IN INVOLVEMENT OF CHRONICALLY ILL OLDER-AGED ADULTS IN HEALTH CARE DECISIONS: A META-SYNTHESIS

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Purpose: By 2030, more than 60% of the older adult population, or almost 37 million people, will be afflicted with multiple chronic conditions. Person-centered care advocates for cognitively capable and interested patients to be empowered to make decisions about health care issues that affect their daily lives in order to achieve outcomes congruent with their individual preferences. For older adults, the treatment of chronic illness is a large part of their daily lives. A major step in the success of person-centered care is the active involvement of patients in health care decision-making to the degree they desire. The purpose of this review was to synthesize the qualitative findings over the last 20 years, describing the meaning of involvement or non-involvement in chronic illness care decisions, as well as the barriers and facilitators to involvement, as perceived by older-aged persons in the community or in nursing homes.

Methods: Five health-related databases were searched for terms including: person-centered, older-age, nursing home, chronic illness, involvement, preferences, autonomy, and decision-making. Studies were included if they: were in English; sampled chronically ill persons ≥ 65 years of age with little to no cognitive impairment; and used a qualitative thematic or interpretive methodology describing older-aged persons’ perceptions of involvement in everyday health care decisions. Studies were appraised for quality based on degree of data transformation. Domain analysis was used to analyze the studies. Trustworthiness was maintained through team discussion of quality appraisal and findings and an audit trail of coding and thematic decisions.

Findings: Initial literature searches yielded 1020 articles, reduced to a final sample of 7 after review for inclusion criteria and quality appraisal. Studies were classified according to design, methodology, sample, and findings. Domain analysis yielded 5 themes: (1) Time is precious; (2) Being recognized because I matter; (3) Unworthy of being taken seriously; (4) Struggle with equality; and (5) Connections and opportunities. A 6th theme, Strive to empower, not control, was specific to the nursing home studies only. Involvement in chronic illness decisions conveyed a validation of personhood and recognition of importance. Not being involved cast doubt on self-worth and equality. Facilitating factors included being recognized as an individual and being treated with respect and dignity, largely through the investment of quality time by the provider. Barriers included inadequate time spent by the provider, lack of information, and provider disinterest. The need to empower rather than control was stressed by the nursing home studies.

Conclusions: Some older-aged people, regardless of residence, have a desire for involvement in health care decisions, benefit from involvement, and may suffer from non-involvement. More work is needed to investigate facilitators for nursing home resident involvement addressing the ongoing conflict between beneficent paternalism and resident autonomy. The concepts of inadequate time, interest, and commitment to the individual by the health care system and providers emerged as the greatest perceived determinants of resident involvement across studies.

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