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Factors Affecting State Policies to Support Family Caregivers

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Nephrology patients who are elderly or disabled are often able to live at home because they receive constant or frequent assistance with activities of daily living (ADL) from unpaid family members. However, the caregiving experience can be accompanied by losses in physical and psychosocial health dependent on the individual appraisal of stress or burden and the benefit of outside assistance. Some states recognize the value of unpaid caregivers and establish programs that assist them directly or indirectly, but these policies are not consistently adopted by all states. The purpose of this study is to describe the factors that have impeded or facilitated the development of publicly funded state programs to support long-term care family caregiving in the home. The goal is to assist nephrology nurses to develop strategies that can effectively be used to advocate for nephrology patients and their families who wish to remain at home despite the need for ongoing long-term care.

A study framework (Ringquist and Garand, 1999) was used to guide the study, identifying internal state factors, factors external to the state, and issue-related factors that typically influence policy formation. A sample of two states enabled comparison of factors affecting policy formation and their contexts in different states. These states were chosen using both theoretical and convenience sampling.

An explanatory, comparative case study method was used in order to answer the research questions using multiple sources of data collection. Informant interviews, review of government and non-government documents, and observation of selected meetings and legislative hearings were used as data sources. A qualitative software program, Atlas ti, was used to organize and analyze the data. Results were described in three parts: a chronology of the first state's policies and programs affecting family caregivers, a chronology of the same type for the other state, and the themes or factors emerging from analysis of all the data as critical to policy development and maintenance.

Results demonstrated substantial differences between the two states in policy development affecting family caregivers. Ten themes or factors that influenced policy were identified – seven internal state factors, two factors external to the state, and one issue-related factor. Primary internal state factors were state fiscal environment and philosophy and advocacy. These factors made a difference in every policy decision and influenced the impact of other internal factors – state agency structure, executive branch support, bureaucratic expertise and capacity, risk of legal liability, and regulatory constraints. Factors external to the state were federal policy changes influencing state policies and interstate influences. Only one issue-related factor, use of research findings, was discovered. Examples of how these factors were exemplified in each state with a between state comparison are detailed in the study results, often using exact informant language. Conclusions provide a guide for nurse advocates who strive to find the right time and methods to lobby for program development or expansion benefiting family caregivers. Suggestions regarding the value of nurses' narratives and partnering with families to circumvent barriers to effective policy development are included.

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