

## Adolescent and caregivers' experiences of electronic adherence assessment in paediatric problematic severe asthma

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## ABSTRACT

This study explored the experiences of young people and their caregivers of having adherence to inhaled corticosteroids assessed through an electronic monitoring device. These devices are increasingly being used for assessing medication adherence, yet there is little information about the patient's experience of these tools. Semi-structured interviews were conducted with eight young people with severe asthma, aged 11-15, who were electronically monitored as part of their care and with their caregivers. Interviews were analysed using thematic analysis. Three themes were identified: "they were trying to help me get better", "checking up and catching out" and "who is responsible?" The themes highlighted differences in priorities between participant groups, the impact of monitoring on the healthcare relationship, and the dilemma of transferring responsibility for asthma management to young people. The findings suggest it is important for healthcare professionals to engage in shared decision-making with patients when introducing electronic monitoring devices.

## Introduction

Asthma is the most common chronic health condition in children and is believed to be the leading preventable cause of morbidity, mortality and healthcare cost worldwide (Heaney and Horne, 2012). Inhaled corticosteroids [ICS] are the mainstay of treatment for most patients with asthma (Hedlin, de Benedictis and Bush, 2012). Taken regularly, ICS decrease airway inflammation, reducing the number of asthma attacks, hospitalisations and asthma related mortality (Fong and Levin, 2007). However, some children and young people experience ongoing and frequent symptoms and exacerbations of asthma despite being prescribed high doses of ICS (Bracken et al., 2009). This population, often described as having “problematic severe asthma” [PSA], are estimated to make up around 5% of the childhood asthma population (Lang et al., 2008). Poor adherence to ICS is viewed as an important contributor in PSA and a variety of methods to assess adherence have been developed and evaluated such as prescription refill rate, canister weight and self-report (Bender et al., 2000). However, it is recognised that the accuracy of existing methods is limited and there is a general consensus that better tools need to be developed to support adherence (Bracken et al., 2009).

Recent research has championed electronic monitoring devices for accurately measuring adherence (Burgess, Sly and Devadson, 2011). The electronic monitoring device [EMD] used in the current study was attached to the patient’s inhaler. Once attached, sensors detect when the device is actuated and record this information. A healthcare professional subsequently accesses this information, which shows the patient’s frequency of inhaler use, the times and dates of inhaler use and the dose of ICS taken. They can then discuss the information recorded on the inhaler with the patient (Burgess et al., 2006). Electronic measures of adherence and other variations of telemonitoring equipment have been extensively evaluated in asthma as well as a range of other chronic health conditions (Spaulding et al. 2012). Smith, Elkin and Partridge (2009) have called for research to consider whether telemonitoring in respiratory care “empowers the patient to self manage their condition” or leads to a “dependence upon advice received back in response to technology-based monitoring” (p.162). However, the literature exploring this is limited and mixed in its findings, with research suggesting that whilst telemonitoring tools can increase the sense of responsibility an individual has for monitoring their own health and self-caring, they may do so in a way that maintains a reliance on the healthcare system (Fairbrother et al., 2013, Seto et al., 2012). These issues are of particular relevance when considering the use of telemonitoring equipment with young people, who are at or approaching a stage in their lives where a desire for independence and a rejection of adult authority become important (Erikson, 1968). Moreover, young people are growing up in a world in which they will have significant experience of surveillance and sharing personal information via social media (Lenhart et al. 2010). These factors could either result in them being more wary of additional sources of surveillance or more accepting of them. Burgess, Sly and Devadason (2010) suggested that giving children and young people with asthma positive feedback on their adherence levels increased their use of preventive medication and benefitted their healthcare relationships. However, McNicholl and Heaney (2013) reported that for some patients overt monitoring, even when done sensitively, will feel too confronting and some may resort to trying to conceal their data (Simmons et al. 2000). Recent research and guidance in asthma has also focused on the need for young people to be supported in taking increasing responsibility for controlling their asthma as they approach adulthood (The British Thoracic Society, 2011). Riekert and Rand (2002) suggest that the process of telemonitoring could assist families in appropriately transferring responsibility of asthma care from parents to adolescents. However, no research has explored this issue.

This study aimed to explore the experiences of young people with asthma and their caregivers

of having their adherence to ICS assessed through an EMD.

The research questions were:

How do young people and caregivers experience being assessed through the EMD?

Does the process of having ICS adherence assessed through the EMD influence experiences of taking responsibility for self-care?

Does the process of being given the EMD influence the relationship between the healthcare professional and the young person/caregiver?

## **Method**

The study was approved by a University Research Ethics Committee, an NHS Research Ethics Committee and the relevant NHS Trust Research and Development Office. Informed consent/age appropriate assent was obtained for all participants. It was conducted in a London-based tertiary service that serves a large population of children with PSA for whom poor adherence is a leading cause of sub-optimal control. The EMD is currently offered to all young people referred to the service as part of the assessment protocol. These young people have long-term asthma and have been using ICS for at least a year.

### *Inclusion criteria:*

- Young person aged 11-16 years.
- Referred with difficult asthma to the paediatric asthma team at the service.
- Issued with the EMD as part of their clinical care during the study period (July 2014 to Jan 2015).

Caregivers of the young people who met these inclusion criteria and who accompanied their child to the hospital were also invited to participate.

### *Exclusion Criteria:*

Only those able to understand and speak English were invited to participate in the study. It was not anticipated that this would be problematic as most young people attending the clinic can speak English.

Young people and caregiver dyads were introduced to the study jointly by a healthcare professional during a routine clinic appointment where the EMD was issued. Those who expressed an interest were then given an information sheet and verbal consent was sought for their details to be shared with the researcher. The researcher then met potential participants to tell them more about the study and to confirm that they would like to take part. Semi structured interviews were carried out in a private setting in the service and took place following the appointment when the EMD was due to be returned (approximately 6-8 weeks after it was issued). Each dyad was interviewed separately, with the young person interviewed first and their accompanying caregiver second. Both young person and caregiver were aware of the others' participation. Two sets of young people and their caregivers requested for their interviews to be carried out jointly due to their time limitations. Interviews were guided by an interview schedule which consisted of several open-ended questions e.g. What do you think the smart-inhaler is for? Can you tell me about any ways the smart-inhaler helps you/or parent take

care/responsibility for your asthma? Or any ways it makes this harder? Interviews lasted on average 27 minutes for the young people and 18 minutes for the caregivers. Interviews were audio-recorded and transcribed. Adherence data were not available to the researcher.

Data were analysed employing Thematic analysis (TA). This followed the guidelines presented by Braun and Clarke (2006). A combination of inductive and deductive approaches was adopted. The interviews with caregivers and young people were treated as a single data set and themes reflect commonalities across all of them. Attention was paid to similarities and differences between the groups.

Eleven eligible young people and their caregivers attended the clinic during the recruitment period of whom 8 consented to participate. Five young people were female and 3 were male, ranging in age from 11-15, (mean = 12.86, SD = 1.57). Caregivers were female and mothers of the participating child. The participants were 75% White British and 25% Asian British.

## **Results**

Three super-ordinate themes were developed .

### **They Were Trying to Help Me Get Better**

This theme concerns the ways in which participants' beliefs about asthma and their understandings of the risks and vulnerabilities it posed influenced their expectations of the healthcare relationship and their experience of being given the EMD. Throughout the interviews, the descriptions of asthma that were shared portrayed the health condition as a frightening and life threatening illness for which frequent hospital admissions and medical treatment were required:

Caregiver: She could be fine one minute and the next minute she could be like wheezing and can't breathe and stuff, she's ended up in intensive care

Researcher: So that means you have to go into hospital quite a lot then?

Caregiver: Now she's had one of them these err asthma related injections she's been fine but before that the last two years it's been really, really hard cause we've been in hospital once a week sometimes twice

ICS were seen as offering freedom from restrictions linked with asthma and protection from some serious consequences of the condition.

Researcher: Why do you think it helps [taking your inhaler]?

Young Person: Because I can do more as in when I didn't have it I tried to do like a mile race or round that and I couldn't but now like the past year when I took it before the race I could do it all

Caregiver: Yeh I mean cause the more if she doesn't forget to take it [the inhaler] then I keep saying to her you won't have to come up the hospital as often

Caregiver: Yeh yeh.... it takes out the need of being in hospital under observation for a while

Additionally, several of the young people described how the EMD was something introduced to

“help” them:

Young Person: They said that they were gonna record me to see if I was taking it cause I weren't really taking it before and they said that they were trying like to help me get better and because I wasn't taking it properly that that I needed to make sure I was taking it to get better and cause I weren't taking it yeh

### **Checking Up and Catching Out**

Whilst participants generally accepted the need to use the inhaler regularly and appreciated the benefits of doing so there were some concerns about the intrusiveness of the monitoring process.

Several interviewees perceived the EMD as something healthcare professionals use to check up on young people and their families:

Researcher: What do you think the EMD is for?

Caregiver: To track his use to check up on us

Researcher: And when you got the EMD what do you think your son thought it was for?

Caregiver: To check up on him

Some caregivers questioned the need for monitoring and conveyed a sense of discomfort in relation to this process:

Caregiver: Yeh because one of my big things is that they always question has he had his medication and of course he does I can't imagine him not I know she said last time some kids don't but I can't imagine him not or any child who needs medication not taking it

Researcher: So what were your views?

Caregiver: Well to be honest me and my husband's view is we're not particularly over-happy with it, it's like their trying to sort of catch you out at cause if it's like she's not taking it and I administer, I'm on her all the time and you know we do feel a bit, I dunno how to explain it really you know, as if they feel well she's not taking it

Many participants likened the introduction of the EMD to a process of covert surveillance:

Researcher: What did you think about that?

Young Person: Hmm err it was a little bit spyee

Researcher: A little bit what?

Young Person: Spyee

Researcher: A bit spyee! Ah! Why do you think it felt a little bit spyee?

Young Person: Well because they are checking up to see if I'm taking my inhaler

The monitoring process also contributed to a sense of mistrust in the healthcare relationship, with participants predicting that the information recorded could land young people in trouble, with limited opportunities to explain their side of the story:

Researcher: And how does it feel for you, kind of knowing that they are going to look at them [the EMD data] in that way?

Young Person: It feels scary cause whenever I don't, whenever I think of taking it but I haven't it's like oh, whenever your found or someone says you haven't done this and you plead innocence they are always gonna say that they won't believe you cause it's the results but you thi-, you say ok I'd thought I'd taken it but I didn't know if I had and yeh

Researcher: And is that different to before?

Young Person: Well if I didn't have the EMD it was like oh oh they won't know so yeh I could take it then fine but then now it's like oh if I don't take it I'll be in trouble

Researcher: And how do you think you would have managed that?

Young Person: I would have explained it but I don't think like they would believe me sort of thing [Researcher: Yeh ok] but I have been [laughs] I have

Several of the caregiver participants acknowledged that the EMD could aid their own ability to monitor their child's inhaler use:

Researcher: And what do you think about having it [the EMD] as part of your routine care and to look at the graphs with the doctors?

Caregiver: Maybe it would be good to see you know, we know he takes it in the evening but it would be good to see you know when he takes it at the other times when we're not around

### **Who Is Responsible?**

This theme focuses on participants' accounts of taking responsibility and ownership for their asthma and some of the complexities surrounding this process. Tensions were apparent between a normative expectation of young people taking increased responsibility for self-care as they mature and a perception that the introduction of the EMD acted against this. There was also an indication that reliance on the EMD could result in a diminution of use once it was withdrawn.

Throughout the interviews participants shared their own ways of managing asthma and the expectation that the young people living with asthma should be the ones responsible for managing it:

Young Person: As I'm older now she tells me it's my responsibility I've gotta remember to take it I've gotta take part in things and make sure I do things and I'm like yeh

For some families however, the introduction of the EMD created tensions in the negotiation of responsibility, with participants describing how the introduction of the EMD had resulted in young people losing their recently acquired responsibility for their inhalers:

Researcher: Yes and you said earlier that your son usually takes responsibility for his inhaler and I wonder during the time you had the EMD did you feel that changed?

Caregiver: Yeh I guess usually we keep it in like a box with his medication but I thought I'd better keep the EMD high up on a shelf because we have babies and I thought they may smash it or they'll think that it's a computer and press all the buttons and confuse it so where he was more independent it removes that say the I'm going to take my inhaler now and my peak flow because we keep it with the peak flow in a box and he can just go and get that himself whereas now he has to stand on a chair to get it because he's nearly 13 you want him to have a bit more independence and say I'm taking my inhaler because he's at high school you know he has to do things like that on his own so it reversed back to being us, which I don't think is good at all because at his age you want him to be taking responsibility

Researcher: That is something I am really interested in how it affects this age group in terms of them taking responsibility for their inhalers

Caregiver: Yeh because when he was at primary school they had all his medication for him in a case but they said as he moves to high school the nurse was like no he's got to take responsibility so if he goes out his blue inhaler he got to make sure he's got his blue inhaler and then we've had to take all that away from him

Researcher: That's really interesting as I guess my next question was about whether you think there are any ways the EMD helps your son take responsibility?

Caregiver: No it was the reverse as they were saying it's so expensive "so expensive don't break it we don't have many".

Additionally, it was suggested that some young people were dismissive of data from the EMD, indicating that they were unlikely to use it to monitor and alter their behaviour:

Researcher: Cause do you think with these sorts of things when they're [young people] then presented with evidence that they've not taken it, do you think that affects them taking responsibility?

Caregiver: I don't know if you're gonna show em a graph they are just gonna go [shrugs and pulls face], you know it's err you know you could probably tell them till you're blue in the face

For young people where the EMD was viewed as something that could help them take some responsibility for taking their ICS regularly, there was a sense that once the EMD was taken away and there was no longer anyone checking, their inhaler use would reduce again:

Researcher: And so you've said about this a bit already but can you tell me about any ways the EMD helps you or your family to take care or responsibly for asthma?

Young Person: It would always make me think about taking it if it was on there all the time

Researcher: So what do you think will happen now that you're going home without it?

Young Person: I'll try and carry on but I think it'll slowly go like I just won't take it properly

## **Discussion**



Most participants described asthma as a serious, life-long condition that needs to be managed through engaging with a variety of healthcare behaviours and had a broadly positive view about using ICS. Participants recognised that the EMD had been introduced by professionals to promote their health, support their self-care and to alleviate some of the negative consequences they experienced whilst living with PSA. However, its use gave rise to several concerns. For the young people, participating in activities and developing independence were priorities. This meant there were occasions when they had not used their inhaler and consequently their perceptions of the EMD were often coloured by feelings of fear, mistrust and blame, with the technology viewed as something that could get them into trouble. They anticipated that their explanations for not taking their ICS would not be listened to by healthcare professionals. For caregivers, a main priority was for family life to run smoothly, with asthma management incorporated into family routines. Here, the EMD could be perceived as a nuisance due to its fragility. In contrast, it was perceived by some as assisting their priorities, such as by helping family life to run smoothly by reducing the need for hospital stays. The experience of having inhaler usage monitored also had wider implications for young people and their carers. For some, particularly those who viewed asthma as a life-threatening illness, monitoring provided a sense of reassurance that healthcare professionals were looking after and “helping”. This is consistent Fairbrother et al's (2013) finding that telemonitoring provided a sense of reassurance and support to patients. It also indicates that when participants viewed the EMD as part of a standard helping process, the practice of health surveillance was accepted within the healthcare relationship. However, for others, there were feelings of suspicion in relation to the introduction of the EMD. Several young people thought the EMD had been introduced because healthcare professionals did not believe they were using their inhaler, giving rise to feelings of mistrust and wariness. Caregivers also reported thinking that the EMD had been introduced because healthcare professionals did not believe them as parents. This could create tensions, not only in the relationships between the professional and young person, but also in their relationships with caregivers. Caregivers' descriptions of hoping to use the EMD to check on their child's adherence for themselves may also be related to this, with caregivers possibly wanting to re-establish their position as reliable sources. These descriptions suggest a chain of observation, where both young people and caregivers are monitored through health surveillance technology while young people may also be monitored by caregivers using the same technology. The young person is thus potentially under surveillance from all sides.

A material consequence of the monitoring process was its effect on the young people's ability to take responsibility for their asthma. Policy, guided by research, has emphasised the importance of transferring responsibility for managing asthma from the caregiver to the young person as the latter approaches adulthood (The British Thoracic Society, 2011). However, our findings indicate that use of the EMD may have a negative effect on this process. Young people were described as having lost any recently acquired responsibility for their inhalers. This responsibility was transferred back to their caregivers, who became more involved, partly in response to their own feelings of having their supervision ability monitored through the EMD. Closely linked with this was the way in which the monitoring process impacted on young people's confidence in being responsible for taking their inhalers. Young people described feeling more worried about forgetting to take their ICS following the introduction of the EMD and they consequently sought reassurance from their caregivers concerning this. The increase in caregiver involvement noted above may have contributed to this process. This is not inconsistent with Spaulding et al.'s (2012) report that electronic monitoring motivated patients to use their inhalers correctly to avoid non-adherence being identified, but it suggests that there is a clear downside to adherence motivated by these considerations. The fact that some participants in our study suggested that once the EMD was taken away and there was no longer anyone checking, their inhaler use would reduce again indicates the potential limitations of an externally based locus of control.

This conflicts with the recent findings of Jochmann et al. (2015) which indicated that the introduction of an EMD led to sustained adherence behaviour change (although in this study participants did receive feedback on their adherence). However, it does suggest that a more phased withdrawal could be beneficial.

The EMD was experienced by some as a form of health surveillance which undermined young people's and caregivers' confidence in taking responsibility for medication use with potentially problematic long-term consequences for disease management. Viewed in this light the EMD forms part of wider advances in medical technology that enable clinicians to monitor the degree to which patients adhere to treatment regimes and protocols and indeed the increasing use of technology to monitor fitness and physiological parameters more generally, such as Fitbit and the Apple Watch. Use of such technology has raised important issues linked with privacy and autonomy (e.g. Levy, 2014) and connects with more widespread concerns about the consequences of surveillance and the negative impact of living in a culture in which surveillance in many forms is increasingly common (Ellis, Harper and Tucker, 2013).

There are some limitations to the current study. One is the absence of male caregivers from the sample. Fathers are under-represented in clinical paediatric research and their perspectives may differ (Costigan and Cox, 2001). Also, participants were interviewed at the appointment where they were due to return the EMD, so there was no opportunity to inquire into what happened thereafter. This is relevant, as it is possible that many of the fears about the EMD that the participant's shared could have been alleviated at this later appointment. Future research should be prospective in nature and carry out interviews at different stages in the use of EMDs.

## **Conclusions**

Introducing EMDs into healthcare can be experienced as a useful support tool for patients when perceived as something that is there to improve their health and self-care ability and as reducing some of the negative consequences of living with a chronic health condition. However, the suspicions of both young people and caregivers need to be explicitly engaged with lest the healthcare relationship become imbued with mistrust. Identifying patients' preferences and priorities in relation to treatment decisions is therefore an important step in the process of shared decision-making and it is important for healthcare professionals to be aware that there may be different priorities for caregivers and young people in relation to management of severe asthma. Considering the use of electronic monitoring tools on a case by case basis, where they are used as part of a needs-driven care plan will likely support this process.

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