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Ethical issues relating to assistive technology

Replacing human care

Care professionals often express concern about the use of assistive technology because they see it as something to replace human care. There is no doubt that there is a real danger that some purchasers may see it in this way, either to save money on the part of local authorities, or to reduce the need for direct support on the part of relatives. Those of us involved in developing such equipment see it more as augmenting human care rather than replacing it. However there are some things technology can do that is better than human support. It doesn't get tired or frustrated, it can operate 24 hours a day, and it clearly doesn't get upset by the behaviour of the person with dementia. There is evidence from our own work that technology can provide a much clearer picture of how the user is getting on than can care staff. Our last client in London had a major sleep problem that no-one had picked up, but as soon as our sensor network was turned on the problem shouted at us. So technology has an important role to play, and can do some things better than human carers, but it cannot be a replacement for human care, and all the expression of feeling, empathy and understanding that humans can provide. There are major ethical concerns if it is viewed as a replacement.

Monitoring

The core of current technology developments in telecare, telehealth and autonomous homes is the use of sensors to monitor people's activities and their interactions with their environment. There are ethical concerns about an intrusion of privacy. This is particularly of concern when the sensors involve cameras. I guess cameras concern people particularly because they mean "someone can see what I am doing", but all sensors are basically building a picture of what people are up to. The key ethical concern is how this sensor information is used. If other human beings are directly watching video output, or are able to see from the detailed information that someone is in the toilet, for example, then this is an unacceptable intrusion of privacy. However in practice it is completely impractical for people to follow this kind of direct monitoring. It is inevitable that the raw data has to be processed to provide a judgement about what the data means. In the case of autonomous homes the data is used to make a decision about what support equipment to bring into play. It might decide to turn the cooker off if it senses that the gas has not been lit, or the user has wandered away whilst cooking. This might just be a complete one-off mistake on the part of the user, and no-one need know that they have done something silly (unless it happens frequently in which case carers are alerted).

So as long as sensor data is used to provide some kind of autonomous response, or is used in a processed way, I feel less concerned about the ethics of monitoring. If carers are told "now he is in bed, and now he is out, etc" that is intrusive, but if they are told "the client has had a poor nights sleep" I would be less concerned, and given the impact it can have on the clients well-being I feel this intrusion into their personal world is acceptable ethically.

Who is the technology for?

There is clearly a temptation for carers to choose to use technology to support someone with dementia because it is of benefit to them as a carer. A piece of technology which would appear to improve someone's safety, such as an automatic cooker turn off, may mean that relatives feel less pressure on them to make personal visits. Such technologies need to be very carefully marketed, particularly if they become more easily available on the high street. The pros and cons should both be raised, and really the decision to use them should involve a care professional to ensure the carer, who is likely to be the main purchaser, isn't just looking for something that just reduces their burden. On the other hand some technologies clearly do have much direct benefit to carers. Devices that will alert a live-in carer if the person with dementia gets out of bed at night can ensure that the carer is more likely to get a good night sleep, rather than trying to remain alert when they go to bed themselves. So there is an ethical issue about who actually is benefiting from the technology, and a need to make sure the technology is primarily being used to benefit the person with dementia.

Development and assessment

Most applications of technology to support people with dementia are quite new, and there will continue to be new items becoming available. It is important that developers and prescribers have evidence of effectiveness based on the impact it has on the independence, dignity, and quality of life of the person with dementia. This is more important (and more difficult) than most items of assistive technology for disabled people because of the difficulty for many people with dementia to communicate their feelings about the device, and the difficulty for carers and care professionals to make proxy judgements about this. The promotion of telecare for people with dementia for example often lists the "issues" that need dealing with and how the products can solve these issues, with very little evidence. The design of this new equipment involves professional engineers who will not have dementia themselves and may have little experience of it. It is for this reason that work in this area really does have to be user-led and involve people with dementia themselves to guide developments and to try out prototypes. There is also a real need for more work on outcome measures so that judgements can be made about the effectiveness of new developments on the basis of its impact on independence, dignity and quality of life, and what the person with dementia feels about it.

Involvement in research

As was argued above it is really important that the developers of new technologies engage with people with dementia to make sure they are looking at

real problems and to check their solutions are actually effective or not. This raises the issue of how ethical it is to involve people with dementia in research. Our own experience has very strongly been that people with mild to moderate dementia are very keen to help test new devices or be involved in discussions or focus groups. It is a positive way of using their disability. But certainly the more disabled they become the less easy this is to carry out. The whole purpose of testing prototypes is to make sure they really are working, and implicit in this process is the fact that they often won't be quite right and will need modifications. This can cause a lot of anxiety on the part of users. They feel responsible sometimes, and feel they have failed yet again because the new device didn't work. They are also anxious anyway about something new to deal with in their environment. This makes iterative designing quite difficult. We have felt ethically that we should involve people in the early stage of dementia as much as possible, and if this isn't appropriate then to use good personal carers in the first instance to try things. They often have excellent insight into how the person they are caring for might react. Devices will still need testing by their intended users but hopefully this will only occur once the prototype is a more mature piece of equipment, and if it still requires modifications they will be minor ones and not cause the same level of anxiety.

The difficulty of making behavioural judgements

There is a danger that the efficient ability of technology to monitor the behaviour of users can lead people to rely on it too much. It is very good at basic monitoring activities, but making intelligent judgements about behaviour is not something it currently does very well. It can tell if someone is in bed or not, but cannot easily make judgements about such things as whether someone is feeling depressed or anxious, for example. There is an assumption in the technology literature that as long as you can collect detailed information it is just a matter of intelligent processing to make conclusions about high-level behaviours. In our experience this is not the case. It is extremely difficult to make the kind of judgements that humans do intuitively. The ethical issue here is that people see the detailed information that can be collected by technology and assume that it can use this information as intelligently and sensitively as humans, and this it cannot do at present.

Types of technology

Can I make a fairly biased comment about the kind of technologies that are being used. It is biased because it reflects our feeling that the approaches we have been following are intrinsically more ethical than technologies such as telecare. Telecare is, as you know, a technology that monitors users and then calls for assistance if something goes wrong. However I feel our use of autonomous homes gets much closer to what users really want in terms of their care and support. Autonomous homes provide a reaction themselves rather than relying on call-centres to be alerted and then initiate a response. Our approach keeps the response local to the user. It means the user keeps much more control of their lives, and they are empowered by the technology rather than being overseen and "dealt with". No-one need know they have done something

forgetful now and again, the house installation will sort it out, unless it is a frequent occurrence when someone then does need to know. Autonomous home technology is not commercially available yet but will be at some stage, and I feel it overcomes some of the ethical concerns about technology acting in a big brotherly fashion.

Poor take-up

You asked a question about why the take-up of monitoring technology does not seem to be that good. This is a complex issue which is bound to be affected by all kinds of issues from promotion to cultural responses. Our own experience is that a key factor is a reluctance on the part of professional carers to make what are perceived to be major changes in their approach to caring. We have had to deal with a wide variety of people in evolving new equipment. People in the early stages of dementia are often very keen to try anything that might help, as are personal carers. The main exception to this has been a reaction on the part of some that even a simple piece of assistive technology somehow underlines the fact that they have a problem, and gets rejected for that reason. But this is an issue with disability equipment generally, and is probably just amplified with something as emotionally charged as dementia. The major problem, and in our experience it has been a major problem, is the reaction of local authority care providers. There seems to be a deeply-felt reluctance to even try out technological solutions, but particularly technologies that seem a little futuristic to them. Part of this is a fear that they are going to be intellectually challenged by it, it is going to go wrong and they won't be able to deal with it. It does contain the dreaded computers after all! Part of it also is a financial one that it is going to involve much more work and managers are constantly keeping an eye on their budgets of course. But there seems to be something a bit more deep-seated that relates to what is perceived as quite a profound change in approach. There is a feeling that what professional carers are providing is a very personal human-centred approach to supporting people. Technology somehow seems to be almost the antithesis of this. It cannot possibly provide what they feel they put into their care practice. This is of course perfectly understandable, and in some sense is a credit to such carers. My own feeling is that from our experiences this might take some time to be overcome, and is really only going to do so once there is a good body of positive evidence about the role and impact of these technologies, and how care professionals can use them rather than be replaced by them. I guess the usual take-up dynamics will apply. There will be early-users who will provide initial evidence until a critical threshold of acceptance is reached when it will take off. However the timing will depend crucially on the quality of the evidence that is collected.