



The genogram as a recruitment tool for identifying primary caregivers of youth living with sickle cell disease preparing for transition

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Abstract

Aims: The purpose of this secondary analysis was to describe the impact of utilizing genograms to identify family caregivers from an original research study which utilized family caregiver-adolescents/young adults (AYA) dyads.

Background: Research to improve transition preparation for AYA with chronic disease is essential as 90% will survive into adulthood. Family-based transition research is specifically

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All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE):

- 1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data
- 2) drafting the article or revising it critically for important intellectual content.

Criteria	Author Initials
Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;	MV, BSB, LLP, KPK
Involved in drafting the manuscript or revising it critically for important intellectual content;	MV, BSB, LLP, KPK
Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content;	MV, BSB, LLP, KPK
Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.	MV, BSB, LLP, KPK

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No conflict of interest has been declared by the author(s).

needed as a majority of transition preparation will occur within the home setting. Dyadic research on transition has not previously described strategies for recruiting appropriate family caregivers.

Design: A descriptive, secondary analysis was conducted using genograms developed during the original study conducted between October 2019 and February 2020.

Methods: For this secondary analysis conducted between July 2020 and August 2021, 50 genograms were analyzed utilizing descriptive statistics to describe family structures, relationships, and responsibilities in families of AYAs living with sickle cell disease.

Results: In 43 genograms, there was only one primary caregiver within the family. In seven genograms, there were multiple primary caregivers who met the inclusion criteria for primary caregiver within a single family. In five genograms, there were two appropriate primary caregivers within a single family, and in two genograms, there were three appropriate individuals within a single family who met study criteria as a primary caregiver.

Conclusions: Findings from the analysis of the genograms used in the original study demonstrated potential ability to improve upon dyad recruitment by more specifically identifying the family member most involved in supporting the AYA's disease management.

Impact: Genograms are an established tool for gathering information on families and application with recruitment could improve research within the realm of transition and other family-based research.

No Patient or Public Contribution: This was a secondary analysis that assessed already existing data.

Keywords

genograms; adolescent; young adults; family caregivers; family; chronic disease; transition; research methods; recruitment; nursing; sickle cell

Introduction

At least 90% of adolescents and young adults (AYA) living with chronic disease require transition to adult healthcare annually. As medical interventions continue to improve outcomes for these AYA, the need for transition processes will only increase (Pai & Schwartz, 2011). Despite decades of research assessing the impact of transition and looking to improve this processes, only 17% AYA with a chronic disease and their families receive assistance with the transition between pediatric and adult healthcare teams and systems (Lebrun-Harris et al., 2018). Health risks to the AYA after transition include: reduced healthcare utilization and engagement, worsening disease conditions, and decrease psychosocial development (Helgeson et al, 2013; Institute of Medicine and National Research Council, 2015; Society for Adolescent Health and Medicine, 2017; Spencer et al., 2018). It is therefore essential that family-based interventions are developed to support AYA living with chronic illness, their families, and clinicians through the transition process to ensure continuity of care is maintained while new relationships are being developed with adult healthcare providers.

Though the body of literature on AYA healthcare transition has grown tremendously in the past decade, research in this area is hampered by a lack of conceptual clarity. Importantly, there is disagreement about how to define concepts such as transition readiness and successful outcomes of transition (Chu et al., 2015; Straus, 2019). Furthermore, researchers have not linked transition outcomes to AYA transition readiness as measured by psychometrically sound measures. The large body of evidence is informed by studies with weak designs, and limited attention has been paid to the needs of family caregivers who are integral stakeholders within the transition process by utilizing a family-based research approach to studying transition (Betz et al., 2015; Betz et al., 2021). To ensure that AYAs live full lives not hampered by poor disease outcomes it is essential that continuity of care during transition be addressed to provide maximal support to AYAs, their family/caregivers, and healthcare team members.

Of the numerous limitations discussed above, the need for family-based research is paramount. Though AYA healthcare transition, hereafter identified as transition, is impacted by numerous healthcare system factors (e.g. availability of providers, insurance status, presence of transition preparation programming), most of the preparation will occur within the home setting and be negotiated between family caregivers (e.g. parents) and AYAs. Whether it is exploratory or interventional research, consideration should be given to the appropriateness of family caregivers to be included in studies, meaning which family caregivers are the most appropriate to include in AYA transition research. The roles and responsibilities of each family caregiver involved in the AYA's medical care must be considered. An actively engaged family caregiver who is part of the decision-making process and assists the AYA with disease management would be a more appropriate research participant than a family caregiver whose primary role is to transport the AYA to appointments. In research about transitions, researchers need to seek out the individual or persons who can most inform the research. Genograms are a simple tool which could assist with identification of the most appropriate family member to include in transition research.

Background

Genograms have a rich history of being used within clinical settings to assist with collecting family level data on everything from genetic risks (Daly et al., 1999; Samson et al., 2019) to family structures/resources/relationships (Darwent et al., 2016; Liossi et al., 1997; Perez et al., 2010; Watts & Shrader, 1998); and as a tool to personalize family interventions (Abatamarco et al., 2021; Clarke et al., 2020; Cuartas Arias, 2017; Thomson et al., 2020). Genograms play a role in family research and have demonstrated utility as an assessment tool, and as a means to assess complex topics such as family stress management skills and handling conflict resolution (Leonidas & Santos, 2015), or to understand health status and risk factors across individual, family, and community levels (McGuinness et al., 2005). Application of genograms allow for richer data collection within qualitative studies (Campacci et al., 2020; de Oliveira et al., 2010; de Paula et al., 2008; Fort et al., 2020; da Mata Ribeiro Gomes et al., 2014; Rempel et al., 2007; Smith et al., 2011) and within quantitative studies to assess family relationships, skills, and resources (Culyba et al., 2018; Culyba et al., 2021; Silveira & Neves, 2019).

To the best of our knowledge, current transition research which includes family caregivers has not described the strategies for ensuring that the family caregiver included in dyadic research was the best participant for inclusion. A majority of transition preparation occurs within the home and is negotiated between family caregivers and AYAs. Recruitment for research often occurs in the clinical setting, and there is no guarantee that the family caregivers present are the participants who can best inform the study. Researchers ought to utilize strategies which help to identify appropriate individuals for inclusion. In this paper we will explore a novel application of genograms in the selection of appropriate family caregivers that were recruited for research regarding family caregiver-AYA dyads undergoing transition to adult healthcare settings. The original study was guided by the Individual and Family Self-Management Theory which recognizes that self-management outcomes are influenced by both AYAs and their family caregivers (Ryan & Sawin, 2009). The secondary analysis discussed in this paper will share how genograms utilized during recruitment in the original study allowed for the researchers' further understanding of family structures, roles, and responsibilities influencing AYAs' self-management during transition preparation.

Aim

The purpose of this secondary analysis was to describe the impact of utilizing genograms to identify family caregivers for an original research study assessing transition readiness which utilized family caregiver-adolescents/young adults (AYA) dyads.

Design

The original study was a correlational cross-sectional quantitative study conducted between October 2019 and February 2020. The secondary analysis described in this paper was a descriptive cross-sectional quantitative study of data collection in the original study. The secondary analysis was conducted between July 2020 and August 2021. This study was reported using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines (von Elm et al., 2008).

Participants

The original study from which these data were collected used a convenience sample of AYA living with sickle cell disease and their family caregivers who were recruited from a large, comprehensive sickle cell disease clinic at an academic hospital in Washington, DC. There were 25 adolescents, 25 young adults, and 50 family caregivers recruited for the original study (Varty et al., 2022). A power analysis was conducted for the original study, but it was not conducted for this secondary analysis due to the design.

Data Collection

The original study's purpose was to explore the relationships between decision-making involvement, self-efficacy, healthcare responsibility, and overall transition readiness from both the perspective of the AYA living with sickle cell disease and their family caregiver (Varty et al., 2022). It was conducted between October 2019 and February 2020 and was guided by the Individual and Family Self-Management Theory. This study utilized

a variety of validated tools including the Decision-Making Involvement Scale (Miller & Harris, 2012), Sickle Self-Efficacy Scale (Edwards et al., 2000), and Readiness to Transition Questionnaire (Gilleland et al., 2012) to address the study aims. Genograms were implemented in this study to assist with recruitment. For the purposes of this paper and to highlight how genograms could support improved recruitment, this paper will describe a secondary analysis completed on the genograms created in the original study. The secondary analysis was conducted between July 2020 and August 2021.

Steps for Drawing and Utilizing Recruitment Genograms—As a part of our recruitment strategy within the original study, genograms were drawn with the AYA to determine which family member was the primary caregiver, who was ultimately recruited to the study. For the purpose of the original study and this secondary analysis, the primary caregiver was defined as a family member who was identified by the AYA as “playing an active role in decision-making regarding disease management and shared the majority of responsibility for the AYA’s disease management.”

Once the AYA consented to participate in the original study, a genogram was constructed to identify appropriate primary caregivers for participation. To begin constructing the genograms, the AYA were asked, “Who lives at home with you?” The principal investigator would start the genogram drawing based upon the initial answer provided by the AYA. For any siblings that the AYA said lived at home, the principal investigator asked if the AYA shared the same mom and dad with this sibling to help clarify if there were biological, stepsiblings, or half-siblings present in the household. Parents’ relationships (e.g., marriage, separation, divorce) were also clarified with additional questions posed to the AYA. Once the initial genogram was drawn, the structure (e.g., nuclear family, single parent household, multigenerational household) and relationships (e.g., biological versus stepparents, biological siblings versus half or stepsiblings) were checked for accuracy with the AYA. Then for each individual listed in the genogram the principal investigator asked the AYA about what each individual did to support the AYA with their sickle cell disease. If the AYA asked for examples of sickle cell disease support, the principal investigator listed examples from the tasks listed in the Readiness for Transition Questionnaire used in the study and other emotional support examples (e.g., “provides support when in SCD crisis”) which were not listed in the Readiness for Transition Questionnaire. Finally, the AYA was asked who played a role in making decisions about their disease. Each of the roles (including tasks, emotional support, and decision-making role) was notated in the genogram. The final genogram was reviewed one final time for accuracy with the AYA. This process took an average time of 5–10 minutes to complete.

Based on the completed genogram the principal investigator would evaluate if the family caregiver who was present still met the criteria of being a primary caregiver as previously defined. If the family member present was the primary caregiver, then the study continued. If not, the study was paused. A mutual time was then found to complete the study over the phone with the AYA and the identified primary caregiver.

After completion of the original study, the researchers decided to conduct a secondary analysis of the genograms to describe family structures, roles, and responsibilities identified in the genograms.

Ethical Considerations

The original study was approved by Children’s National Hospital and the University of Missouri-Columbia and was conducted between October 2019 and February 2020. This secondary analysis was approved by the Colorado Multiple Institutional Review Board Institutional Review Board, where the principal investigator is now employed.

Data Analysis

For this secondary analysis, descriptive statistics were calculated for a variety of factors in the genograms including family structure, number of primary caregivers, gender of primary caregiver participating, relationships of primary caregiver to AYA, gender of other primary caregivers, relationships of other primary caregivers to AYA, secondary caregiver present, relationship of secondary caregivers to AYA, secondary caregiver roles, presence of siblings who support sickle cell disease management, and siblings’ specific roles in sickle cell disease management.

Validity and Rigor

For this secondary analysis, each genogram was analyzed for family structure, family member roles, and relationships. Two members of the research team (M.V. and K.P.K.) reviewed all genograms for classification of roles, structures, and relationships. The primary author did the initial analysis and then a second author (K.P.K.) reviewed the analysis to ensure there was consensus on the final classifications.

Results

Within the original study’s sample, a total of 50 dyads were recruited. Of these, 25 dyads included an adolescent (age 13–17) and a primary caregiver, and 25 dyads included a young adult (age 18–21) and a primary caregiver. Forty-four of the primary caregivers were female and six were males. All male primary caregivers were fathers. Of the female primary caregivers 41 were mothers, one was an aunt, and two were older sisters. The AYAs included in the original study came from a variety of family structures. Twenty-six came from homes with married parents, six came from families with divorced or separated parents, and 18 came from single-parent households (see Table 1).

The original intention of using the genograms within the original study was to identify primary caregivers who would be appropriate for study inclusion. As previously noted, a primary caregiver was defined as a family member who was identified by the AYA as “playing an active role in decision-making regarding disease management and shared the majority of responsibility for the AYA’s disease management.” In 43 of the genograms, only one primary caregiver was identified for study inclusion as illustrated in Genogram 1 (see Figure 1), and in seven genograms, there were multiple primary caregivers who met criteria for inclusion as primary caregivers. In five of those seven genograms, there were

two appropriate primary caregivers as illustrated in Genogram 2 and 4 (see Figures 2 and 4 respectively), and in two cases, there were three appropriate individuals who met the study definition for primary caregiver in the original study as illustrated in Genogram 3 (see Figure 3). In some cases, it was a mother or father who could have been recruited as a primary caregiver, but there were other cases when a grandparent or aunt met the definition of a primary caregiver as illustrated in Genogram 3 and 4 (see Figures 3 and 4 respectively).

A secondary finding of the genogram was the identification of a variety of secondary caregivers. These individuals did not meet the decision-making criteria as a primary caregiver, but they played a role in supporting the AYA with managing their sickle cell disease. Twenty-two of the genograms demonstrated the presence of secondary caregivers in AYAs' as illustrated in Genogram 1 and 4. Most of these secondary caregivers were fathers (n = 16); however, secondary caregivers also included grandparents, aunts, uncles, cousins, and mothers as illustrated in Genogram 4 (see Figure 4). Secondary caregivers performed a variety of tasks including but not limited to providing assistance with medication adherence, transportation, reminders about self-care, offering emotional support, and attending appointments with the AYA.

Sibling support was reported by the AYA and identified through the genograms. Thirty-one of the AYAs in the original study reported having sibling support whereas 17 did not. A majority of the AYAs reported that the main role their siblings played in helping with their sickle cell disease was providing emotional support; however, other siblings roles reported by AYA included receiving reminders about medications, receiving support when experiencing a sickle cell disease pain crisis, transportation, attending appointments, and receiving reminders about self-care as illustrated in Genograms 1, 2, and 4 (see Figures 1, 2, and 4 respectively).

Discussion

Previous research in AYA transition to adult healthcare has utilized dyadic recruitment methods to gain a wider perspective about the influence of family factors on transition by including more than one viewpoint (e.g, AYAs and family caregivers, Gumidyala et al., 2018; Lapp & Chase, 2018; Miller & Drotar, 2007; Pham et al., 2021; Sheng et al., 2018; Speller-Brown et al., 2015; Tsang et al., 2021). Findings from the analysis of the genograms used in our original study demonstrated potential ability to improve upon dyad recruitment method by more specifically identifying the family member most involved in supporting the AYA in managing SCD. In the original study, the majority of AYA had one primary caregiver who met the original study's inclusion criteria. However, other AYAs identified multiple individuals who met inclusion criteria as a primary caregiver. In a few cases, the individual attending the appointment with the AYA did not meet the inclusion criteria for being a primary caregiver. The genograms were invaluable in helping the research team to identify the correct primary caregiver to complete research measures. In this study we identified that other AYA family members played an important role in AYA disease management in addition to the primary caregivers and could potentially influence their transition preparation. To the best of our knowledge, prior dyadic studies in transition research have not described a recruitment process to ensure that family caregivers were

selected based on the role they actual played in care of the AYA and not only on their family role as a parent.

It was unexpected that genograms helped the research team to identify that a majority of the AYAs included in the original sample had a wide variety of secondary caregivers and siblings who provided some type of disease management support. Between the primary caregiver, secondary caregivers, and siblings, the AYAs often had numerous individuals involved in disease management and underscores that this process is a family process. These findings highlight the complexity of family structures that support AYA's chronic disease management. Furthermore, this study identified the importance of family assessments to understanding the nuance of family structures, relationships, and roles that may have impacted the transition to adult healthcare for the AYA. Genograms not only have implications for transition research but could also provide benefit to clinicians supporting AYAs care and transition preparation.

Genograms allowed our team to conduct a quick assessment of the family caregiver's role in the AYAs' disease management to ensure that they were the appropriate individual to include in the study. While it could be a safe assumption that family caregivers who attended clinic would be appropriate for family dyad transition research, there may be special cases where individuals who attend clinic are not as involved at home as they appear in the clinic. The quick assessment gave us insight into the family structure, roles, and responsibilities of other individuals living at home with the AYA who were not present for the clinical appointment. Traditional recruitment methods would have missed these valuable findings.

Ideally, research on topics such as transition should focus on recruiting key family stakeholders who are knowledgeable about the care of the AYA. Not all family caregivers may be involved at the same level or impact the AYA's disease management in the same way. Families are inherently different; there may be instances where two parents jointly share a primary caregiver role for their AYA. It is equally likely that in other families one parent may serve as the primary caregiver while the other parent is only passively involved (Kelly & Ganong, 2011). It is important to note that genograms were designed based upon the concept of nuclear families, so when employing this recruitment strategy, it was critical to remember this limitation. Family structures and types are highly diverse and when using genograms, the researcher must remember to ask participants to review the final construction of the genogram to ensure accuracy. Recruitment is a challenging part of any study and this easy method has the potential to help researchers better target appropriate subjects within family research and provide more insight into the structures, roles, and responsibilities of different family members at the same time. Future research should be conducted to compare the impact of utilizing genograms for research recruitment versus without utilizing this approach. This would help to establish validity of this method for recruitment.

A future consideration from this analysis is that genograms may also provide benefit to transition care within the clinical setting. Ambulatory clinic visits offer small, yet important opportunities to provide support to AYAs living with chronic diseases and their family caregivers as the AYA is preparing for transition. To capitalize on these limited moments, healthcare providers could better target education and interventions if they had a better

understanding of the family caregiver and AYA's responsibilities for disease management. While healthcare providers may default to only providing education and intervention to the parent or legal guardian who is present in the clinic, this may not effectively impact other family caregivers who are actively engaged in the AYA's disease management at home who do not attend clinic. Beyond research recruitment, genograms could also support healthcare providers providing routine care for AYAs living with chronic disease as they prepare for transition. More research is needed to assess how genograms could impact transition preparation interventions in the clinical setting.

Limitations

There are limitations to genogram recruitment methods. While genograms may not be valuable in every research study, we strongly believe that this method could help to inform family-based research on transition care and preparation. For this study, creating the genogram only took 5–10 minutes; however, needed information gathered during the development of a genogram will determine the length of time this process takes, meaning that for some studies creating genograms could become a cumbersome, lengthy process. Self-reporting of family relationships is another limitation of this method. Participants could forget to report important details or incorrectly report information. To reduce self-reporting bias, researchers and clinicians could triangulate this information by gathering information from more than one research participant (e.g., AYA family and family member). This would help to verify information but could also increase the time needed to complete this method.

Within this secondary analysis, there were a few limitations. The original study used a convenient sampling method so the genograms included were not from a random sample of participants. In addition, inferential statistics were not performed in this secondary analysis due to small sample size. Finally, the findings of this secondary analysis are limited to one chronic disease condition so future research should explore this method in other disease populations.

Conclusions

We described a novel way to apply genograms to ensure appropriate caregivers were identified for a dyadic research study assessing AYA preparing to transition from child-centered to adult-centered care. When doing research with dyads, validity of the findings can be influenced by informants. It is important to be careful in the selection of the research participants so that those individuals with the most information specific to the topic are included. Genograms can be a useful way to explore the quality of family relationships and help to provide a comprehensive holistic picture of the AYA's environment and the family's caregiving patterns. It is also the best way to identify the persons who should be recruited for transition research to learn more about transition preparation at home and to provide targeted family and family member interventions support successful transition.

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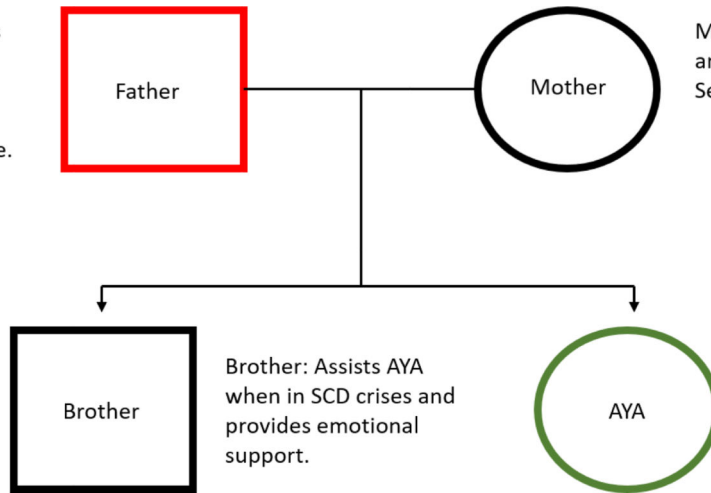
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Father: Primary caregiver. Provides support for setting and attending appointments, making decisions, stays on top of daily SCD care including medications and self-care. Study Participant.



Mother: Takes a role in setting and attending appointments. Secondary caregiver.

Brother: Assists AYA when in SCD crises and provides emotional support.

AYA: Study participant.

Figure 1:
Genogram 1

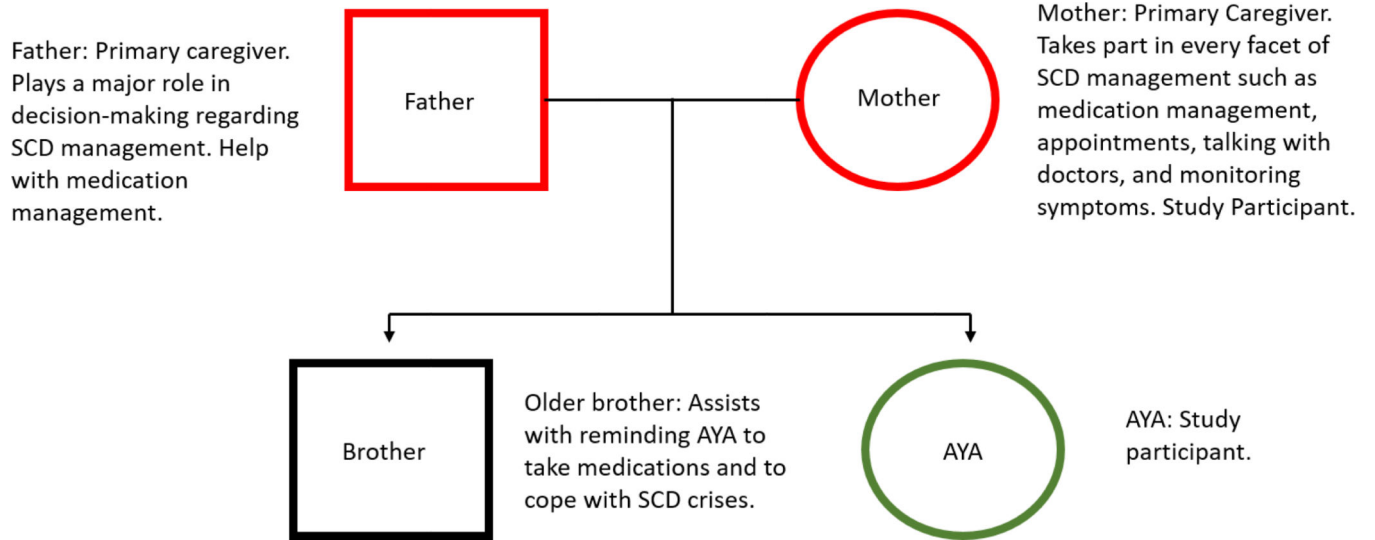


Figure 2:
Genogram 2

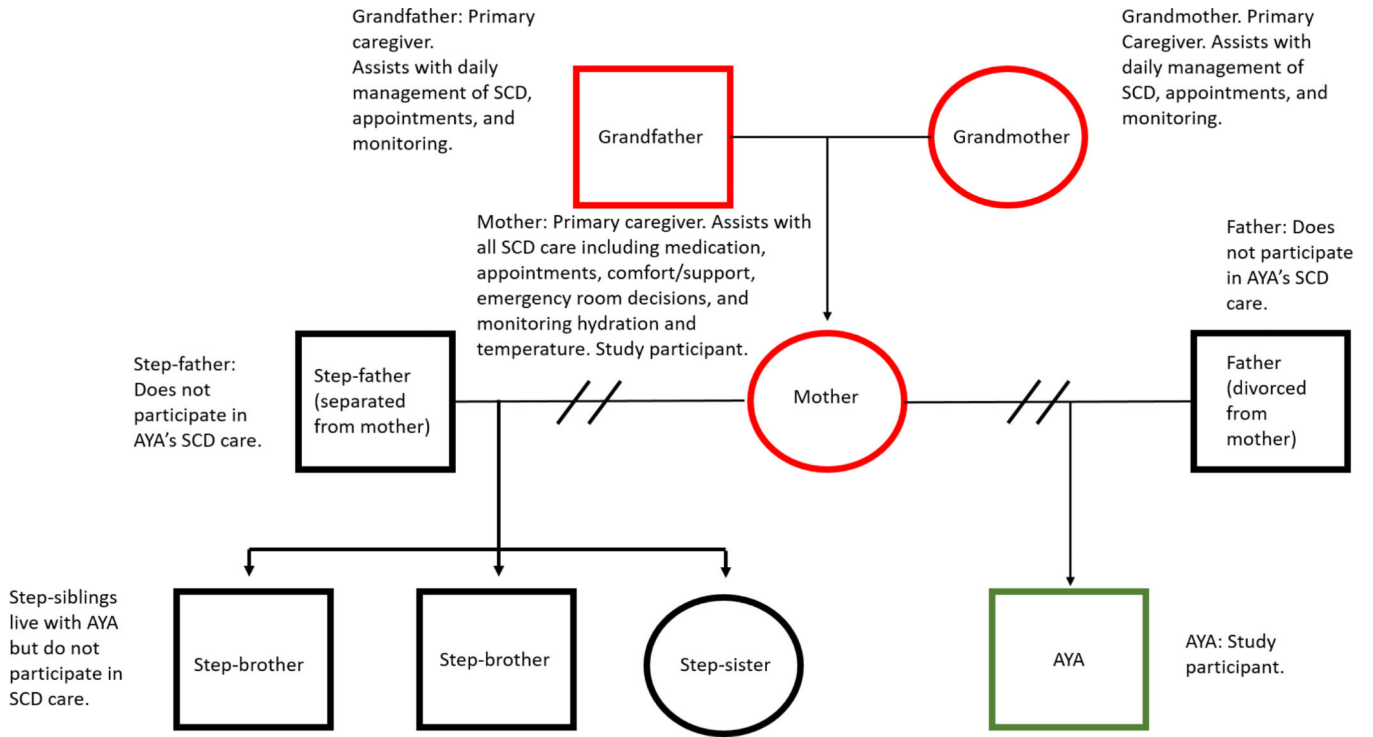


Figure 3:
Genogram 3

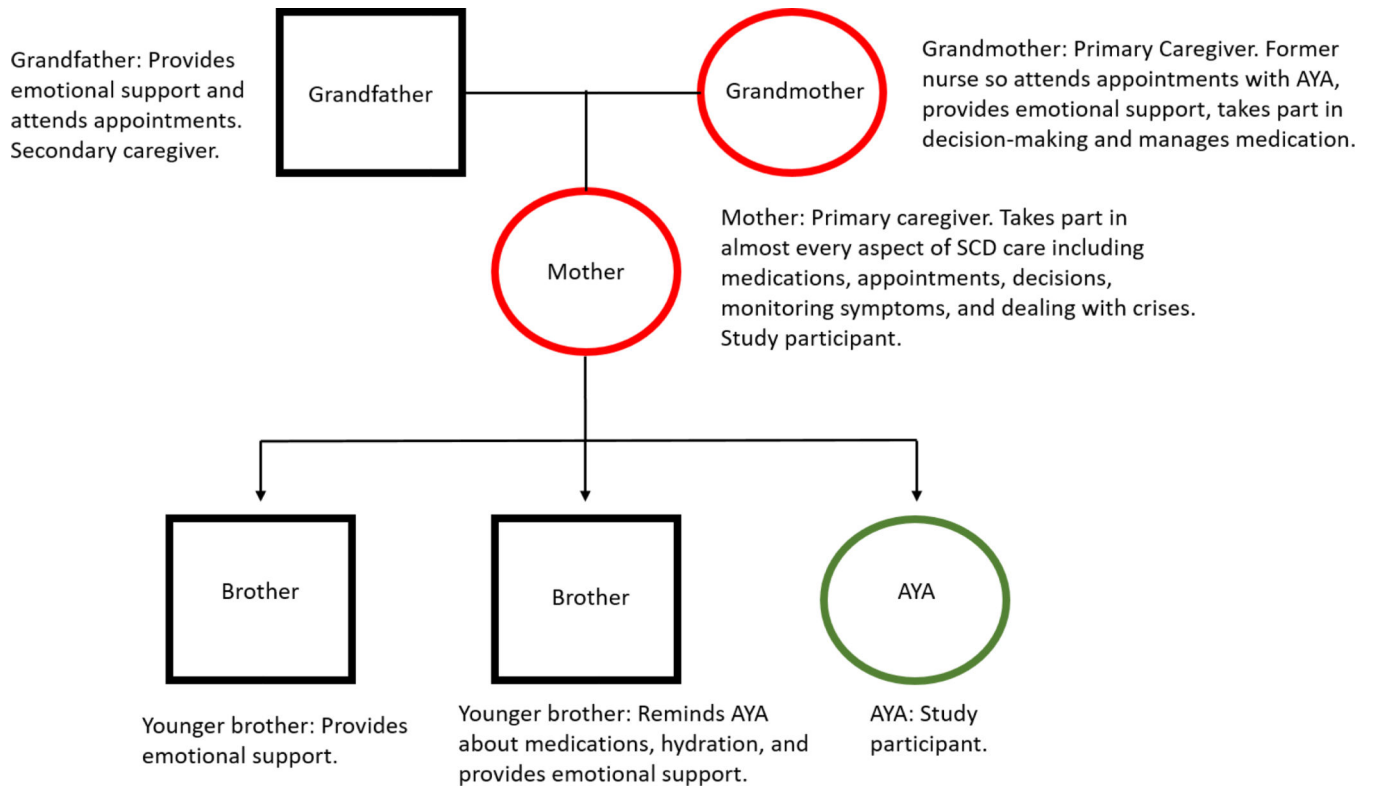


Figure 4:
Genogram 4

Table 1

Sample Characteristics

Variable	n(%) or M(SD)
Parents marital status	
Single parent	18 (36%)
Married	26 (52%)
Divorced/separated	6 (12%)
Number of Primary Caregivers	
1 Primary Caregiver	43 (86%)
2 Primary Caregivers	5 (10%)
3+ Primary Caregivers	2 (4%)
Primary caregiver gender participating in study	
Female	44 (88%)
Male	6 (12%)
Relationship of Primary caregiver	
Participating in Study	
Mother	41 (88%)
Father	6 (12%)
Aunt	1 (2%)
Older sister	2 (4%)
Gender of Primary caregivers not	
Participating in Study (n = 8)	
Female	4 (8%)
Male	4 (8%)
N/A	42 (84%)
Relationship of Primary caregivers Not	
Participating in Study (n = 8)	
Mother	1 (2%)
Father	3 (6%)
Aunt	1 (2%)
Grandmother	2 (4%)
Grandfather	1 (2%)
N/A	42 (84%)
Secondary Caregivers Present at Home	
Yes	22 (44%)
No	28 (56%)
Siblings Provided Support to AYA	
Yes	31 (62%)
No	17 (34%)
N/A	2 (4%)