Stakeholders' views on a collaborative decision support system to promote multimorbidity self-management: barriers, facilitators and design implications

Talya Porat, PhD[1], Nadin Kökciyan, PhD[1], Isabel Sassoon, PhD[1], Anthony P. Young, PhD[1], Martin Chapman, PhD[1], Mark Ashworth, DM, MRCP, FRCGP[1], Sanjay Modgil, PhD[1], Simon Parsons, PhD[1], Elizabeth Sklar, PhD[1], Vasa Curcin, PhD[1]
[1]King's College London, London, UK

Introduction

An estimated of 50 million people live with multiple chronic diseases (multimorbidity), and €700 billion is spent on chronic diseases in the EU.[1] Multimorbidity is one of the main challenges facing healthcare systems, as these patients often have complex health and social care needs.[2] The management of multimorbidity is complicated since both clinicians and patients struggle to integrate and balance the benefits and risks of multiple recommended treatments.[2] Involving patients in the management of their own health has shown long-term health benefits, for example, self-management of blood pressure has been shown to improve patient outcomes.[3] With the unique capabilities of smartphones and wireless sensors, individuals can monitor a wide range of health and wellness data at home (e.g., blood pressure, activity), and many mobile "apps" to support self-management have emerged. However, each device operates in isolation and is disconnected from both the patient context and the treatment plan. By adopting a collaborative approach based on integrating and combining information from multiple sources, such as wireless sensors, patient's electronic health record (EHR) and clinical guidelines, we aim to provide a tailored decision support system (DSS),[4] supporting patients with multimorbidity to self-manage their treatments in home settings and clinicians to make informed decisions on treatments. In this study, we engaged stakeholders to identify facilitators and barriers to the adoption of such a DSS. Stroke survivors were selected since multimorbidity is very common in this cohort.[5]

Methods

We engaged 34 stakeholders, including stroke survivors with a range of disabilities and carers (N=14), healthcare professionals (N=11) and researchers (N=9), in focus groups and face-to-face interviews. Stroke survivors and carers were recruited from the South London Stroke Register. Healthcare professionals were recruited through the authors' established links with networks of clinical professionals. A focus group consisting 26 participants (10 stroke survivors and carers, 7 healthcare professionals and 9 researchers) was conducted at King's College London, where participants were introduced to the purpose of the study and to the concept of "self-management" and "Decision Support System". This was followed by separate focus group discussions guided by a topic guide with: 1) stroke survivors and carers and 2) healthcare professionals to identify stakeholders' needs, facilitators and barriers from a collaborative DSS. The two groups came back together as one larger group for further discussion and priority setting. We also conducted eight face-to-face individual interviews with stakeholders who could not participate in the focus groups (4 stroke survivors and 4 healthcare professionals), using the same topic guide. Focus groups and interviews were audio-recorded and qualitative data were analyzed thematically to identify emerging themes.

Findings

Facilitators for a collaborative DSS to promote self-management

Stroke survivors and carers indicated that there was no continuity of care after stroke, including no regular follow-ups with healthcare professionals. General practitioners (GPs) are not specialized in stroke management, which enhance the importance of self-management. There was a big variation among stroke survivors in their willingness to monitor health measures such as blood pressure and heart rate on a regular basis, with a few stroke survivors who are satisfied with monitoring these measures once or twice a year at the GP practice, through stroke survivors who would like to monitor these measures at home but act only when needed, to stroke survivors who already self-manage their condition at home and will be happy to use a DSS that collates all the information and provides advice. Both stroke survivors and healthcare professionals noted that patient profile is changing and patients are becoming more technology-savvy and health-oriented which would facilitate the adoption of the DSS. Healthcare professionals commented that devices with longer monitoring capabilities are desired and saw an advantage in receiving and viewing patients' continues measures (such as blood pressure, heart rate and rhythm), which could help them in making decisions regarding medications. They believed these measures could also increase patients' empowerment and concordance with medications (e.g., seeing an improvement in their blood pressure, will encourage them to preserve with the medication). Furthermore, they believed the DSS could help in diagnosing conditions such as atrial fibrillation (distinguishing between regular and irregular heartbeat), sleep apnea, and occurrence of a further stroke.

Barriers and needs to the adoption of a collaborative DSS

Stroke survivors felt they might not be knowledgeable enough to understand the information displayed from the different sources and how to act upon them, they desired the system to inform and guide them and to receive advice also from a healthcare professional who will interpret the data. In addition, a few stroke survivors perceived that smart-watches and health devices are for healthy people, and not for people who had a stroke; that stroke survivors have many health conditions, and hence what to monitor for self-management is not clear, and that for some patients, information overload could mean more stress and anxiety. The consensus among stroke survivors and their carers was that the information and advice should be personalized, based on the specific characteristics of the patient and followed up by carers and healthcare professionals. Healthcare professionals emphasized the importance of context attached to the sensor readings (e.g., for explaining high heart rate). They thought it would be useful to enable patients to enter symptoms, which could help the healthcare professional in interpreting the data. Stroke survivors, carers and healthcare professionals raised a concern that the sensors will only measure the physical aspect, however, the emotional and social aspects should also be part of the self-management support. Stroke survivors and healthcare professionals recommended that the DSS will offer peer support to help people connect with other patients and to deliver joint programs, such as exercise. They claimed that the DSS should empower and motivate patients to self-manage their health, which can be done by providing information (e.g., the patient could ask 'why am I doing or taking this treatment?'), setting goals, medication reminders and rewards.

Implications for design

The collaborative DSS should: 1) be **personalized and tailored** to the patient based on their specific characteristics (e.g., age, co-morbidities). Every patient may have different thresholds and hence different, personalized advice; 2) **provide real-time monitoring and information** on patient's risk factors (e.g., blood pressure, heart rate, heart rhythm, oxygenation, atrial fibrillation, sleep apnea, occurrence of another stroke); 3) **provide personal advice** based on the risk factors' information, such as adjusting medication, information on healthy lifestyle (e.g., diet, exercise), stress control, triggers that could cause exacerbation of the risk factors, alert if values exceed a certain threshold; 4) **enable communication and consultation with a healthcare professional**; 5) **support both "passive" users**, patients who would like to monitor their health for reassurance but do not want to use or interact with this information unless needed, and "active" users, patients who would like to monitor and manage their health regularly; 6) **monitor and support physical, emotional and social aspects** of self-management; 7) **integrate behavior change techniques** (e.g., goal setting) to motivate patients in self-managing their health; 8) provide healthcare professionals a **useful summary of the patient's information** integrated with the patient's EHR.

Conclusion

Advanced capabilities of integrating data from a varied of sources, such as wellness sensors, EHR and clinical guidelines could facilitate personalized care in home settings. Involving stakeholders in understanding needs and barriers to the deployment and adoption of a collaborative DSS to promote self-management, and throughout the development of the DSS, is a critical step in ensuring the integration of data is not just a technical ability but will contain features and functions that would best suit users' needs.

References

1. Rijken M, Struckmann V, Dyakova M, Melchiorre MG, Rissanen S, Ginneken EV. ICARE4EU: Improving care for people with multiple chronic conditions in Europe, 2013.
2. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. The Lancet 2012;380(9836):37-43.
3. McManus RJ, Mant J, Bray EP, et al. Telemonitoring and self-management in the control of hypertension (TASMINH2): a randomised controlled trial. The Lancet. 2010 Jul 17;376(9736):163-72.
4. Kokciyan N, Sassoon I, Young P, et al. Towards an argumentation system for supporting patients in self-managing their chronic conditions. Health Intelligence Workshop at AAAI conference on Artificial Intelligence, 2018.
5. Karatepe AG, Gunaydin R, Kaya T, Turkmen G. Comorbidity in patients after stroke: impact on functional outcome. Journal of rehabilitation medicine 2008;40(10):831-835.