

HOW DO FAMILY AND INFORMAL CARERS OF PATIENTS UNDERGOING HD INFLUENCE ADHERENCE TO TREATMENT?

Mari Louise Mc Peake Ward Manager Antrim Area Hospital

Dr Helen Noble Senior Lecturer Queens University Belfast

Dr Peter O Halloran Senior Lecturer Queens University Belfast

Introduction

- Incidence of end-stage kidney disease is increasing
- Treatment burden is high
- Adherence can be a issue for many patients.
- Family and informal carers may be able to influence care



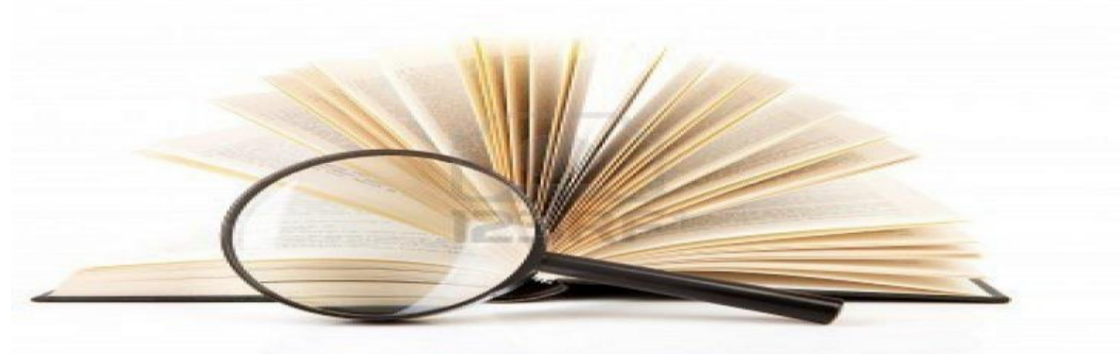
Why is Adherence a problem?

- Mood
- Self-efficacy – belief in self to achieve goals
- Treatment perceptions – health vs illness
- Social support
- Patient demographic characteristics related to patient adherence:
 - Young age
 - Race
 - Educational level



Literature Review

- To investigate how family and informal carers of patients undergoing HD influence adherence to treatment
- Systematic review of the literature
- Key words used included haemodialysis, dialysis and hemodialysis (American spelling) family, loved ones, carers, significant others, adherence, compliance and concordance



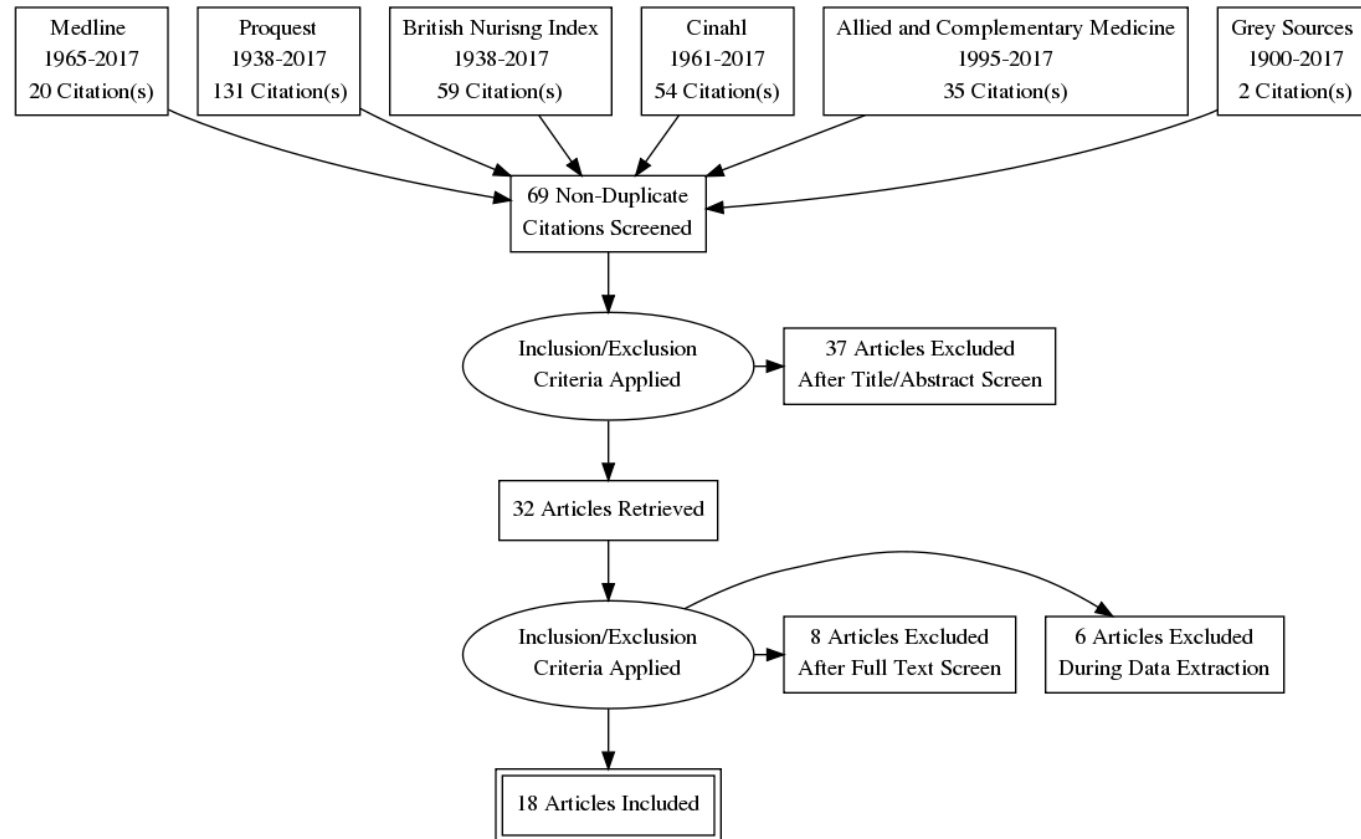
Literature Review

Inclusion Criteria

- Studies which related to how family and informal carers of patients undergoing HD influence adherence to treatment
- Written in English
- No year restriction



Prisma Flow Chart



Findings

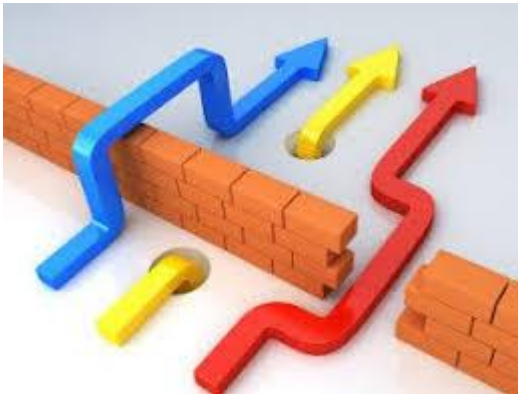
- Family and informal carers can and do influence adherence.
- The **relationship** between carers and patients requires careful consideration.
- **Healthcare professionals** need to be able to manage expectations.



shutterstock.com · 188696462

Findings

- **Regular support and feedback** required for carers to continue in their role.
- **Barriers** to engaging with carers need to be overcome to ensure patient centred evidence based care is achieved.



Impact on Practice

- Enhanced education and training for H
- Use of specialist nurses
- Peer support/expert patients
- Education programmes for patients and carers



Further Research

- **Collaborative approach** to research with informal carers.
- Deepen understanding of the **relationships** between informal carers and patients and how these may help **influence care**.
- How to best provide **education and support** to patients to help improve adherence
- Develop strategies for healthcare professionals to **overcome barriers** to engaging family and informal carers

Thank you

- Any Questions?



Supporting References

Ashby M., Hogg C., Kellehear A., Kerr P.G., Brooks D., Nicholls K., and Forrest M. (2005) Renal dialysis abatement: lessons from a social study. *Palliative Medicine* 19: 389–396.

Avril-Sephula B., Meekums B., and Jackson C. (2014) How do partners living with patients undergoing HD cope? *Journal of Renal Nursing* 6(3): 133-137.

Axelsson L., Klang B., Lundh H C., and Jacobson S. (2015) End of life patients treated with HD as narrated by their close relatives. *Scandinavian Journal for caring Sciences* 29(4):776-784.

Axelsson L., Klang B., Carina L., Jacobson S., and Glessman S. (2015) Meanings of being a close relative of a family member treated with HD approaching end of life. *Journal of Clinical Nursing* 24(3-4): 447-456.

Baillie J., and Lankshear A. (2015) Patient and family perspectives on peritoneal dialysis at home: findings from an ethnographic study. *Journal of Clinical Nursing* 24(1-2):222-234.

Ciccolini G., Palma E., Simonetta C., and Di Nicola M. (2012) Influence of family carers on HD patient's adherence to dietary and fluid restrictions: an observational study. *Journal of Advanced Nursing* 68(11):2410-2417.

Efe D., and Kocaoz S. (2015) Adherence to diet and fluid restriction of individuals on Hemodialysis treatment and affecting factors in Turkey. *Japan Journal of Nursing Science* (2015) 12, 113–123.

Lee S. (2002) Dietary and fluid compliance in Chinese hemodialysis patients. *International Journal of Nursing Studies* 39(70):695-704.

Lowney A., Myles H., Bistrowe K., Lowney E., and Shepherd K. et al (2015) Understanding what influences the health related quality of life of patients undergoing HD. A collaborative Study in England and Ireland. *Journal of Pain and Symptom Management* 50(6):778-785.

Reiss D. (1990) Patient Family and Staff responses to End Stage Renal Failure. *American Journal of Kidney Diseases. The Official Journal of the National Kidney Foundation* 15(3) 194-200.

Morales L., Burrows J., Gizis F., and Brommage D. (2007) Dietary Adherence in Hispanic patients receiving HD. *Journal of Renal Nutrition: The official Journal of the Council on Renal Nutrition of the National Kidney Foundation* 17(2):138-144.

National Health Service. (2011) Home Dialysis: Who cares for the Carer? Better Kidney Care for All. Prolog Sudbury. Accessed online www.kidneycare.nhs.uk Last accessed 22/4/17.

Untas A., Rasclé N., Idier L., Lasseur C., and Combe C. (2012) Family relations, mental health and adherence to nutritional guidelines in patients facing dialysis initiation. *Psychology and Health* 27(7): 753–766.

Ziegert K, Fridlund B, and Lidell E. (2006) Health in everyday life among spouses of patients undergoing HD: a content analysis. *Scandinavian Journal of Caring Sciences* 20: 223–228.