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Challenges and Opportunities of Health and Care Co-production with Social Media: a Qualitative Study

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Abstract. Future of health in EU faces the triple challenges of ageing, fiscal restriction and inclusion. Co-production offers ways to manage informal care resources to help them cater for the growing needs of elderly people. We investigate the opportunities and the challenges in use of Social Media (SM) as an enabler of co-production in healthcare. In order to do this, we conducted a qualitative study using interviews and online observations of activities of professional carers, voluntary organisations and informal carer. We found that particular types of SM are currently used to enable co-production through coordination and communication across boundaries. However, there are still many other types of SM, which are rarely used in this sector due to their limitations. Nevertheless, carers showed interest in using systems which help them to engage people in shaping of services, sharing of experiences and encouraging care activities.

Introduction

Informal carers, which consists of 10% of the UK population, play a very important role in caring for the increasing population of elderly in the UK. Their value is approximately equal to the total annual cost of UK health spending (Buckner and Yeandle, 2015). As a result the UK government is reshaping service delivery, which needs to consider how to utilize existing resources, including formal and informal carers (Boyle and Harris, 2009). The government announces the need for better coordination and integration (Christie, 2011). In order to do this, the concept of co-production is used by the government to better manage the existing resources. The full participation of informal carers in the co-production of healthcare has the potential to play a significant role in the sustainability of healthcare delivery. A key question for co-production of healthcare is how can the informal care resources be coordinated and co-deliver care along with the formal healthcare system. This massive resource is wide spread and uncoordinated in responding to pupils needs. SM is seen as a key enabler to overcoming these challenges as it enables co-production (Lin and Lu, 2011). Communications is a key element in co-production that enables coordinating across various boundaries. SM helps to communicate across boundaries. However, its effect on healthcare co-production for elderly care is poorly understood.

Therefore, this paper, which focuses on organisations that provide/support care service, explores how SM enables this co-ordination.

Objective and Methodology

Our study investigates the SM as an enabler of co-production in healthcare. Two main sets of questions are asked: what are the current uses of SM in health and social care? How can SM be reshaped to enable (and reshape) health and care co-production?

Material and methodology: This is part of wider qualitative study which investigates the sociotechnical aspects of the current and possible future uses of SM by different organisations and groups of health and social care as an enabler of co-production in UK. Our appraisal adopts a socio-technical technique, (May and Finch, 2009) using a mixed methods framework including multiple methods.

Theoretical framework: Normal Process Theory (NPT) has been used as our theoretical framework to enables us to obtain meaningful understanding of the complex socio-technical processes involved in use SM tools and service within healthcare co-production. NPT, us in better conceptualization of analysis in complex adaptive systems.

Data collection: We conducted 18 interviews with employees of private professional care companies, voluntarily organisations, which support carers or support patients in the UK, and informal carers. The interview guide (developed from NPT framework) focused on the services offered, the types of online applications (SM) used, their challenges and future possibilities. Additionally, we followed the online activities of the organisations and individuals (interviewees) and their uses of SM for health purposes.

Data analysis: Data were coded in NVivo and thematically analysed for each type of SM. We inductively identified emerging themes surrounding the benefits and challenges of SM in enabling co-production in healthcare. Those, that did not fit within the narrative, were explored in most detail. We categorised our results based on the type of care organisation.

Findings

In this study, we focused on three types of care systems, which used SM for carer purpose: Carers (informal), charity and voluntarily organisations, and professional organisations which provide care services. We discuss the findings in terms of these three groups.

Professional carers: Professional carers rarely use SM for their work. Our observations showed that the main purpose of use of SM in these companies is for advertisements or sharing of information. We also found that some line manager in organisations appreciated the work of carers through SM (Facebook), which was a way to have an informal relationship between carers and the care organisation. However, carers were not keen to engage in SM activities of the organisations they work for. The organisations too did not want to be connected to their professional carers through their SM sites because professional carers worked for them for a limited time.

"Company has a Facebook page but we are not interested in this because they don't want to be connected with carers again on the professional level."

Literature shows that SM reduces isolation of patient or carers (Mittal et al., 2012); whilst we agree with this, our findings also show that the SM connection between people is not the solution to all the patients needs, in particular physical needs.

"It's about relation... They need to see a human being, they need word of mouth"

The privacy of data is one of the biggest controversial issues of online activities (Norval, 2012). In SM applications, patients information sharing and safety and privacy of data are two important challenges. Professional carers, explained that they cannot discuss their patient stories with others due to privacy issues, leading to reduced online activities.

"I think there is a risk, personal data issues."

The population of elderly, who use SM has been increasing more than other age groups (Brenner and Smith, 2013). This shows a change of communication: one of the aspect of co-production. However, the professional carers believed that there is still a big gap between the two generations in use and familiarity with these kinds of technologies. This means despite the growth, there are still many people who cannot benefit from using SM.

"There are still the generation who are not so much convinced.".

Finally, some professional carers were very interested in use this application for their work.

"my boss is not so keen to push this direction, but this is for my own sake. I was desperate to find application for using on iPhone and iPad so it can help me everywhere I go."

Charity and voluntarily organisations: In most cases, we observed that in charities and voluntarily organisations SM is used for some specific collaboration with other organisations through sharing of information or advertisement of events, campaign or fund raising. We observed some professional health-related SM, such as healthunlocked.com, which were used by organisations to share information or help other organisations to broadcast various information. Despite the general belief that use of SM can reduce some costs and resources (Chou et al., 2013), charity and voluntarily organisations did not use SM widely in their daily activates. For instance, they did not make private groups for discussion with their users. The main reason was said to be the lack of resource, clear approach or budget for managing and maintaining. For example, an organisation which uses blog for their daily work consider that managing of some SM need a lot resource.

"It does take time. Somebody does need to be keeping an eye on this every day... there have occasionally been problems where people haven't always been respectful of each other."

This organisations mainly used general SM for broadcasting or advertisement of their own activities as well as others. SM was also used for fund raising or campaigning in these organisations. In some cases, it was used to coordinate between activities of different organisations. These kind of collaborations, can be consider as co-delivery of resources.

"We use SM to broadcast information to people so every day we get something on Facebook, and twitter. We might share information from other organisation..."

The observation of websites of the voluntary or charity organisation showed that they used mostly web 1.0 and the users had limited contribution on their online site. In some organisations, there were limited use of blogs in their website for sharing stories of their

patients or carers. This was an effective way of sharing user experience and making motivation to be more active in this space. However, there were concerns that some stories had problems such as giving medical advice which may not be correct. So, organisations had to introduce policies with regard to what can and cannot be shared on the blog.

"...forum is going to be a difficult one because it's people posting their own experiences and that might not be medically right. Their experience might not match up with what a healthcare professional says, but I suppose our way of mitigating that is that we have a clear policy about what we allow on the web community [...] and it tends to self-managed."

So, to avoid sharing bad information, charities had to adopt various strategies. Some charities avoided their users to put their stories directly on the blog. Instead, they filtered the inputs to their blogs by checking them before they were shared. Other charities allowed information to be published, but monitored them later for breach of policies.

A set of problems faced by many organisations could be categorised as the "problem of access". The foremost challenge highlighted by charity and volunteer organisations, in terms of access, was that access to the internet was not available for some of their patients and carers. This was due to a large number of socio-economic factors such as educational level, income level or geographical situation. Although, carers use online information. Some also referred to reasons for not accessing internet as artificial barriers. These reasons include lack of desire or sufficient encouragement from the younger generations.

"I think there are people who [...] don't want to engage."

A second challenge in terms of access was finding the right groups.

"So, we'd like to be able to easily search and find what groups there are on Facebook and what groups are going on. Because that's been really difficult at the moment."

SM can increase the knowledge of patients and carers on how to cope with the disease and how to communicate with health professionals like GPs (Daneshvar et all, 2017). However, it can also lead to too much reliance and trust on the information provided online. This could lead to confusion or reduction of contact with professionals that may be risky.

"I think it's becoming over-reliant on one source of support rather than what I see as a network of support including your healthcare professional, any carers, family, etc."

Carers (informal): Carers use SM for a wide range of activates. Carers were interested to use SM to reduce isolation caused by care activities. Through SM they connected with other carers or patients with similar. One common kind of SM used by carers, was blog, on which they shared experience and care stories.

"*... the blog is base of story centre and you can always reflect back at it ..."*

In this situation, we can see SM as tool for making co-delivery of service to share knowledge and experience and receive feedback from other people with same condition. They used blogs to share stories, ask for support, and to receive emotional support.

"*I was scared and I was lonely, the blog was my only way of reaching out to people"*

In other words, SM is enabling co-service as carers can share their feeling or circumstances and get confidence without intervention of government or other organisations.

"*when my mum was to go to bed I would write about how I felt that day, how did we fear? ...from the confines of my own house, so it opened up a different world to me."*

Different kind of SM could be helpful in different situations. Involvement of carers in blogs was seen as a long-term investment. However, they also used SM for short-term and quick responses. For instance, to ask questions they used micro-belonging (twitter). It was seen as a quick platform with a lot of professional individuals being online.
"I think Twitter is about more what's happening right now [...] Twitter is more than the blog, I think Twitter is more a faster engagement whereas the blog is slow"
Despite its benefits, carers and patients also faced challenges in using SM. The main barriers for carers in use of SM was confidence to contribute and knowledge of setting up.
"I think that was my main challenge at first was really my self-confidence in myself…"
A different type of challenge was about conflict of feelings, lack of understanding or dispute on the stories shared on SM, which could make carers and patients disappointed.
"some people might not understand how you feel… My own blog is more of how I feel. [...] it's how I feel about my love for my mum when I was caring for her. It's how I feel about how I felt when I was doing it, so reactions to that can be quite a challenge."

Discussion and Conclusion

We can conclude that existing SM (in particular Twitter, FB, and blogs) are currently used to enable co-production. We discus three main actors playing an important role in healthcare system in UK. These groups have different extent of use of SM: 1) Professional carers did not use SM widely compared to other groups; 2) Voluntary organisations such as charities used SM for certain activities such as fundraising, campaigning, and information dissemination; 3) Informal carers used SM more than others in their daily healthcare activities. However, they are used for particular purposes such as advertisement and information diffusion for charity and volunteer organisations, and connection and emotional support between carers. We also argue that there are a wide range of opportunities in broadening the use of SM for organising and individuals who provide care for elderly populations. There are current challenges in use of SM such as low skills, awareness, and literacy, high setup and control, accessing to online resources, and security and confidentiality concerns. Moreover, current SM does not cater for all the needs of elderly people and their carers. Most user of SM are young people and the gap between the carers and patients who use SM is wide. Also, we identified a set of barriers we called "problem of access", which refers to carers or patients having problem to access the internet, access the appropriate group, or the suitable information. Therefore, new functionalities aimed at this particular group needs to be designed to better coproduce healthcare and manage the needs of elderly people.
Further work is needed to find out the new services (e.g. workforce co-ordination and cooperative organisations) which can be offered with existing SM. Then we will be exploring the possibilities of designing a new SM to cater for the existing need and new services required.

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