The Importance of Raising Chronic Kidney Disease (CKD) Awareness for Young People and Parents:
Young People with Chronic Kidney Disease (CKD)

Shahid Muhammad, The Renal Patient Support Group (RPSG), Bristol, UK

Barbara Sen, University of Sheffield, Sheffield, UK

ABSTRACT

Chronic Kidney Disease (CKD) in young people is complex, with many requiring Renal Replacement Therapy (RRT). Young people may be disenfranchised by perceptions of helplessness and feelings of powerlessness against a backdrop of diminished health, consequently impacting on their capacity for effective coping. Not surprisingly, young people and parents/ guardians seek online support through social media which offers advantages over standard forms of engagement/ education. The claim here is that future clinicians are unable to best practice unless they get more involved in patient-led initiatives and better appreciate how young people with CKD and their parents use the internet/ social media as an effective learning resource. Social media can positively influence young people, parents/ guardians to gather resources, supporting them to develop self-care and enhance shared-decision-making, empowering them to adopt coping strategies. Health professionals should have an understanding of what resources are available to young people and parents/ guardians.

Keywords: *Chronic Kidney Disease, Coping, Empowerment, Facebook, Internet, Social Media, Young People*

INTRODUCTION

Chronic Kidney Disease (CKD) (stages 4-5) in young people is complex, with many requiring renal replacement therapy (RRT). Young people may be disenfranchised by perceptions of helplessness and feelings of powerlessness against a backdrop of diminished health, consequently impacting on capacity for effective coping. Coping is not a stand-alone phenomenon; it encompasses all changes as they occur during continued exposure to health and social care challenges. Coping

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is thus central to the life of a person living with any long-term or chronic illness; poor coping is linked to increased risk of morbidity and mortality (Ray et al. 1982).

It has been documented that 80 to 90% of all care for people with Long Term Conditions (LTCs) is undertaken by patients themselves and their families (Vickery et al. 1983). Most young people living with chronic illnesses such as CKD spend the vast majority of their life with parents/ guardians looking after them, and under the direct care of a clinical team. Coping strategies are therefore fundamental to dealing with chronic health problems. However there are few studies of coping among people living with advanced CKD, and especially among younger people.

Social media usage has also grown exponentially with social media sites such as Facebook, Twitter, Instagram and others now representing 20% of time online and much more in young people (Nielsenwire 2013). Not surprisingly patients and carers seek peer-to-peer support via social media which offers advantages over standard forms of engagement/ education with wide accessibility, immediacy and offers an opportunity for patient education (Timimi 2012). The paediatric nephrologist needs to ensure they are providing the best care with the understanding of what resources are available to their patients.

AIM

The aim of this work is to highlight the importance of raising awareness for CKD for young people and parents, coping and how using social media can influence care and shared-decision-making. The claim here is that future clinicians in paediatric nephrology are unable to develop 'best practice' unless they get more involved in patient-led initiatives and better appreciate how young people with CKD and their parents use the internet/ social media as an effective learning resource.

THE PAEDIATRIC NEPHROLOGY SPECIALTY

Paediatric nephrology brings scope to collaborate amongst various organ specialties, platforms of disease-states, research in clinical and laboratory medicine, and with the intention of more science translating into mainstream practice. In appreciating the care for young people with CKD, paediatric nephrology (like many other paediatric specialties) has long implemented a clinical science ethos and thus conventionally has maintained an academic stance. Whilst nephrology is specific in its own right, paediatric nephrology becomes more intricate because of physicians caring for infants and adolescents with renal disease, Chesney (2005) states:

The future will be the focus of paediatric nephrology training. (Chesney 2005)

CLINICAL MEDICINE

Clinical Medicine is a very 'hands on' from of medical practice, but to emphasize how rapid changes in methodologies take place; if 'yesterday's' protocols, for example, those in renal medicine that might be used to treat young people 'today', this could mean a subtle (but significant) difference between patient mortality, survival and morbidity 'tommorrow' (Trichopoulos 1996).

The immune system in young renal patients will become heavily compromised owing to infection, RRTs and a variety of other medical regimens. The physician needs to bear knowledge on entities of the immune system/ immunology and inflammation. The immunology discipline