

THE RENAL PATIENT SUPPORT GROUP: SUPPORTING PATIENTS WITH CHRONIC KIDNEY DISEASE THROUGH SOCIAL MEDIA

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Muhammad S., Allan M., Ali F., Bonacina M., Adams M. (2014). The Renal Patient Support Group: supporting patients with chronic kidney disease through social media. *Journal of Renal Care* **40**(3), 216–218.

SUMMARY

Background: The Renal Patient Support Group (RPSG) is a voluntary Facebook group that was developed in 2009 in the UK. The RPSG now has in excess of 5000 members.

Objective: To highlight the work of the RPSG and to describe how the use of social media has helped raise awareness of chronic kidney disease (CKD). The RPSG offers online peer support internationally, with members sharing their experiences.

Methods: Since the RPSG is mainly a Facebook platform, this medium has lent itself to raising CKD awareness, also allowing group members to share real-life stories.

Conclusion: The RPSG continues to expand and invites health professionals to gain opportunities provided by social media networks to improve the health of their patients by facilitating and getting involved in 'real' discussions.

KEY WORDS Chronic kidney disease • Facebook • Social media • Patient involvement

INTRODUCTION

Chronic kidney disease (CKD) is a life-threatening, enduring condition that requires lifelong treatment such as renal replacement therapy (RRT) (Kaltsouda *et al.* 2011). The prevalence of CKD appears to be increasing globally and is likely to increase further as a consequence of ageing and increased prevalence of Type II diabetes mellitus (Hamer & El

Nahas 2006). Approximately 6–7% of adults in England have Stage 3–5 CKD (de Lusignan 2006).

There is a correlation between coping with the stresses of living with a chronic condition and health-related quality of life (HRQL). There is a consistent association between a decline in HRQL and increases in morbidity, hospitalisation and adherence with treatment (Kaltsouda *et al.* 2011).

This paper describes one initiative where patients and carers have developed an on-line support group for people with CKD. It is also an example of user and carer involvement in clinical practice and research.

One example of a user-involvement initiative is the Kidney Research and Education Initiative (KREI), a group at City University London with the focus to promote excellence in education and renal research in collaboration with all stakeholders including service user, carers and clinicians (Chamney *et al.* 2012).

Patient and carer members of the KREI have been influential in shaping education and research proposals, enabling the views of those accessing services to have direct involvement in their design. The KREI initiative provides an example of the greater

BIO DATA

Shahid Muhammad is a co-founder for The Renal Patient Support Group (RPSG). He is a specialist biomedical scientist and registered scientist and has a specialist interest in paediatric nephrology. With two fellow co-founders, Shahid set up the RPSG initiative in (2009) to support patients and carers with CKD.



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involvement of service users in sharing their life experiences, which in turn impacts on practice.

SOCIAL MEDIA

Healthcare professionals need to be responsive to opportunities for change by being able to deliver and create rapidly responding, high-quality and accessible care through innovative and potentially novel methods (Kalisch & Begeny 2010). These include social media platforms (e.g. Facebook, Twitter) that create virtual environments for people to connect to one another without the need for a physical presence. These information technology-based modes of communication are increasingly popular methods for people in contact with health and social care provision to share their experiences and to help inform each other.

Social media has also helped health professionals and researchers to better comprehend some of the more detailed care requirements needed by patients with chronic illness. There have been several papers published to inform the use of social media in health care (Murray *et al.* 2004; Farmer *et al.* 2009; Greene *et al.* 2011).

THE WORK OF THE RENAL PATIENT SUPPORT GROUP (RPSG)

The RPSG is a voluntary Facebook group developed in October 2009 by three individuals, two of which receive specialist renal services and one a long-term carer. The initial intention of the RPSG developers was to help support fellow people in south-west England, following routine clinical outpatient appointments. The RPSG developers were aware of the challenge to provide face-to-face support by clinicians in the outpatient setting, owing to limited time.

The RPSG now has a growing population of over 5000 members at various stages of CKD and has 10 volunteer members in the administration team from the UK, Italy, Australia and the USA, who have several roles. In addition, the RPSG is active in research, with 5 of the 10 core group facilitators being active patient researchers.

The RPSG developers explored several online platforms. Facebook was chosen because it has a recognised global reach, is accessible, user-friendly, commonly utilised by a broad demographic and allows the sharing of 'real-time' lived experiences. The RPSG offers online peer support globally, with members in both a sharing and a caring role. The RPSG site has a number of

sections all of which are well used by members. Amongst a number of activities, the RPSG has also organised online learning education seminars inviting health professionals and renal academics to contribute in support of World Kidney Day in two consecutive years (2012–2013).

The growing membership of RPSG demonstrates its accessibility outside the region of the local hospital to which it was initially targeted. The RPSG's reach has now extended beyond the UK to create a global community, allowing interaction in real time to educate people on CKD, provide support and share answers.

The RPSG developers aimed to empower people accessing specialist renal services to be active in their local Kidney Patient Associations (KPAs), which support renal patients via their respective hospitals. In addition to the RPSG Facebook page, in March 2012, the RPSG set up its BlogSpot (<http://shahidrpsg.blogspot.co.uk/>) to inform members on up-to-date information gathered through activities such as conference and seminar attendance. The BlogSpot has become increasingly popular, attracting health professionals and researchers to utilise the platform to collect data. For example, the RPSG research team has supported projects for organisations including Renal Patient View (RPV) (www.renalpatientview.org), the National Kidney Federation (NKF) in the UK (www.kidney.org.uk) and academics in higher education.

RPSG PROJECTS

The RPSG was invited to a British Minority Ethnic (BME) Health Awareness Day 2012 providing insight to the group's efforts raising CKD awareness in ethnic minority groups. The RPSG was also represented at the Westminster Health Forum at the House of Commons, London, UK, 2013, highlighting how there should be tighter collaborations between primary and secondary health care in order to prevent CKD. The RPSG research team have also presented further background highlighting the use of social media in renal care at a number of conferences including Excellence in Paediatrics Madrid, Spain (2012), the Second Paediatric Nursing Association (PNAE) conference (2013) and EHI-Live, Birmingham, UK (2013).

Ongoing, the RPSG is drafting an organ donation campaign titled: The Bristol City Council's Blood and Organ Donation Campaign; The Champions/Drivers Report (2013–2014). The campaign aims to develop strategies to promote organ donation and awareness using education, awareness,

addressing ethics, looking at the science behind transplantation, exploring religious/cultural beliefs, promotion and taking ownership. The campaign aims to have professional collaborations to achieve its outcomes. The RPSG 7-Step Organ Donation campaign is being drafted following the NKF UK Manifesto to Improve Kidney Donation and Transplantation within UK Black & Minority Ethnic Communities. The RPSG organ donation campaign will focus on communities taking ownership in their decision to provide formal consent to organ donation. The RPSG will help increase awareness pathways, helping to increase the organ donation pool and also highlight where service providers can take ownership in meeting further educational and awareness challenges.

IMPLICATIONS FOR PRACTICE

Online technology is becoming ever more advanced, with novel uses for e-health and social media emerging. One of the main implications for future practice is that the RPSG can potentially help patients, carers, parents/guardians and health professionals understand a number of important topics relating to CKD, such as coping, well-being, social care.

Using the RPSG may also support further understanding on how patients with CKD and carers adopt different coping strategies in times of uncertainty. Certainly the understanding of coping strategies is now becoming more central to health care (Muhammad *et al.* 2012). Also, social support, as viewed from a stress-coping model, can be an important factor influencing positive patient health outcomes (Ell 1996).

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CONCLUSION

The RPSG international online community allows its members to explore complementary insights into the care they receive and using social media has helped many gain perspective and answers to questions rapidly. The RPSG platform allows all members to actively seek information from peers. The RPSG continues to expand and invites health care professionals to join social media networks and get involved in 'real' discussions.

ACKNOWLEDGEMENTS

John Gardner, Co-founder and Chief Administrator for the Renal Patient Support Group (RPSG), UK. Vicky Gardner, Co-founder and Chief Administrator for the Renal Patient Support Group (RPSG), UK. Lorraine Pooley, Honorary Researcher and Administrator for the Renal Patient Support Group (RPSG), UK. Lisa McGee, Administrator for The Renal Patient Support Group (RPSG), UK. Sylvia Seth, Administrator for The Renal Patient Support Group (RPSG), UK. Rob Argue, Administrator for The Renal Patient Support Group (RPSG), Australia.

CONFLICT OF INTEREST

No conflict of interest has been declared by the author(s).

AUTHORS' CONTRIBUTIONS

SM: Lead/Corresponding Author and Principal project manager. MA: Read final manuscript and supported coordination of preparing manuscript. FA: Helped to draft manuscript and approved final manuscript before submitting. MB: Edited manuscript. MA: Edited manuscript.

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