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Huby, K, Swallow, VM orcid.org/0000-0001-8504-4704, Smith, T et al. (1 more author) (2017) Children and young people's views on a web-based application to support personal management of long-term conditions: A qualitative study. Child Care Health and Development, 43 (1). pp. 126-132. ISSN 0305-1862

https://doi.org/10.1111/cch.12394

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Title Page

Title: Children and young people's views on access to a web-based application to support personal management of long-term conditions: A qualitative study

Short Title: Children and young people's views on web-based support

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Key words*:* children, young people, information, chronic kidney disease, qualitative research methods

Acknowledgements: This paper presents independent research commissioned by the National Institute for Health Research (NIHR) under the Research for Patient Benefit Programme. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health. We would like to thank the following for their help: the children and young people who generously provided data and members of the wider Research Team and the project Steering Group.

Word count (excluding title page, table and references): 3574

ABSTRACT

Background: An exploration of children and young people's views on a proposed web-based application to support personal management of chronic kidney disease (CKD) at home is important for developing resources that meet their needs and preferences.

Methods: As part of a wider study to develop and evaluate a web-based information and support application for parents managing their child's CKD, qualitative interviews were conducted with 26 children and young people aged 5-17 years. Interviews explored their views on content of a proposed child and young person appropriate application to support personal management of their condition. Data were analysed using Framework Technique and Self-efficacy theory.

Results: One overarching theme of Access and three subthemes (Information, Accessibility and Normalisation) were identified. Information needed to be clear and accurate, age appropriate and secure. Access to wifi was essential to utilise information and retain contact with peers. For some it was important to feel 'normal' and so they would choose not to access any care information when outside of the hospital as this reduced their ability to feel normal.

Conclusion: Developing a web-based application that meets children and young peoples' information and support needs will maximise its utility and enhance the effectiveness of home-based clinical care-giving, therefore contributing to improved outcomes for patients.

INTRODUCTION

Long-term or chronic (hereafter referred to as long-term) conditions affect at least 15% of children and young people (Brooks et al., 2011). They have distinct information and support needs to enable them to share condition management as they move towards adulthood (Sawyer et al., 2012; Colver and Longwell, 2013). Children and young people value being involved in decisions about their care(CMO, 2012). They perceive themselves as experts in their own conditions and want healthcare professionals to recognise them as partners in managing their care. Involving children and young people, therefore, helps to empower them, helps professionals to fully understand how their condition affects them, helps them feel prepared and less anxious about their treatment regimens and equips them with the skills to share decisions about their healthcare (Valle et al., 2012; DoH).

Prensky (2001) recognises that this generation of children and young people have grown up surrounded by technology and are 'digital natives', fundamentally different to previous generations. This will affect the range of communication methods used by healthcare professionals to empower children and young people, to promote optimum quality of life and improve clinical outcomes. The rising levels of internet use by children and young people make it increasingly likely that they will search online for supplementary health-care information and support. Yet inaccurate sites exist and few web-based health-care resources were co-produced with children and young people with long-term conditions. Computer-based programmes which combine health information for adults with long-term conditions with online peer-support, decision-support, or help with behaviour change, found that they improved users' knowledge and clinical outcomes, and were more likely than not to improve users' self-efficacy (Murray et al., 2009). However, little evidence exists on the effectiveness of age-and developmentally appropriate online support for children and young people (Kirk et al., 2013) so it is now timely to co-create such support to supplement (not replace) traditional forms of support (Fox, 2009; Coulter and Ellins, 2007).

Using chronic kidney disease stages 3-5 (CKD) as a paradigm for other long term conditions; this paper explores and discusses the views of children and young people with

CKD on their desired components for web-based information and support. Although the opinions of children and young people are important in the development and evaluation of health care policy and services (Lewis and Shribman, 2014; CMO, 2012), developmentally-appropriate, CKD-specific, online resource provision is patchy and has little evidence-base (DOH, 2006). CKD is a progressive, complex set of disorders with a wide range of primary causes and complications (Nolte and McKee, 2008); children and young people are at risk of long-term complications so early diagnosis and optimal management as they progress through the CKD stages and move towards independence are essential (DOH, 2006; Goldstein, 2009; Harambat et al., 2012), Interventions are required to equip children with the capacity to manage their health, participate in community, engage in 'permissible' recreational activities, progress in their studies, and remain vigilant in dialysis and treatment responsibilities, for improved health and treatment outcomes (Tjaden et al., 2012).

The research described here is one aspect of a larger study that developed and evaluated an online parent information and support (OPIS) internet application for parents of children with CKD stages 3-5 (Swallow et al., 2012). The study is shaped by Medical Research Council guidance on developing and evaluating complex interventions (MRC, 2008). Working with patients, parents and the multidisciplinary team (MDT) in one UK children's kidney unit, the project defined and identified desirable components for the OPIS application (Phase 1). In phase 2, resources were developed to address the identified needs; and in phase 3 a pilot, feasibility randomised controlled trial was undertaken of standard care versus standard care supplemented by OPIS, to inform a future protocol for a full national trial of OPIS. We previously reported children and young people's views on a proposed parent resource (Swallow et al., 2014), here we report their views on the types and forms of information they would like included in a proposed child and young person-relevent web-based application.

METHODS

Study setting: A children's kidney unit in the North of England

Design: A qualitative study underpinned by Bandura's Self-efficacy theory; this theory (Bandura, 1997; Ritchie et al., 2013) helped organise and explain our findings. The theory proposes that an individual's belief in their own self-efficacy comes from four main informational sources: mastery experiences, vicarious experiences, verbal persuasion, and physiological and affective states.

Recruitment: To achieve maximum sampling variation, patients with CKD stage 3-5 were identified from hospital records using a purposive sampling approach based on age, sex, ethnicity and CKD stage. Study information was provided according to age and level of understanding. Patients aged over 16 years provided signed consent after receiving written and verbal explanations; verbal consent (and where appropriate, written assent) were obtained from patients aged 5-15 years provided written assent and their parents written consent to enable these children to participate. Because the study involved only one children's kidney unit, information about diagnoses which could lead to participant identification is omitted from the reporting.

Data collection and analysis: We undertook individual semi-structured interviews to explore views and experiences. Children and young people were engaged in data collection in different ways according to age and context. The researcher was introduced to the children, young people and their parents/carers in the outpatient clinic by a member of the MDT. Thereafter, the researcher provided age appropriate explanations and study information to the children and young people, and reassured them that if they chose not to participate then the MDT would not be notified of their decision.

Children aged 5-10 were encouraged to ‘draw and tell’, this method alleviated the power imbalance and pressure on a developing child to respond to conversation, allowing them to draw their experience at their own pace and in comfort. The researcher invited these children to draw a memorable experience from their healthcare; this minimalized any pressure on the child to perform conversationally. Children aged 11-15 were engaged using face-to-face discussion due to their readiness to explain their condition, the researcher offered a listening space in interviews for these young people to express any opinions or fears. Young people aged 16+ were addressed as adults, they were inquisitive and interrogative about the purpose of the research so it was important to explain in plain, succinct language exactly what and why the researcher was asking them specific questions. This developed their confidence in the researcher and topic and enabled them to provide informed consent to participate in the research.

Interviews were conducted by IC in venue specified as appropriate by the interviewee, such as the family home or in a quiet space in the hospital. No interviewees required a translator. Interviews were informed by topic guides and were digitally recorded, transcribed verbatim and anonymised. Specific topic guides were developed respectively for patients aged 5-10 years, 11-15 and 16-19 years; these included a range of topics and prompts addressing the following broad areas: health information needs, problems with health information, and sources of health information, suggested formats for receiving of health information.

Data were analysed using Framework Analysis, a systematic and rigorous approach to qualitative data, cataloguing, organisation and analysis; this involved five iterative stages: (i) familiarization with the data, (ii) identification of a theoretical framework, (iii) indexing, (iv) charting and (v) mapping/interpretation. Two researchers independently read and coded the first transcripts searching for patterns in the data, iteratively seeking explanations for patterns before comparing and discussing these until a consensus was reached and a final framework developed and applied to all transcripts. Each coded transcript was analysed and selected data were transferred to a spread sheet for charting and labelling for retrieval during reporting. The iterative process of moving backwards and forwards between stages (Ritchie and Lewis; Swallow et al., 2003) revealed a framework of one theme and three sub-themes relating to patients’ requirements for the proposed web-application [Fig 1]

Ethical approval to conduct the study was obtained from the NHS Research Ethics Committee (Reference: 11/N/W/0268) and the NHS Trust Research and Development Department

RESULTS

Results

Twenty six children and young people were recruited (Table 1)

One overarching theme of Access emerged from the data and within this three subthemes were identified; Information, Accessibility and Normalisation. (Figure 1)

Access

Respondents were clear that an online information and support resource (resource) would only be useful if it was accessible on all platforms, on any device and in the presence of a Wi-Fi signal:

> "... I'd find it good if I could use it on my iPad if I can find it accessible... Yeah because some websites that I can't access because they've got Flash Player which is really frustrating…" (Participant/124)

The lack of a Wi-Fi signal in hospital was highlighted as frustrating meaning access to the internet was limited to a mobile phone signal. Wi-Fi not only permitted access to information and support, it also enabled contact with friends and the 'outside world':

> "It would just be really good because I Skype with my friends…so I don't feel that I can't see any of my friends or talk to them" (Participant/013)

Information

Information needed to be clear, condition specific and accurate. Respondents did not want to navigate through pages of information to find what they were looking for. They wanted quick access to relevant, key information. This not only influenced the type of information but also how the information was displayed:

> …Having useful information. Not just everything there, just the main stuff… (Participant/038)

If information was accessible and clear it could be used to educate others; not just inform young people and parents living with CKD. This could be useful as one participant discussed the difficulties in explaining their condition to friends:

> It's just a bit difficult trying to explain my condition to them…Because they don't know what it's like to have it…(Participant/013)

Some thought information relating to potential procedures and treatments may reduce some of the associated fear. However, some felt that too much information could cause anxiety:

> …it would be helpful to know what could happen… of how it's going to play out in maybe a few years' time or a longer period. (Participant/013)

> …They wouldn't like to see, like, any of it, because, it would just scare them to death! (Participant/045)

It was recognised that everyone was on an individualised journey and acknowledged that experiences may differ. Some felt understanding that outcomes may be different was helpful, others felt that highlighting their own experiences may not be useful for others:

> …I mean to me when I first got it [CKD] and I had to have loads done - someone else might just have to have a minor bit done. Then it would just give people a bit - they won't feel like 'oh my god'… (Participant/047)

The ability to offer support to others receiving specific treatment may be beneficial. One participant had already supported another family who had found it useful to speak to someone who had:

> …come through the other end. (Participant/124)

However, not all participants felt that being able to share their own experiences would be helpful and some were clear they would not take this approach:

> No not for me, I'd rather just keep it to myself and get on with it. (in relation to using social media) (Participant/142)

Concern was expressed about following advice from certain websites due to uncertainty about the accuracy of information:

> …they might not be the right thing, they might just be about - I don't know - someone who's done a blog or something like that. (Participant/047)

The proposed resource would only be used if the information was trustworthy and checked for accuracy by health professionals.

Accessibility

Accessibility was different to access, participants stated information needed to be age-appropriate, acknowledge different learning styles, and be secure. Accessibility could be increased by providing information in age appropriate ways. Dividing the website into age appropriate sections would also make finding appropriate information easier:

> …a section for younger kids, which is more games and stuff to help them learn, and then a part for older people, more my age, that would obviously read a bit more… (Participant/003)

The use of colours and games was considered essential to engage younger children in contrast to young people themselves who were more concerned that the information was stated clearly.

> It could be eye catching for the kids, as well, like colourful… (Participant/007)

> No, it's not really about being colourful or not, it's just about the information that's there… (Participant/038)

The presentation of information depended not only on individuals' ages but also on their learning styles. There was a recognition that some people liked to read a lot whereas others preferred videos, cartoons or interactive games.

The information delivered affected the way it should be presented with many feeling videos would be useful when learning new skills. Being able to refer to videos would enhance, not replace, the face-to-face teaching currently received from healthcare professionals. For those that travelled some distance to receive their treatment it may reduce travelling:

> Yeah, had to come over quite a lot of times and it's quite far as well…so if we did have videos it would be much better (Participant/126)

The need for personal information to be kept secure was essential. Participants were aware of accounts being 'hacked' and fear of this would limit use of certain functions on any website. Privacy settings were important along with control over who saw personal information posted:

> I don't really like the idea of it being on Facebook…I mean people can hack into you to see what you've been writing and people can, without hacking into you; see what you've written… (Participant/047)

Normalcy

Many young people thought the development of an age-appropriate resource was beneficial and would increase access to information. In contrast some wanted to forget that they had CKD when they left hospital and would never look at the information provided:

> …I can't be bothered with it outside of hospital. (Participant/142)

The need to be seen as normal and limit the individuals who knew about their condition was important to some young people:

> …I mean at my school, only my best, best friends know that I've got a problem…But I mean, everyone else doesn't know… (Participant/047)

The importance of staying healthy and following advice was known but they didn't always want to consider long-term consequences and outcomes. Choosing not to access information when they weren't in hospital allowed them to feel normal:

> No, because, when I'm not in the hospital, I, just, have a normal life. *(*Participant/045)

DISCUSSION

Few studies have sought the views of children and young people living with long-term conditions on the desired components for information and support web-based applications as part of a phased approach to development and evaluation of a complex intervention such as the one we propose (Council, 2008; Richards and Hallberg, 2015). To our knowledge this is the first study to address this issue with a cohort of children and young people living with CKD. Collectively, our findings indicate that access to a web-based application is central to the children and young peoples' requirements but that the proposed resource would only be useful if they could access it on all platforms regardless of where they were and whatever device they used. Difficulty with accessing a Wi-Fi signal leads to the conclusion that interventions utilising modern mobile electronic technologies may be a more suitable way to provide information and support in a resource efficient manner than interventions utilising the internet (Dennison et al., 2013; Free et al., 2013; Gray and McDonagh, 2013).

However, a recent systematic review of the evidence for effectiveness of mobile apps for young people aged 10-24 years with long-term conditions identified only four evidence-based apps; this is in stark contrast to the thousands of apps available on the app-market that are not evidence-based or user/professional informed. Three studies reported some patient involvement in app design, development and/or evaluation. Health-professional involvement in the modelling stages of apps was reported in all studies although it was not always clear whether specific clinical expertise in working with adolescents was represented. More studies involving larger samples and with patient/health-professional input at all stages are recommended to determine mobile apps' acceptability and effectiveness (Majeed-Ariss et al., 2015)

Working in partnership with children and young people and responding to their views potentially enhances the success of any health information delivery system by providing useful and informative resources that help develop understanding and skills to manage their condition. Our data suggest that participants want quick access to relevant, key information that is age-appropriate, accommodates different learning styles, and is secure. This reflects what young people want from face to face services (Robinson, 2010). It also has to be remembered that for some participants, not accessing information is a choice that enables them to feel normal.

There are challenges to developing web-based applications with and for children and young people. Age appropriate resources that provide each age group with information and support that is relevant to their needs and style of learning are time consuming and exacting to develop. Any resources developed must be endorsed by the MDT so that children and young people recognise that the resources have credibility (Yonker et al., 2015). On-line resources require a good Wi-Fi signal to access them, requiring significant investment by healthcare institutions. Alternatively they draw on mobile technology which may have cost implications for the end user.

Web-based applications are best used in conjunction with face-to-face discussion, as a means of enhancing education and learning. Working with a child or young person and helping them to navigate the information, which they can return to at a later date, ensures consistent information provision. However, Yonker et al. (2015) found that unless resources were updated frequently engagement with the resource reduced.

Strengths and limitations: A strength of the study is our approach to obtaining informed consent. It was important that the children and young people recognised that the researcher was endorsed by the MDT but did not inform the MDT whether or not the children and young people consented to participate. This approach enabled a rapport to be developed and minimised barriers to trust between the researcher and the patients. A limitation relates to the amount of information obtained from children within the study. The young people were more clearly able to articulate their ideas which may mean the views of children were under represented.

Conclusion: Web-based applications potentially have a huge impact on children and young people's engagement in their health condition; finding ways to meet their health information needs in today's electronic world, is essential. However, each patient will have different views on what they want to know and how and if they want to access the information. Whilst clinicians have the challenging role of assisting children and young people with this journey and meeting their information needs it is clear that children and young people have distinct ideas about the information to be included and the way it is presented. Failure to involve children and young people in the design and development of resources may lead to limited engagement and impact.

Key messages

Children and young people are digital natives and understand the benefits and challenges to using web-based resources. They understand digital security and want control over their information.

Children and young people need to be involved in the development of any resources related to managing their long term conditions to ensure all of their needs and expectations are met.

Individuals who do not utilise these resources may have made a conscious decision not to do so in order to retain control and be 'normal'. This needs to be respected by health professionals.

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Tables

Table 1: Children and young people's variables and characteristics:

Characteristics	**n=**
Patients' age (years)	
5-10	7
11-15	10
16+	9
Gender	
Female	12
Male	14
Ethnicity	
White British	15
South Asian	11
CKD stage	
3	9
4	6
5	11

Figure 1

Figure 1: Themes