE (ID: 508)	26-Mar-2021	5/5 (100%)
International Research - SBE (ID: 509)	26-Mar-2021	5/5 (100%)
Research and HIPAA Privacy Protections (ID: 14)	26-Mar-2021	4/5 (80%)
Internet-Based Research - SBE (ID: 510)	25-Mar-2021	5/5 (100%)
History and Ethics of Human Subjects Research (ID: 498)	25-Mar-2021	4/5 (80%)
Avoiding Group Harms - U.S. Research Perspectives (ID: 14080)	25-Mar-2021	3/3 (100%)
History and Ethical Principles - SBE (ID: 490)	25-Mar-2021	4/5 (80%)
Hot Topics (ID: 487)	26-Mar-2021	No Quiz
Populations in Research Requiring Additional Considerations and/or Protections (ID: 16680)	25-Mar-2021	5/5 (100%)
International Studies (ID: 971)	26-Mar-2021	3/3 (100%)
The IRB Member Module - 'What Every New IRB Member Needs to Know' (ID: 816)	26-Mar-2021	5/5 (100%)
Vulnerable Subjects - Research Involving Workers/Employees (ID: 483)	26-Mar-2021	4/4 (100%)
Conflicts of Interest in Human Subjects Research (ID: 17464)	25-Mar-2021	5/5 (100%)
University of Texas Health Science Center at Houston (ID: 1000)	25-Mar-2021	No Quiz

For this Report to be valid, the learner identified above must have had a valid affiliation with the CITI Program subscribing institution identified above or have been a paid Independent Learner.

Verify at: www.citiprogram.org/verify/?k277c79ff-43ae-4dc4-964b-c5edbfee0ad1-41745927

CURRICULUM VITAE

Judith M Odityo, MSN, MBA, RN, CPN

EDUCATION

University of Texas Health Science Center at Houston, Cizik School of Nursing
PhD **08/2018 - 05/2023**
Dissertation: *Shared Decision Making in Self-Care Management and Health Outcomes of Adolescents and Young Adults with Sickle Cell Disease.*

University of Texas Health Science Center at Houston, Cizik School of Nursing
MSN **08/2015 - 05/2017**
Area of Concentration: Nursing Leadership and Administration

University of Texas Health Science Center at Houston, Cizik School of Nursing
MSN **08/2017 - 05/2018**
Area of Concentration: Nursing Education

Texas Woman's University (Houston, TX)
MBA **01/2013 - 05/2014**

Texas Woman's University (Houston, TX)
BSN **01/2006 - 12/2007**

LICENSURE & CERTIFICATION

Registered Nurse, Texas # 752189	**02/2008 - 02/2024**
Certified Pediatric Nurse, Pediatric Nursing Certification Board	**02/2010 - 02/2024**
Basic Life Support for Healthcare Provider, American Heart Association	**03/2022 -03/2024**
Pediatric Advanced Life Support, American Heart Association	**05/2022 - 05/2024**
Advanced Cardiovascular Life Support, American Heart Association	**05/2022 – 05/2024**

PROFESSIONAL EXPERIENCE

MD Anderson Cancer Center Nurse Manager, Emergency and Observation Nursing	**01/2018 - Current**
Houston Christian University School of Nursing Clinical Instructor	**08/2018 - Current**
MD Anderson Cancer Center Nurse Manager Ad Interim, Emergency Department	**04/2016 - 12/2017**
MD Anderson Cancer Center Staff Nurse	**06/2012 – 04/2016**
Children's Memorial Herman Hospital, Texas Medical Center staff nurse	**05/2008 – 06/2016**

HONORS & AWARDS

Sigma Theta Tau Nursing Honor Society	**2018**
Nominee, Mentor Award, MD Anderson Cancer Center	**2018**
Nominee, Daisy Award, MD Anderson Cancer Center	**2013**
Nominee, Houston Chronicle Salute to Nurses	**2012**
Good Samaritan Award, Children's Memorial Herman Hospital	**2011**
DAISY Award, Children's Memorial Herman Hospital	**2010-2012**
Pillar Award, Children's Memorial Herman Hospital	**2010-2012**

PRESENTATIONS

Odityo, J. (2022). Models of care for the transition of adolescents and young adults to adult centered care. Poster presented at The University of Texas Houston Health Science Center School of Nursing, Houston, TX.

Odityo, J. (2020). The Relationship between sickle cell transition programs and self-efficacy in adolescents and young adults. Paper presented at The University of Texas Houston Health Science Center School of Nursing, Houston, TX.

Odityo, J. (2019). Patient – provider concordance: A conceptual framework for the adolescent patient with sickle cell disease. Paper presented at The University of Texas Houston Health Science Center School Of Nursing, Houston, TX.

Odityo, J.; Gruner, S., & Fourman, N. (2019). Opioid overdose death rates: Analysis of historical data to forecast future trends. Paper presented at The University of Texas Houston Health Science Center School of Nursing, Houston, TX.

Odityo, J. (2017). The feasibility of a pressure ulcer program in an oncologic emergency department. Paper presented at The University of Texas Houston Health Science Center School of Nursing, Houston, TX.

Odityo, J. (2017). Designing a pressure ulcer prevention program for a level I trauma emergency department. Poster session presented at The University of Texas Houston Health Science Center School of Nursing, Houston, TX.

PROFESSIONAL MEMBERSHIPS

Southern Nursing Research Society	**2021 - Present**
Sigma Theta Tau International Honor Society	**2018 - Present**
Emergency Nurses Association	**2018 - Present**
American Nurses Association	**2010 - Present**
Texas Nurses Association	**2010 - Present**