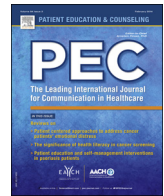




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Review article

The TRIO Framework: Conceptual insights into family caregiver involvement and influence throughout cancer treatment decision-making

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This paper is dedicated to the memory of our colleague, the late Professor Cathy Charles, who made a major contribution to the TRIO conceptual framework.

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ABSTRACT

Objective: Family caregivers are regularly involved in cancer consultations and treatment decision-making (DM). Yet there is limited conceptual description of caregiver influence/involvement in DM. To address this, an empirically-grounded conceptual framework of triadic DM (TRIO Framework) and corresponding graphical aid (TRIO Triangle) were developed.

Methods: Jabareen's model for conceptual framework development informed multiple phases of development/validation, incorporation of empirical research and theory, and iterative revisions by an expert advisory group.

Results: Findings coalesced into six empirically-grounded conceptual insights: i) Caregiver influence over a decision is variable *amongst* different groups; ii) Caregiver influence is variable *within* the one triad *over time*; iii) Caregivers are *involved* in various ways in the wider DM process; iv) DM is *not only amongst three*, but can occur among wider social networks; v) Many *factors* may affect the form and extent of caregiver involvement in DM; vi) Caregiver influence over, and involvement in, DM is linked to their *everyday involvement in illness care/management*.

Conclusion: The TRIO Framework/Triangle may serve as a useful guide for future empirical, ethical and/or theoretical work.

Practice implications: This Framework can deepen clinicians's and researcher's understanding of the diverse and varying scope of caregiver involvement and influence in DM.

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1. Introduction

Family caregivers regularly attend cancer consultations with an adult patient (accompaniment rates range from 64 to 86%) [1,2]. Typically one key family caregiver attends, and this is usually the patient’s spouse/partner or adult child (less commonly a patient’s parent, sibling, other relative or friend) who is involved in the care of the patient [3]. This key family caregiver also often participates in the decision-making (DM) process [4]- some in a supportive or facilitative capacity, while others are involved more directly in DM.

The involvement of family caregivers in DM may be particularly important among some families, as medical decisions often impact not only the patient, but also the family caregiver [5,6]. For example, the spouse of a young adult patient is likely to be directly impacted by a decision to undergo treatment which affects fertility. Correspondingly, daily life will be affected for the adult child caregiver of an elderly patient who decides to receive daily outpatient treatment requiring transportation and accompaniment to the hospital. Finally, family caregivers will be impacted by a decision for the patient to receive home-based palliative care and die at home. Despite the frequent involvement of family caregivers in consultations and decisions, most conceptual papers discussing medical DM published to date have focused on the clinician-patient dyad [see 7]] rather than the clinician-patient-family caregiver triad and larger social networks. However, a growing empirical literature acknowledges the significant role of family caregivers in medical DM.

Most cancer patients (49–84%) and family caregivers (54–59%) report both preferring and experiencing some family caregiver involvement in DM [8–12]. However the form and extent of family involvement in DM appear to vary widely. Most patients and family caregivers prefer family caregivers’ involvement to be facilitative or collaborative [9,12], and this preference is reflected in practice. In a US study examining the experiences of over 5000 patients with lung and colorectal cancer, 1.5% of the sample reported their family made important decisions on their behalf, 49.4% reported equally sharing decisions with family, 22.1% reported some family involvement, and 28.5% of patients reported little or no role for their family in DM. Interaction analyses of audio/video-taped medical consultations similarly highlight that family caregivers are often actively involved in consultation communication [e.g. 2,13]], and DM [13–15]; and also reveal that family caregiver involvement in DM is variable both across consultations and among different triads [13]. Family caregiver involvement in DM can vary on a spectrum from passive to dominant [4,16,17] and the form/extent of involvement may be influenced by contextual factors such as the patient’s age, gender, health status, cultural background and

relationship with the family caregiver [11,18]. Despite the growing empirical evidence base, there remains limited conceptual description of family caregiver involvement in DM.

1.1. Conceptual frameworks of family caregiver involvement in DM

Whilst the majority of conceptual publications to date have focused on the clinician-patient dyad, some more recent publications have started to acknowledge the importance of significant others, including family caregivers. For example, Rapley’s [19] account of ‘distributed DM’ highlights that decisions are embedded within and are shaped by social interactions, which can include family and friends within and outside the medical consultation. Additionally, Epstein and Street’s [20] concept of ‘shared mind’ proposes that decisions may be made within social networks, where new ideas and perspectives may emerge through the sharing of thoughts and feelings between individuals (including family and friends of a patient). Elwyn et al.’s [21] model of collaborative deliberation similarly acknowledges that DM is not usually done in isolation and recognises the value of collaboration between individuals (including clinicians, family, and friends). Additionally, Légaré et al.’s [22] Interprofessional Shared DM model (IP-SDM) explains that many members of the inter-professional team as well as family caregivers are involved in the treatment DM process. Whilst these conceptual publications of medical DM have started to acknowledge the input of family caregivers in DM, clear delineation of family caregiver roles and dynamics within the DM process remain largely unexplained.

A limited number of more specific conceptual descriptions of family caregiver involvement in DM have also been published. These conceptual descriptions have predominantly been typologies based on qualitative data, which describe how family caregiver involvement in the DM process varies along a spectrum from passive to dominant [16,17,23,24]. Two triadic process models have also been proposed [25,26], which posit how triadic interactions and patient outcomes (e.g. satisfaction, knowledge, and adherence) are influenced by factors including patient/family/clinician personality, knowledge, and attitudes. However, these existing descriptions do not capture the complex interactions and dynamics of all three participants (physician-patient-family caregiver) in the DM process.

1.2. The issues with ‘ideal’ or ‘gold standard’ DM styles when caregivers are involved

Besides Krieger [27], who proposed that aligned patient-family caregiver preferences for the extent of caregiver involvement in

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