This extended literature review investigated the disadvantages of mobile phone interventions use for promoting HIV treatment adherence. Database searches retrieved six papers identifying four themes- ‘issues with confidentiality of HIV diagnosis’, ‘frustration due to technical issues’, ‘lost or stolen mobile phones’ and ‘importance of professional support’. It is apparent that there are disadvantages that arise from using mobile phone interventions as a method to support treatment adherence for people with HIV. These issues need addressing with further research into new and existing methods of mobile phone based patient support.

Although there is still no cure for Human Immunodeficiency Virus (HIV) the right treatment, including access to antiretroviral medications, can help reduce complications such as contracting fatal conditions (News Medical Life Sciences 2019; American Nursing World 2019). This will not only help improve the quality of life for a person with HIV but can help stop the spread of HIV to others (Centres for Disease Control and Prevention 2019). HIV is an important issue for both individuals and for society, as it can have an extensive impact upon an individual's physical health due to becoming immunocompromised. HIV can also have a negative impact upon an individual's mental health by thinking that one is a burden; or it can create a negative attitude towards self-image due to the belief of infecting partners (Tavanyar 1992). This can emanate from stigma attached to an HIV diagnosis evoking negative reactions from others which can then affect the individual's well being and adherence to treatment (hiv.gov 2021).

As well as these personal challenges, there are also social challenges. For example, the cost of treatment to the National Health Service (NHS) in England for a person with HIV, could cost between £280,000 and £360,000 for lifetime treatment (Public Health England 2015). Therefore, it is important to have the right support networks and services to promote treatment adherence of people with HIV (Department of Health 2013).

Mobile phone interventions (MPIs) use in healthcare services has been successful as a method for sharing information with patients efficiently. MPIs can improve patient care outcomes and be initiated quickly and effectively (Pai & Alathur 2020). The NHS, for example, produce mobile phone applications to help view patient information which aim to efficiently provide patient care (NHS Digital 2019). As the ownership of mobile phones globally has increased, new MPIs have been developed and assessed. As mobile phones have developed, these devices have become the norm for interacting with a person with HIV regarding their treatment and care. The aim of this extended literature review (ELR) is to investigate the apparent disadvantages of using these MPIs (including applications, texting and phoning and recorded messages) for people with HIV.

Methods

The PEO (Population or Problem, Exposure and Outcome) model chosen for this ELR (table 1) is frequently used in literature reviews (Josette 2012). By using the PEO model when developing a research question, this ensures that literature searches remain focused (Williamson & Whittaker 2014). The use of keywords is the most important part of the literature searching process (Burns & Grove 2010). For this ELR, keywords were identified as a result of using the PEO tool as suggested by Kiteley & Stogdon (2014) as this helps unite the databases searched. The keywords included ‘antiretroviral medications’, ‘phone’, ‘HIV’, ‘disclosure’, ‘intervention’ and finally ‘mobile’. To ensure that the literature search was extensive, synonyms were also developed (Wakefield 2014). Boolean operators were used to connect the keywords and aid database searches.

To maximise legitimacy, inclusion and exclusion criteria were created based upon clinical relevance (Nelson 2014) (table 2). It is important to note that the use of international research papers was required in this ELR due to a lack of retrieved research conducted within the UK. During the development of the focus question, it was clear that the ELR warranted both qualitative and quantitative approach. Therefore, it was decided to incorporate both types of research papers within the ELR.

Literature searches were applied to the BNI (British Nursing index), PubMed and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) online databases. This search strategy retrieved six primary research papers (table 3). To evaluate the credibility and validity of the chosen papers, a critiquing framework was selected which is suitable for both quantitative and qualitative articles created by Caldwell et al., (2005). The chosen papers were analysed, and four themes were identified relating to the ELR focus question.

Findings

Issues with confidentiality of HIV diagnosis

Research by Dworkin et al.,(2009) relied upon an electronic pill counter as an alert system for their study in conjunction with an MPI. The design of the pill counter caused some issues, and this is evident by study participants stating "*I thought it was a taser".* Another study participant reported *"that's pitch black and looks like a tool*". This is viewed as a disadvantage as the appearance of the pill counter could draw attention and result in possible disclosure of a HIV diagnosis.

In contrast, Swenderman et al., (2015) used questionnaires and a focus group to collect data; although they emphasised the issues of confidentiality for study participants, it was difficult to recruit people for the focus group. Furthermore, using the term 'HIV' in the messages within an associated MPI, was viewed as embarrassing by some study participants who feared this could cause a breach of confidentiality. Study participants also reported fears that *"overheard general messages"* would be an issue regarding MPI use. Such a fear is a disadvantage of MPIs, as any messages could include sensitive information relating to a person with HIV's diagnosis.

The qualitative study conducted by Duggal et al., (2018) interviewed people with HIV to elicit their views about MPIs and issues of confidentiality in relation to the disclosure of their diagnosis. One study participant stated, *"we fear they might call and create a problem"* and also stated that *"so we have not shared our number*" as they did not want to be called by the nurse who was involved with the research study. Clearly, the study participants were concerned about possible disclosure of their HIV diagnosis which also limited the study findings.

All the papers used within this theme identify that fear of exposure of an HIV diagnosis was more likely if sensitive information is sent by text message. Privacy was an important factor in the study by Christopoulos et al., (2017) and the researchers ensured that there was no mention of the word 'HIV' in any of the sent

text messages during the study. This was an important factor identified in Dworkin's et al., (2009) study who referred to a suggestion by a study participant that messages could use other language instead to describe HIV.

Frustration due to technical issues

Poor technology skills posed a barrier as reported by Smillie et al., (2014). Study participants were frustrated with the processes of learning how to write and send a text message. This was also reported by other study participants who suggest that they *"would rather pick up the phone rather than to take up time trying to write"* than *"try and wrestle with the numbers".* Nevertheless, despite initial frustration by having to learn to use text messaging, this subsided once study participants got used to using the mobile phone.

The second barrier associated with technical issues, was service interruption due to a poor credit balance as reported by Christopoulos et al., (2017), Smillie et al., (2014) and Swenderman et al., (2015). All three studies found that where participants used their own mobile phones, the inability to pay for these phones created an issue within the research. Some participants were unable to receive and send messages after using up all their 'talk time minutes'. To counteract this, the study by Christopoulos et al., (2017) provided $25 credit on an *'Obama phone'* for the purposes of their study. Other study participants could not understand how to load credit onto their mobile phones or the parameters of their service plans (Smillie et al., 2014). The demographic of these study participants showed being within an economically disadvantaged group could mean that they were not able to pay for their mobile phone credit and therefore could not receive any messages (Christopoulos et al., 2017).

The final issue associated with technical issues is software malfunctioning, as identified in the studies of Christopoulos et al., (2017) and Swenderman et al., (2015). Software malfunctions were evident within the study of Christopoulos et al., (2017) as there were issues with the automated response system. Study participants

forgot that they were replying to an automated response system. When thanked about the feedback the one participant wrote *“who is 69822 that I’m talking to? Is this a machine?”*, which caused frustration for this individual. Swenderman et al., (2015) also reported frustration with malfunctioning software technology when study participants’ mobile phones broke with responses such as “*since then I am facing mobile connectivity problems*”. However, there is a difference from the Christopoloulos et al., (2017) study, as this was due to damage to the mobile phone rather than issues with the MPI itself.

Lost or stolen mobile phones

Martin & Upvall (2016), Smillie et al., (2014) and Christopoulos et al., (2017) report this as an issue for MPI use. Smillie et al., (2014) recorded that the loss of a mobile phone as having negative implications upon study participants with feelings of being distraught with responses such as “*I was so depressed*” and “*to me that was my lifeline*”. Within the study, counselling support given showed that this is just as important than simply giving reminders of taking medication and also helped people with HIV feel ‘connected’ during the study. Finally, the last study that suggested that lost or stolen mobile phones is a common occurrence is by Christopoulos et al., (2017). The researchers found that seventy five percent of the study sample had reported to have lost or had their mobile phones stolen. This suggests that study participants losing mobile phones can be a major issue for MPIs used to promote adherence with HIV treatment.

Importance of professional support

The final ELR theme further identifies the importance of using professional support. The study conducted by Martin & Upvall (2016) raised the importance of professional support whereby researchers, who were from a nursing background, helped to show participants the relevance of the study. This became an advantage for the study as the people with HIV knew these nurses, consequently, they built trusting relationships with these researchers. However, this was also viewed as a disadvantage of the MPI as use of this personal connection could introduce bias into the study reducing its rigorousness and validity.

Additionally, Dworkin et al., (2009) report that if study participants omitted medication for seven consecutive days, a healthcare professional would contact them to help resolve any problems preventing treatment adherence. The disadvantage here is that such a model could censure, rather than support a person with HIV. However, Dworkin et al., (2009) suggest that if these healthcare professionals have training, this could be a supportive strategy making sure that no harm happens to these people with HIV.

Discussion

Swenderman et al., (2015), Duggal et al., (2018) and Dworkin et al., (2009) recognise that confidentiality around HIV diagnosis could be an issue, and thus a disadvantage of MPIs. This could be detrimental to people with HIV who did not want their diagnosis accidentally disclosed. The stigma of HIV continues to exist for many reasons, one being the lack of education on the subject, which can have a negative impact upon a person with HIV's life and relationships (Unaids 2017).

A technical barrier to the use of MPIs for adherence to medication, is the reliance of 'pay as you go' mobile phone use, rather than people with HIV having a permanent contract phone. By using 'pay as you go' phones, people with HIV sometimes have insufficient funds and cannot access messages which support their treatment. Some of the researchers who produced the chosen ELR papers helped overcome this with the provision of mobile phones for study participants, but it remains to be seen if this is a viable option in the 'real world' healthcare setting. Additionally, software malfunctions can also cause frustration to people with HIV and potentially decrease adherence to their treatment. However, it is believed that such errors may be the result of human action such as when an algorithm picked up the word '*stop*' and so this indicates the provision of MPI training to people with HIV rather than a specific software issue which needs addressing (Huang 2017; Christopoulos et al., 2017).

Adherence to treatment which relies wholly upon MPIs can be disrupted when a mobile phone is lost or stolen. Smillie et al., (2014) demonstrate a realistic

understanding of lost or stolen mobile phones, as the study explains in depth, not only the number of participants this affected but, furthermore, the implications this had upon the participants. This is supported by Mailley et al., (2008) who states there are not only financial implications but also the emotional effect in conjunction with lost or stolen mobile phones. This is a significant factor in the study by Christopoulos et al., (2017) where it is acknowledged that lost mobile phones can have a negative outcome for the study, as with no phone at hand, study participants could not respond to or receive messages. Therefore, Christopoulos et al., (2017), quickly resolved the issue of a lost phone, as study participants were given replacement phones, enabling the continuation of the study. This was not a factor explored by Martin & Upvall (2016) as the participants were not given a replacement phone therefore had to leave the study thus impacting upon the findings. A way that this issue can be resolved is by the people with HIV having a method to directly message healthcare support workers so that they would not miss a response; this information can be provided in a paper patient information leaflet (Moule & Goodman 2009). Similar issues are investigated by Senn et al., (2017) who concurs that solutions must be created to mitigate against disruption of MPIs use for adherence with treatment caused by a person with HIV's mobile phone being lost or stolen.

Lastly, Martin & Upvall (2016) indicate the importance of personalised professional contact used with MPIs. Smillie et al., (2014) agree and state that interventions should be used as a support network. This aspect of support from healthcare professionals was also reported by Duggal et al., (2018) where nurses called the participants during the study with good effect. Their findings clearly demonstrate the value of telephone-based counselling as a personalised intervention enabling the study participants to access information when they needed it. Therefore, engaging with an MPI inclusive of healthcare professional support can be more successful than a purely a message-based intervention. Duggal et al., (2018) report success in healthcare professionals using mobile phones to offer support to ensure the safety and welfare of their patients, checking that they are well without being intrusive or being critical of these individuals. It can therefore be suggested that these same skills need to be developed by all nurses who use MPIs to provide care and support to people with HIV.

Implications for practice

One implication for practice for using MPIs to promote adherence to HIV treatment, are potential breaches of confidentiality, due to possible disclosure of information within text or voice messages. This could have catastrophic effects upon people with HIV and the continuity of care received. It is important that messages are given in a sensitive manner, perhaps by using code words that have been agreed with the person with HIV making it personal and avoiding any references to their diagnosis (Christopoulos et al., 2017). Thus, if any other person sees the confidential message, they would not make the connection to HIV.

Another implication for practice concerns the technical issues identified in this ELR. This includes mitigating against the impact of lost or stolen mobile phones which can lead to losing contact with a person with HIV and reduced monitoring of adherence to treatment. It could be suggested that back up methods of communication would need to be put in place, such as sending emails or letters to a person with HIV. Additionally, it is important to ensure that an MPI reflects a person with HIV's preferred method of communication, which may simply be a recorded voice message. Healthcare professionals, including nurses, must understand barriers posed by these technical issues to ensure adherence to HIV treatment (Swenderman et al., 2015; Martin & Upvall 2016).

Education is imperative for both healthcare professionals and people with HIV, as MPIs could become the norm to keep responsibility of treatment adherence and empowering people with HIV to make the right choices about their health (Martin & Upvall 2016). Further research is required to explore if healthcare education via MPI can maximise adherence with this care. Another factor which needs further investigation is whether counselling support should be used in conjunction with MPIs (Duggal et al., 2018). Furthermore, Swenderman et al., (2015) recommend that the use of personalised (rather than automated) messages should also be investigated in further detail as again this could increase a person with HIV's adherence to their treatment. Awareness of all associated implications for practice could benefit the practice of nurses involved with the care of patients living with HIV (table 4).

Strengths and limitations of the ELR

An overall strength of this ELR is that the focus question has been effectively addressed. The use of qualitative and quantitative research papers has given a broader understanding of the associated issues. Three internationally recognised online databases were used in gathering the chosen ELR papers. The overall search strategy was robust and relevant research papers were retrieved.

Limitations to the ELR include a lack of UK based research papers however, this did help enrich the ELR findings, and identified limited UK based research as a gap in the existing literature. It was concluded that some of the chosen papers had limitations themselves such as small sample sizes and being conducted in one geographical area. Lastly, access to databases was limited due to the availability via the associated university resources. Therefore, other relevant papers present in other databases may have been excluded from this ELR.

Conclusions

This ELR has reported upon possible disadvantages of MPIs for promoting people with HIV's adherence with their treatment. One important factor identified the possibility of accidental HIV diagnosis disclosure. Therefore, it is suggested that any MPI needs to use coded language and not mention the term 'HIV'. Questions should be asked about the specific requirements and design of MPI based pill counters, to make these less obvious. Technical issues such as software malfunctions, are also a factor which could affect adherence to HIV treatment using MPIs. A person living with HIV's preferred MPI also need to be acknowledged in care planning. Implications of a lost or stolen mobile phone can cause frustrations and complications to people with HIV accessing an MPI. This ELR also found that counselling support is important, and that healthcare professionals involved with MPIs will need training to develop these skills.

It is apparent that MPIs, especially when used in conjunction with healthcare professionals support, can be effective in promoting adherence with HIV treatment.

MPIs can be also used to advise on other matters which may concern a person with HIV. However, although the use of MPIs can be advantageous, people with HIV can experience disadvantages using MPIs which need to be recognised and addressed further to ensure optimal effectiveness of MPI use in future practice.

Table 1: PEO

P	Population or problem	Adult HIV patients
E	Exposure	Mobile phone intervention
O	Outcome	Disadvantages

Table 2: Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Primary research articles	Secondary research articles
Peer reviewed articles	Not peer reviewed articles
Literature presented in English language	Literature not published in English language
Academic journals	Non academic journals
Articles published between 2014-2019	Articles published before 2014

Table 3: Summary of chosen ELR papers

Author and date	Methods	Findings
Christopoulos et al., (2017)	Random control trials and a feasible study with a comparison group of study participants across 5 studies age ranging from 19-74 years of people with HIV.	Implementation challenges occurred in three categories: (1) service interruptions; (2) billing/overage issues, and; (3) the participant user experience. Response rules for automated text messages frequently frustrated participants. The inability to reload minutes/texting capacity remotely was a barrier to intervention delivery.
Duggal et al., (2018)	Open-ended interviews were conducted with HIV-positive women and key informants at a government HIV centre in India. Data were analysed with interpretive techniques.	Most women perceived phone-based counselling as a personalized care approach to get information on demand. Findings indicate that, when compared with text messaging, mobile phone-based counselling could be a more acceptable way to engage with the women.
Dworkin et al., (2019)	Focus groups and individual interviews were performed among young HIV-positive patients exploring perceptions regarding device issues and concerns about inclusion of support staff.	Participants found the proposed intervention useful. Privacy was a major concern for participants especially with possible disclosure of their HIV status by receiving a text that someone else might view. There was concern that the device could be confused with a taser.
Martin and Upvall (2016)	Semi-structured focus group discussions were	Findings suggest that when individuals are

	conducted over a 3-month period at an AIDS Services Organization in USA. The data were thematically analysed.	offered the necessary resources, such as a mobile phone medication reminder application, they may have greater adherence to treatment.
Smillie et al., (2014)	A qualitative pilot study was conducted to adapt the WelTel intervention for HIV-infected patients at an HIV clinic in Canada.	Participants described the intervention as a useful way to communicate with healthcare providers, thus increasing the ability to access services, report side effects, and attend appointments.
Swenderman et al., (2015)	A pilot study aimed to design, pilot, and refine an automated interactive voice response (IVR) intervention to support antiretroviral adherence for people living with HIV, in India. Mixed-methods research included a community advisory board for IVR message development, with 1-month pre-post pilot and post-pilot focus groups.	One-month pilot results found significant increases in self-reported treatment adherence. Messaging content and assessment domains were expanded for testing in a planned randomized trial.

Table 4: Summary of implications for HIV nursing practice

- Nurses need to regularly review the effectiveness of any MPI interventions
- Nurses should ensure bespoke support for each individual patient
- Nurses need to recognise the possible disadvantages of MPI use to help inform care planning and optimise the patient journey

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