

## Sigma's 30th International Nursing Research Congress

### Incorporating Future Planning Into the Medical Plan of Care for Adults With Down Syndrome

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**Purpose:** Due to advances in medical technology and greater access to care, adults with Down syndrome (DS) are now living longer than in past generations. It is now common for adults with DS to live into middle and even old age, which means they are likely to outlive their parents. Most adults with DS remain in the family home with the parents as primary caregivers until the parents are unable to care for them any longer due to disability or death. Adult siblings have been identified as the most likely future caregivers, but little is known about what it is like to be a primary caregiver for an adult sibling with DS.

**Methods:** In an effort to fill the gap in the literature, a descriptive, phenomenological study was conducted to examine the experience of being an adult sibling of someone with DS and assuming primary caregiving responsibilities for that sibling upon the death of the parents. Data collection was achieved by doing a series of three, 60-90 minute interviews each with seven participants who were partial or full caregivers for their siblings who had DS. Interviews were audiotaped and transcribed verbatim by the researcher. Standard data analysis techniques of sorting, coding, and thematic analysis were applied. Findings were reported in rich, narrative format and detailed what this experience was like in the words of the participants.

**Results:** This paper reports findings related to the management of chronic healthcare conditions of the aging adults with DS. The experience is described by five of the participants in the study who transitioned into the primary caregiving role upon the deaths of their parents. Findings suggest that participants not only lacked general knowledge about DS, but also had no idea about specific medical issues affecting their siblings with DS. No medical information had been passed down to the new primary caregivers by their parents to assist them in their new roles as caregivers. There was a lack of formal planning for the succession of caregiving in these families. In some cases, participants had to "rebuild" health histories by taking their siblings for full medical and psychological examinations to detect health conditions. There were gaps in continuity of care and in access to support services until new health care contacts and support services could be established. Participants reported caring for the present medical issues of their siblings was a "huge responsibility" and anticipating future medical issues related to aging caused additional stress and anxiety for them.

**Conclusion:** The findings of this study provide implications for advanced practice nurses (APNs) who care for adults with DS and their caregivers. During medical visits, APNs can initiate the sensitive discussion of planning for the future care of the adult with DS when the parents are no longer able to provide this care. Parents should be encouraged to ask potential adult sibling caregivers to participate in medical visits and have access to medical information and care plans while the parents are still the primary caregivers. By encouraging and supporting future planning for the succession of care for the adult with DS, APNs can decrease dangerous lapses in care upon the death of the parents, ease the burden of assuming primary caregiving responsibilities on the adult sibling, and ultimately improve the health and quality of life for the adult with DS.

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**Title:**

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**Keywords:**

Advanced Practice Nurses, Down syndrome and future planning

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## Abstract Summary:

By the end of this session participants will be able to discuss common medical conditions that affect adults with Down syndrome as they age and develop care plans that include planning for the succession of the primary caregiving role.

## Content Outline:

**Detailed outline of material to be included in the presentation:**

## Introduction

- Overview of health issues that affect adults with DS and complications of aging
- Discussion of primary caregiving responsibilities for adults with DS performed by primary caregivers
- Introduction to background of the phenomenological study about the experience of becoming a primary caregiver for an adult sibling with Down syndrome upon the death of the parents

## Discussion Points

Main point #1: Review of findings related to medical care taken from phenomenological study about the experience of being a primary caregiver for an adult sibling with Down syndrome.

Main point #2: Discussion of how the lack of future planning for care succession affects the quality of health care for an adult with Down syndrome when there is a change in primary caregivers.

Main point #3: Discussion of ways Advanced Practice Nurses can include future planning into the medical plan of care for adults with Down syndrome by including parents and siblings in the care plan and encouraging future planning for succession of care.

## Conclusion

- It is necessary for parents to plan for the succession of caregiving for their adult children with Down syndrome, but making these decisions are difficult for parents to do without appropriate support.
- Advanced Practice Nurses can initiate these discussions and support parents with the sensitive decisions that need to be made to ensure the continuity of care for adults with Down syndrome.
- Advanced Practice Nurses can decrease gaps in continuity of care for adults with Down syndrome upon succession of primary caregivers and make the transition of care easier for these families.

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**Author Summary:** Dr. Sciscione is an Assistant Professor in the Nursing Department at Monmouth University. She teaches both undergraduate and graduate nursing courses. Dr. Sciscione completed her PhD in Nursing Theory Development and Research from Seton Hall University. Her dissertation research was a phenomenological study about the experience of being a partial or full caregiver for an adult sibling with Down syndrome. She is the mother of an adult daughter with Down syndrome and two adult sons.