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Bryce, Carol; Ignatowicz, Agnieszka; Huxley, Caroline; Hamilton, Kathryn; Dliwayo, Thandiwe Rebecca; Forjaz, Vera; Sturt, Jackie; Griffiths, Frances

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Staying connected: the importance of timely communication for young people living with a long term condition and their clinical teams

Authors

Carol Bryce, Unit of Academic Primary Care, Warwick Medical School, University of Warwick, UK
Agnieszka Ignatowicz, Institute of Applied Health Research, University of Birmingham, UK
Caroline Huxley, Division of Health Sciences, Warwick Medical School, University of Warwick, UK
Kathryn Hamilton, Research Department of Clinical, Educational and Health Psychology,
University College London, UK

Thandiwe Rebecca Dliwayo - ???

Vera Forjaz - ???

Jackie Sturt, Florence Nightingale Faculty of Nursing and Midwifery, King's College London, UK

Frances Griffiths, Division of Health Sciences, Warwick Medical School, University of Warwick, UK

Corresponding author:

Carol Bryce
Unit of Academic Primary Care
Warwick Medical School
University of Warwick
Gibbet Hill
Coventry
CV4 7AL
c.bryce.1@wrwick.ac.uk

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Abstract

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Timely communications are important in enabling young people with long term conditions to stay engaged with their health and manage their condition successfully. This study considers the role of digital communication in helping young people engage with services and the clinical teams providing their care. Data is drawn from 165 young people and 173 NHS staff across 20 clinical settings in the UK treating a variety of long term conditions. Although not the focus of the main study the intersection of digital technologies and timely communication in keeping young people engaged was apparent. We drew on theories of time to understand how time was conceptualised and used in the digital communications between young people and their clinical teams. Through the lens of time we show that digital communications are valued differently by young people with long term conditions and their clinical teams. In the current policy landscape where there is an emphasis on digital technology understanding the temporalities of different groups will help in the introduction of appropriate digital communications channels. Done well digital communications have the potential to improve young patients' autonomy but this must be balanced with the needs of clinical teams, particularly loss of control over work patterns.

Key words

Time; long term conditions; young people; digital communication; health services

Introduction

Managing a long term condition well requires patients and clinicians to develop timely communications pathways. Timely communication can be conceptualised as engaging with the right person at the appropriate time to enable effective condition management.

Drawing on data from a wider study that reported how digital communication technologies were used to facilitate communications between clinicians and patients (Griffiths et al., 2017), we ask: how does understanding the intersection of digital technologies and timely communications help to enhance the value of digital communication within a healthcare setting? Unpacking the idea of timely communication we will explore the temporalities of patients and clinical staff alongside time as it relates to the social, to knowledge and to work.

The study focused on young people in the United Kingdom (UK) who are being treated for long term conditions along with their clinical teams. This group is important as long term conditions are not uncommon among young people in the UK. There are 25,000 under 25's living with Type 1 diabetes (Diabetes UK, 2010) and between 10-20% of adolescents experience mental health conditions in any given year (World Health Organization, 2018) many of whom will live with their condition for a year or more. It is well documented that young people living with long term conditions struggle to stay engaged both with their

treatment and their health care teams (Bacigalupe, 2011; Howard et al., 2010; Musumadi et al., 2012; Van Walleghem et al., 2008; Witherspoon & Drotar, 2006) often resulting in negative health outcomes (Bacigalupe, 2011). Furthermore, the period of transition from paediatric to adult services is a particularly vulnerable time for young people which has led to the development of national guidance in the UK on the provision of transition services (NICE, 2016). Whilst transition services have been shown to improve engagement and have demonstrated health benefits, their uptake has not been widespread across the UK (Annunziato et al., 2013; Petersson, 2016). Health sector factors known to negatively affect young people's engagement with services include poor communication, lack of access to people and information, and lack of continuity of care (Bacigalupe, 2011; Bell & Sawyer, 2010; Kennedy et al., 2007).

Keeping young people engaged with services is vital and key to this is timely access which has been shown to be as much about its appropriateness in terms of time, place or clinician seen as it is about speed of contact (Boyle et al., 2010). Digital technologies are seen to have a significant role in engaging patients with healthcare. This is reflected in UK health policy which focuses firmly on the role of digitisation over the next ten years to improve access to services and the ability of patients and their carers to manage their health (NHS England, 2019). However, research has suggested that the introduction of new technologies must consider the impact on patients and staff (Hillman et al., 2013) and the specific issues it is aiming to address (Wachter, 2016) rather than being used as a means of saving costs (Adamson, 2016). With the growing pace of change in the field of digital health, including health apps, these considerations cannot be ignored. Added to this is the increasingly

connected patient who uses digital communication to access health information online and to develop their own expertise to become an 'informed patient' (Henwood et al., 2003; Henwood et al., 2011; Maller, 2015). The changing digital landscape enables individuals, patient groups, and patient advocacy groups, a space in which to challenge both the health professional as dominant expert and the conceptualisation of the passive patient (Goldner, 2006; Koteyko et al., 2015; Oudshoorn & Somers, 2006). Furthermore these transformations in technology are reconfiguring traditional boundaries and fostering new kinds of engagement between doctors and patients (Morrison et al., 2016). Within this context of fast changing digital health, our study examined communications between clinicians and young people who are becoming independent managers of their long term condition.

Although not the main focus of the study, the intersection of digital technologies and timely communication to keep the patient group of young people engaged, was a dominant issue (Griffiths et al, 2017).

Perceptions of time

Adam's (1990, 1995) seminal works on time theorise that individual conceptualisation of time impacts on the ways in which we relate to everything in our lives, including our bodies and health. Furthermore, time must be understood in relation to social systems and the way these systems are reproduced over time (Adam, 1990). Adam (1995) asserts that it is through the link between time and money that time can be conceptualised as a resource, with Western societies equating efficiency with performing tasks in the shortest time possible. Time spent away from production is conceptualised as free. It then follows that time is not equal rather is experienced as a hierarchy with that which can be commodified taking precedent over that which cannot (Adam, 1995). Time is thus experienced individually

even during interpersonal interaction. For example, during a consultation a clinician and a patient will experience time differently according to their role and the purpose of the consultation. Understanding the social construction of time will enable the understanding of these interactions. Clinicians work in an environment where services are commissioned; bounded by competition, contracted volumes, wait times and markets (Wenzel and Robertson, 2019). Time, as a resource within this marketized system, is therefore commodified (Zigmond, 2020). For young people, time is contextual and bound by norms set in different contexts where it is imbued with value judgement and hierarchies (Bennett & Burke, 2017). In health settings young people with long term conditions have been found to prioritise short term gains over prioritising their long term future (Reach, 2019). Although clinicians may conceptualise this as having a poor time projection it can be considered a logical response for young people for whom distant future health has less salience (Reach, 2019). Furthermore, technologies which could be expected to help young people manage their health (i.e. health apps) prove more complex as some young people find they disrupt their temporal relation to healthcare activities (Trnka, 2016). In understanding how young people construct and understand time and temporality in relation to health it is important to consider the context in which they are operating.

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Hospitals have been the focus of much work on temporality in healthcare settings with an emphasis on understanding socially based temporal order (Ancona et al., 2001; Blue & Spurling, 2016; Reddy & Dourish, 2002; Zerubavel, 1979). This work helps us to understand the organisational practice and behaviour of hospitals from the large scale (shift patterns) to fine grained activity (lab results) (Ancona et al., 2001; Reddy & Dourish, 2002). Zerubavel

(1979) also recognises that at the individual level doctors and nurses have differing temporal logics based on activity. This work focuses on the organisation of hospitals and clinicians but does not consider the temporality of patients. Toombs (1990) considers time conceptualised by clinicians and patients, arguing there is a dualism that enables us to recognise that patients and clinicians will experience the temporality of health and illness differently. Patients prioritise internal or lived time over the external or clock time that governs the experience of clinicians (Toombs, 1990). Furthermore patient satisfaction is linked to their experience of time in a consultation where the quality of the interaction is more important than its length (Sterponi et al., 2019). The differing temporalities within a hospital setting are not experienced equally. Marineau (2015) argues that some times are dominant and others marginalised through mechanisms of power where clock time has become dominant through the link between time and value within capitalist societies. In this way the clock time of a clinician in a marketized NHS (Zigmond, 2020), particularly a consultant, during a consultation can be conceptualised as more valuable than that of a patient, particularly patients whose time is more loosely connected to production, such as students.

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How we, as individuals, function within our complex world is impacted by time with the need for slowness as a counter-balance to the arguable acceleration of time in modern society (Wajcman, 2008, 2015). Cilliers (2005) explored the concept of 'fast' and 'slow' time arguing that a 'certain slowness' can, at times, be appropriate, allowing for reflection on what is remembered and anticipated and on what is important to the person. In a paper written with a clinician, he contends that a 'certain slowness' is important for a healing

relationship between clinicians and patients (Sturmberg & Cilliers, 2009). Enabling slowness is not easy in pressured health service environments and some turn to technology in an attempt to relieve time pressure. Analysing the perceived acceleration of time in modern society, Wajcman (2008) suggested we look to digital technologies for solutions, however, she described a paradox - we 'turn to digital technologies to alleviate time pressure and yet blame them for driving it' (Wajcman, 2015, p. 2). Whilst digital technologies may enable work to be organised over time rather than space, the extent of their positive or negative effect on time pressure in the workplace is largely dependent on an individual's autonomy over their work patterns (Wajcman, 2015). This may apply to clinicians providing healthcare and extend beyond the workplace to those accessing healthcare.

This paper draws on data gathered from 20 different clinical settings in the UK using interviews with young people and their clinical teams that sought to understand the ways in which digital technologies were used to enhance communication. We argue that by using the lens of time we can usefully help in understanding the value of new forms of communications for clinical teams and patients.

Methods

This paper reports analysis of data collected for a study on the use of digital communication between clinical teams and young people with long term conditions, known as the LYNC study (Griffiths et al., 2017; Ignatowicz et al., 2018; Kim et al., 2018). Using a mixed method case study design (Yin, 2009), the study examined patient safety, ethics, cost and the clinical

impact of the use of digital communication between clinical teams and young people. In addition we considered how digital communications are used and their perceived impact.

The study and its participants

We identified a total of 104 clinical teams, across England and Wales, as potential case study sites through web searches for information in publicly available NHS Trust documents and through snowball recruitment through professional networks and organisations. Inclusion criteria for clinical sites were: provision of specialist care for young people (we included those aged 16-24 years) with long term conditions and the clinical team expressed interest in the use of two-way digital communications. Of those teams, 47 were eligible and interested in participating and we purposively sampled 20 teams to give a range of clinical condition, digital clinical communication, size and geographical location [Table 1 near here].

We use the term clinician to refer to any member of the clinical team interacting with the young person about clinical issues e.g. consultant (senior doctor), specialist nurse, therapist, dietician. Within each study site we undertook individual semi-structured interviews with young people with long term conditions and their clinicians. Interviews lasted between 20 and 50 minutes and face to face interviews were undertaken in the clinic in a private space. Interviews were guided by a schedule that considered how digital communications were used for clinical purposes, focusing on the advantages and concerns participants had about its use. At each case study site we aimed to interview up to 15 clinical team members,

ensuring that we had included representatives of all professions. For teams with fewer than 15 members we intended to interview all members of the team. We aimed to interview 15 young people at each clinic. When based within a clinic all young people who had appointments to see a clinical team member were sent information about the study ahead of their appointment. When they attended clinic they were approached by a member of the clinical team or one of the researchers and asked if they would participate in the research. In the UK young people aged over 16 are considered capable of giving consent to participate in health research (NHS, 2018). After consent was obtained all participants were given the choice of being interviewed face to face, or by telephone, and young people were also given the choice of interview by email, Skype, Facebook or text. Transcripts were generated from transcribing verbal interviews verbatim and through saving email, Facebook and text interactions with each participant being given an anonymised identifier.

A researcher was based with each clinical team for between 2 and 10 days. The local collaborator at each site made the team aware of the study and researchers wore a T-shirt identifying them as researchers. Posters were displayed in clinics during the study period to advertise the study. General observation data were collected on a pro forma noting how the clinic functioned, the use of digital communications within the team and how it was used in the wider clinic space. These data were collected ad hoc when the researcher was in the clinic and not undertaking interviews or shadowing staff. We shadowed members of staff as they went about their day-to-day work using a separate pro forma to record if and how digital communication was used for clinical purposes. Staff members were approached for interviews and shadowing and consent was obtained for each.

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All interview data were digitally recorded, transcribed verbatim and uploaded into a data management software programme (NVivo, 2012). All transcripts, along with observational data, were coded for our LYNC study topic areas – patient safety, ethics, cost, use and perceived impact, along with coding for the research question 'what works for whom, where, when and why?' The broad 'what works' coding was further coded using a thematic framework initially devised by FG and CB, based on detailed analysis of two clinics. The codes and framework were refined in an iterative process as each subsequent clinic was analysed in depth and discussed by the wider group of researchers until no new themes emerged. Consensus on the meaning and understanding of the codes and thematic framework was reached using this process. The observational data contextualised the interview data and aided in the interpretation. Time and timeliness was a major theme identified during this process. This paper focuses on the data related to time and timeliness. The quotes in this paper are labelled as follows: condition, site number (if more than one site with that condition), young person or clinical team role, interview number for that site numbered for the clinical team and young people separately.

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The study received ethical approval from NRES Committee West Midland – The Black Country. (14/WM/0066)

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Findings

We interviewed a total of 173 clinic staff and 165 patients aged 16-24 years and shadowed

79 members of staff [Table 2 near here]. Of the staff interviews 148 were conducted face to face and 25 by telephone. Most patient interviews were conducted over the telephone (n = 82) or in person (n = 41) with the rest conducted by e-mail (n = 35), via Facebook (n = 4), via Skype (n = 2) and by text messaging (n = 1). Synchronous interviews (in person, telephone or Skype) took between 20 and 60 minutes, with most taking approximately 30 minutes. Asynchronous interviews took longer to complete; the longest, via e-mail, took 2 weeks. Staff shadowing duration was led by the clinician and usually lasted between 1-2 hours but was occasionally longer (maximum 7 hours). The number of patients recruited per site ranged from 5 to 23 (except for the school nurse service where it was not possible to recruit participants because contact with the service is anonymous). The number of staff interviewed ranged from 4 to 22 and the number of staff shadowed ranged from 1 to 11.

Patients

Managing long term health conditions: temporality and digital communications

Successful management of long term conditions requires good communication between the patient and their healthcare team. Irrespective of their condition, the young people in this study were becoming autonomous patients, many of whom were taking over condition management responsibilities from their parents and guardians. They were building independent relationships with their healthcare teams and the communication channels open to them were important to that communication being successful. Digital communications fundamentally changed patient interactions with their clinical teams, in particular how such communication impacted their daily lives. Young people often talked of

how digital technologies enabled communication to fit easily into their lives thus minimising disruption:

So, an email is just quite a quick thing...rather than going home and finding the number and ringing them, you can just kind of email them quickly on the go. Cystic fibrosis 1

Young person 01

Fitting their condition management into their everyday lives highlights these young patients' focus on internal or lived time (Toombs 1990). For them it is not about clock time controlling their communication rather it is 'quick and easy' therefore fitting into their lives at the moment communication is required. This enabled the young people to control the time they took to manage their condition.

Most, but not all, of the digital communications were initiated by the young people, helping them to take control and to fit condition management into their lives on their own terms.

Being able to send a message when a question or thought occurred to them, even if during the night, was greatly valued. This was done with no expectation that a clinician would be there out of work hours to answer queries.

If we email one say 10 o'clock at night they'll always pick it up the next day rather than having to wait and to set aside, you know, half an hour [the next day]. Liver Young person 17

A further consideration for many young people contacting their clinician was privacy as they wished to text or make a mobile phone call without others overhearing or seeing their communication. Some would struggle during the day to be apart from colleagues, friends and

family:

Time wise as well, especially if you are working. I don't have time to find my own space and have a private conversation. I don't want people around me to hear. So, being able to send him a quick text is so helpful. Cancer 1 Young person 07

The young people prioritise lived time in relation to the management of their condition and value digital communications because it enables them to fit their condition management into their lives.

Speed and ease of communication: digital communications save time

Contacting clinicians through an NHS hospital switchboard can be a time-consuming business. The young people talked of the time it took to get transferred to the correct number, being on hold and the frustration of calls frequently being unanswered or getting through to find the staff member away from their desk:

Just because I know it is such a fuss getting through; you get through to switchboard and then you can get put through to the wrong department and it's happened so many times that I just can't be bothered. Liver Young Person 07

These barriers can be enough to dissuade young people from contacting their clinical team.

The young people in the study valued the difference being able to text or email made to them:

It [text] was quick and easy, it meant that I didn't have to sit, you know, find time in my day to sit and try and get hold of someone for two hours. Cancer 1 Young person

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The availability of digital channels differed by clinic and the young people made judgements on which they were willing to use and for what purpose. Text and email were most often offered by clinics and where available were generally well liked and used. Some young people preferred to use synchronous communication, as this young person talks of the mobile phone they can call directly, as they considered asynchronous too slow:

You're talking to someone that can answer your question directly, you don't have to wait too long for them to reply. It's just a lot more quick and direct Cystic fibrosis 2

Young person 07

These young people are not making the distinction between urgent and non-urgent queries rather are prioritising their time and willingness to wait over other considerations. Wajcman (2015, p. 103) argues that people move between synchronous and asynchronous modalities as a way of 'developing multidimensional time practices, creating new rhythms of work'. We found young people in our study created similar 'multidimensional time practices' whilst working to manage their health and happily moved between them as their needs and circumstances changed.

If I had kind of a specific question that's not particularly in depth or necessarily revealing about my health.....that would be something I would be quite happy emailing.....if I have a more in depth question or something that's probably going to require going back and forth or.....personal I probably wouldn't email.....ideally a phone conversation or.....a face to face appointment. Liver Young Person 21

For the young people in this study, the use of different channels of communication was part

of their way of managing their condition on their terms. Although the clinicians controlled the types of communication that were available, it was the young people who made the decisions around their use.

The need for taking time: a certain slowness

There were situations when the young people talked of needing to be more measured in their communication and slow time down. Asynchronous communications (usually text or email) allowed patients to do this.

I think my main reason for preferring to use email rather than phoning is because you can plan what you're going to say and therefore give more detail in your answer and not be put under pressure to answer straight away. Inflammatory bowel disease 2 Young Person 13

If I've got something that I think one of my doctors can answer, I'll send an email and when they can pick it up they will pick it up...it's just nice to have somewhere you can just like, well I'm going to dump my thoughts here and then I might get a reply in a few days and that will be fine, you know. Liver Young Person 23

The slowness afforded by asynchronous technologies allowed the young people to formulate questions, ask difficult or embarrassing questions and take time to answer the clinician's questions. Furthermore, the young people articulated an awareness of their questions creating a burden on their clinicians and saw asynchronous digital communication as a way of reducing this burden.

Autonomy and management of long term conditions over time

Using digital communications to contact their clinical teams was seen by the young people as a way of retaining autonomy over their health and its management away from the gaze of others. Heaton et al. (2016) consider the relationship between control and autonomy for young people managing long term conditions and argue that control and autonomy were independent and non-linear elements of young people's lives that had potentially conflicting goals. If young people focus too much on controlling their condition it could take over their lives causing them to lose some autonomy, therefore, they tried to balance their condition control to allow themselves a satisfactory level of autonomy (Heaton et al., 2016).

Prioritising autonomy over control may result in young people disengaging with their clinical teams, therefore, giving them access to their clinical team in ways which enhance autonomy, such as through digital channels, may counter this.

Balancing autonomy and control is further complicated when the young person's state of health was susceptible to rapid change. Digital communications were cited as one important way that enabled the young person to act to stabilise their condition as this young person explained:

I have my phone on me most of the time, and like say I'm at college and something has gone wrong then I could text them... Diabetes 1 Young person 01

Digital communication enabled young people to gain autonomy by controlling the time of their communication, disassociating it from the clinic in a physical sense (Wajcman, 2015).

The young people reported that using a variety of communication methods that they were

comfortable with helped them to better organise their own care and keep their condition under control.

Clinicians

Using digital communications: clinicians' perspectives

Within the clinical teams we studied, specialist nurses most frequently used digital communication with patients (Griffiths et al., 2017). Staff at all levels used digital communications however consultants reported the lowest use of digital communications with young patients and were most likely to be concerned by the potential for patients being more demanding. 'Boundaries that's what I am worried about.' Inflammatory bowel disease 2 Consultant 07.

For team members regularly contacting the young patients, digital communication was welcomed as another way to engage young patients with their care.

That's [text] how a lot of young people do communicate now, so ... and often if I'm struggling to get hold of a young person, if you text them you normally do get a response. Cancer 1 Young people worker 04

They used both synchronous and asynchronous channels to help them make successful contacts with their young patients whilst enabling their patients to retain some control over the interactions.

The practitioner sends a text to a young person before he phones them. The text asks if it is alright to phone at that time or to warn them he will phone in five or ten

minutes. It helps with the young person's agency as they can control the timing of the interaction. Observation notes from shadowing Mental health 3 (outreach team)

Mental health practitioner 06

Asynchronous communication (email, text and web portal) was more frequent and included one-off communications, more complex exchanges requiring a number of iterations and therapy delivered over a specified period of time.

We encourage it * with the DBT's [patients participating in Dialectical Behavioural Therapy], we encourage them to get hold of us should they feel that they want to self-harm so that we can remind them which skills to use. They have to use the skills afterwards, they have to text us with the intent of using what we're asking them to do. Mental health 3 (outreach team) DBT co-ordinator 10[*phone support delivered by text]

Our data suggest that, within the constrained choice of digital channel available for communication between clinicians and the young patients, the preferences of the young patients and their clinicians for synchronous or asynchronous communications depended on the purpose of that communication and were in broad agreement.

Clinicians were hesitant about the use of digital communication in some situations, such as when discussing a particularly sensitive or complex issue or when they did not have an existing relationship with the patient.

If it's somebody that you haven't necessarily met before, I'd be a bit more reluctant

to give them a lot of advice over email, because you can't judge as well, I think, how knowledgeable the patient is,... if you talk to them on the phone, you have a bit more of a clue into their disease understanding. Inflammatory bowel disease 2 specialist nurse 05

Time, communication and the workplace

This research was considering the role of digital communications between young people and their clinicians therefore the communications we report were all work related for the clinicians. Unlike the young people who are trying to fit communication into their lives, clinicians in the work environment, are trying to manage their workload therefore experience time through the clock (Toombs, 1990). Clock time is an important organising element of their work into which digital communications fits irrespective of whether it is seen positively or negatively. Talking about their day-to-day work, some clinicians valued the use of digital communications for organising their time and responding quickly to simple questions:

...you can give that small bit of advice that isn't urgent but you can give that quickly and then they've got the advice they want. Diabetes 1 HCA 01

Others found it a burden, especially lengthy text exchanges:

So if you're sort of just speaking to someone over the phone you're able to have free flowing conversation....I can do this time, can you do that time? Obviously if it is by text message that could end up being ... I can't do that time, can you do that time?

Mental health 4 (Early intervention) Assistant Psychologist 15

If something was considered 'urgent' synchronous communication was preferred by all

clinicians as it was considered the quickest way of resolving an issue. Some clinicians raised concerns over the possibility that a young person would contact them out of hours using an asynchronous digital channel which would not be picked up in a timely manner. Although it was a concern there were few examples given where it had transpired. Most clinical teams had guidelines on the use of each technology which patients generally followed.

Time as a resource for clinicians

All the clinics we observed were busy places with team members interacting to accomplish a complex set of tasks during the working day. Clinicians valued changes to working practices that reduced the time burden of tasks. For some, getting in touch with young people using digital channels made that task more time efficient:

It's just a quick way to get their query answered and saves time. Otherwise previously they would have phoned in, a secretary would have had to take the message, then the secretary would have to find me, then I would have to phone them back and they might not be there, so that takes ages whereas I can just whip off a two line email.

Liver Consultant 02

This consultant demonstrates the ways in which the clinicians conceptualise time as a commodity to be spent or saved (Adam, 1995). Adam (1995) talks of the commodification of time leading to the creation of hierarchies of value and within teams, time saving for consultants could be viewed more highly than for the administrators or indeed patients.

However, the consultant quoted above identifies the importance of time savings for all those involved thereby disregarding the traditional dominance of those in positions of

power (Martineau, 2015). Our data also suggests that the clinical teams are recognising the importance for young people of fitting their engagement within their lived experiences thereby levelling out the hierarchy between paid clinicians and their patients.

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The commodification of time for clinicians highlights that their time is a resource that has economic value (Adam, 1990, 1995). Whilst not referencing cost saving per se clinicians talked of constant efforts to manage their worktime efficiently. Many clinical teams regarded email and text messaging as time saving:

And I think the advantage of email is that I can answer in my time, I don't have to break off from a patient or I don't have to spend time trying to phone back another patient and not getting through... It seems to be less frustrating having an email conversation than it is having a voicemail conversation, playing telephone tennis.

Cystic fibrosis 1 Specialist nurse 03

Managing time here is closely aligned with an individual's need for autonomy over the organisation of their work.

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There was some disagreement among clinicians about how much time was saved by the introduction of digital communication. For some, not having to spend time chasing young people on landlines that they rarely use, has to be balanced with the amount of time taken to write a text or email, as texts and emails must be carefully constructed to ensure that their content is clear and unambiguous.

People feel that it's easier to ask over text, but I think what's harder to do is to

actually answer them over text because it is, from a professional point of view that's quite hard ... quite often if people text me and it is quite a difficult conversation then I would ring them back. Cancer2 clinical nurse specialist 08

Clinicians did not see themselves as creating more time through any time saved by contacting young people using digital communications. Wajcman (2008) calls this 'time displacement' – time saved in one way is countered by activity in another.

.....communications with patients is key and it's a part of everyday working life, it has to be done in one form or another..... you engage more with a patient if you do it the way they want it done. Cystic Fibrosis 2 Physiotherapist 10

Of equal importance to this clinician is communicating in a way that is most acceptable to the young patient. Clinicians recognised that the use of digital communication had improved the quality of some of their communication with patients, allowing a certain slowness (Cilliers & Sturmberg, 2005, 2009).

It does give you as a clinician a luxury that you don't normally have, because normally your communication is face to face or over the phone and therefore it's very instantaneous ... it means that the patient can take things in their own time. Cystic fibrosis 1 Specialist physiotherapist 02

Time, space and autonomy

Clinicians did not have more time but using digital channels they could manage their activity based on time rather than space because they could communicate from anywhere (Wajcman, 2008). Not being tied to a landline or desktop computer in an office they could

respond to communications when they had a few minutes of unallocated time or they set aside dedicated time during the day.

So it means you're not interrupting your daily [work]... that you can collect them all

Some clinicians felt overwhelmed by the potential constancy of digital communication and felt unable to ignore or switch off their work channels when at home. Wajcman (2015) argues that technologies are adopted differently by individuals within one organisation, and that feeling under time pressure is related to the extent to which an individual feels they have autonomy and control over their workload and work pattern. Control and autonomy are often associated with seniority in organisations; however, within our study those who talked most about the constancy of email and the loss of a work/life distinction were the consultants.

Before emails I did have working hours, now I don't. I will be sitting at my desk at, you know, midnight answering emails, that is not clinically related but it is work related'

Cancer 1 Consultant 01

It is not just digital communications with patients that is problematic but the general increase in workload associated with email communication which they considered to be eroding their work/life balance. Senior clinicians were fearful that opening digital access to patients would lead to an increase in patient demand for responses which they might be expected to deliver over ever shorter time periods. Although consultants are considered the most senior clinician there is evidence they feel they have lost much of their autonomy over their workload and work pattern (Watt et al., 2008). This may influence their reaction to the

use of digital communication with patients.

Conclusion

Using the lens of time, we have shown that digital communications are valued differently by the young people and their clinical teams, and they experience different temporalities even when they are interacting with each other. The use of digital communication influenced the young patients' sense of autonomy and control over their health condition, allowing them to find their best balance. It changed the clinicians' sense of autonomy and control in their work, but the direction of change varied between clinicians. It was also clear that temporality influenced how technologies were valued by clinicians and young people which is important to take account of when introducing new digital communications technologies in healthcare.

This study adds to the body of work considering temporality in healthcare. A patient's experience of time during a consultation has been shown to impact patient satisfaction however it is the quality of the doctor patient interaction rather than the length of the consultation that is of most importance (Sterpani et al., 2019).

Our study takes the consideration of temporality in healthcare deeper than the structures and process of healthcare organisations (Ancona, 2001; Blue & Spurling, 2016; Reddy & Dourish, 2002; Zerubavel, 1979) into the level of interaction of individual patients and clinical teams. Our results echo work by others on the wider meaning of timely access to healthcare beyond speed alone (Boyle et al., 2010). The experience of time by young people

managing their health condition as outpatients impacts on their experience of healthcare as it does for inpatients (Sterpani et al., 2019). We found young people with long term conditions as they move to independently manage their condition valued the ways in which digital communications enabled them to engage with their clinicians at a time that suited them. Other studies have found, as in our study, that digital communications worked best when clinician-patient relationships were already established (Griffiths et al., 2017; Greenhalgh et al., 2018,). It must be acknowledged that access to digital technologies is not equal, nor is the ability to take advantage of new technologies, potentially resulting in increased health inequality (Estacio et al., 2017). The provision of sufficient support for groups who have been identified as at a disadvantage can ameliorate this disparity (Tieu et al., 2017).

Recent UK health policy has emphasised the importance of widening access to health care through longer hours and weekend appointments (NHS England 2016, 2019). We argue that longer hours themselves will not solve access issues as timely access is not just about clock time. We have shown that different digital technologies have the capability of enhancing access if clinical teams and young people share an understanding of how they are best used. Our study suggests that the introduction and expansion of the use of digital communication for healthcare will be aided by understanding the differing experiences of time by patients and clinicians and how these can vary. We wish to add the caveat that expanding the use of digital technologies in the NHS to address issues of access to services must also take account of equality of access which we were not able to address in this study but requires further research to ensure disadvantaged groups are not left behind.

552	
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