

A SYSTEMIC APPROACH TO NON-DIALYSIS MANAGEMENT

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This presentation draws on systemic theory in discussing working with individuals and families when withdrawing or not initiating dialysis is being considered. It highlights the shared and often very different needs and expectations of all involved in the process, the patients, their families and health care teams. Key concepts of palliative care are outlined noting the distinction between the palliative care delivered by all health professionals and specialist palliative care teams who educate and support other health professionals, taking direct referrals where there are difficulties around symptom control, psychosocial and spiritual care. Emphasis is placed on palliative and renal care teams working together and home, hospice and hospital care.

Despite opposition to withdrawing other life-sustaining support, one seldom hears opposition to the withdrawal of dialysis. Nonetheless the decision not to treat is extremely complex: few have the language to talk about dying. It is at this stage of the condition that the boundary between family and professional is likely to be most ambiguous. Despite the need for discussion, staff and families find this extremely stressful and intimidating, compounding the difficulty of decision making.

Protocols have been developed to assist families and staff through this important passage of life. Key issues to consider include legal clarity concerning the patient's ability to reach an informed choice; culture of the renal unit; clear professional strategies for assessment and decision making; value of pre-set but flexible pathways of care for the dying, initiating discussion of advanced care planning early with patients. Consensus is that good end of life care brings about: physical comfort, emotional support and shared decision making; the dying person is treated with respect; information and emotional support is provided to family members; the setting allows for resolution and reconciliation; co-ordination across care settings; absence of avoidable suffering and stress on behalf of patients, families and staff, consistent with clinical, ethical and cultural standards.

Unresolved grief can have long term psychological consequences. Recognizing the importance of "getting it right" can be useful or paralyzing, resulting in anxiety about how to pace what is said or holding back for fear of intruding. For the family, the anticipation of death may re-evolve feelings that relate to prior separations and loss, compounded the difficulties of "getting it right enough". Differences may also arise in the fit of beliefs between staff and family. As such, the presentation explores what might contribute to difficulties and considers ways of working with this.

The presentation ends with discussing the cultural context, and the dilemma of applying ideas about truth telling and advanced planning, based on individual autonomy, to people who place greater values on family connectedness and the family's role in decision making. Noting growing evidence that black and minority ethnic groups are overrepresented amongst this patient group, the paper questions the meaning of the right to choose when one has experienced inequitable access to health care, and ends with a plea for more research, training and consultation.