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DL4.1 Appendix F
UK Case study (Full Version)
Bridie

Bridie is an 82 year old lady with vascular dementia who joined the project in May 2016:

Background

Bridie is widowed and lives alone with her dog, Bodger, in a small rural village just outside the town of Bridport, in Dorset. Originally from Fulham, Bridie grew up and spent most of her life in London where she attended Grammar school and later worked in the accounts department of the Shell Oil Company. Bridie is private about her diagnosis and does not want anyone to know she has dementia.

Bridie and her husband retired to Dorset nearly 30 years ago and after her husband died Bridie continued to live in the same house they moved to. Bridie has 2 children, a Son who lives in Australia with 3 grandchildren and a Daughter Kate who lives a 20 minute drive away and works full time. Kate supports Bridie daily with all household tasks; Kate's husband has been unwell recently so she is also giving him extra support as well as several of her neighbours who she helps with pet care, DIY and daily checks. Kate has 2 Daughters Anna lives in London and Ginny is at university in the UK.

Circle of Care

Bridie continues to enjoy living in the small rural village and a positive of this is that Bridie is both familiar with the community and well known to them; most residents in the area Bridie lives know each other and are also elderly and retired. Bridie is well known at the local shop that she visits each morning for her newspaper. The manager Catherine supports her independence and has arrangements with Bridie's daughter Kate about paying for shopping and generally keeping an interest in her wellbeing when Bridie comes in; reporting any issues to Kate.

Bridie is also involved with the local church and is in touch with the Vicar and Brenda the Church Warden and there is a coffee morning held in the church each Friday that Bridie used to attend regularly. Bridie also visits and receives social visits from her neighbours a couple of times per week, her friend June down the road and Julia who lives opposite call in regularly, however they are all becoming more elderly and not always able to leave the house to visit each other but keep in touch by phone. Bodger takes up a lot of

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her time being a blind but lively and friendly Jack Russell but walking him is not possible for Bridie as he is very nervous outside the familiar house and garden.

Medical History

Bridie was successfully treated for breast cancer shortly after she retired. Bridie is type 2 diabetic, has High blood pressure, suffers Depression, has a diagnosis of Vascular Dementia and had Arthritis in her spine and knee and walks with a stick. Bridie reports her biggest challenge is her balance and her memory. Bridie's reports feeling more dizzy and this is affecting her confidence on the stairs. At the start of the project Bridie reported that her memory had been bad for about 3 years when all of a sudden she couldn't seem to remember anymore, this left her very confused and disorientated, but says her long term memory seemed better now, the everyday stuff is still a problem. Bridie has been a victim of door to door conmen in the past and also vulnerable to phone salespeople, giving large amounts of money to charities that ring up, unsolicited. Bridie reported her mood was often low and she felt depressed a lot but as soon as she sees family of friends she feels ok.

Care needs

Bridie receives 2 formal care calls per day that are funded through Adult and Community Services as a statutory provision (Dorset County Council fund care for those with an assessed need who have under £24,000 in savings). She is also receives visits from Tamsin the Care Co-ordinator at the local GP surgery. Tamsin visits about once per month and more frequently acts as a local contact and coordinator for Kate if she notices anything that may need extra support, such as a fall or the start of an infection. Accessing formal Carers in a rural area can be challenging, due to the nature of the demographic, Dorset experiences a shortage of Carers given the localized high demand. The high cost of living coupled with low wages for formal Carers compounds this.

The Carers come in twice per day. Each morning they support Bridie, originally to help with breakfast and to help her get dressed they now help her get washed and dressed and also shower once per week, Bridie was previously physically independent with this at the start of the project but her care needs are slowly increasing as her conditions progress. They also make her a cup of tea and toast to ensure Bridie has eaten. Each afternoon the Carers visit to make sure she has a hot meal at tea time, "check I am ok and I have got my Careline pendant on"

Kate supports Bridie with all other tasks, arranges all appointments, hair dresser, outings etc. Daily checks x2 over the phone. Kate pays all bills, arranges all health checks for Bridie and Bodger too! Bridie falls a lot and in the past she has phoned Kate but now uses careline. Kate has power of

attorney to allow her to manage Bridie's finances; Kate has also organized meals on wheels to come in each week day to deliver a hot lunch. This is a local firm run by Norma and the drivers going in each day do flag up any concerns they notice, although they do not spend more than a minute in the house to leave the food and collect the empty plate.

The care situation was set up following the fall that lead to a hospital admission, Bridie received Reablement after being discharged from hospital. Bridie remains at a high risk of falls and is often unable to get up from the floor. Bridie's dementia has progressed through the project and Bridie recalls what happened when prompted but can be unable to recall finer details.

Assistive Devices

Bridie has a few aids to help her cope with the limitations she experiences. She has a trolley in the house so she doesn't have to carry things. Bed rails "so I don't fall out" Grab rails in the toilet and bathroom and outside the doors. Bridie has a walk in shower and uses a swivel cushion in the car. Bridie's family bought her a day clock "to let me know the day and time" however Bridie unplugs everything at night so this switched off unintentionally and Bridie does not remember to plug it back in the morning.

The downside of living in such a small rural village is that mobile phone signal is very patchy and there are many dead spots including Bridie's street. The signal is poor at best, the broadband is also very weak and drops out a lot, several times per day. There are also mostly retired people living locally so there is little diversity of skills and abilities to draw on with regard to technology usage and physical ability.

Attitude to technology

Bridie is open minded about new technology. In the past Bridie's role at the Shell Oil Company included using one of the new desk top computers. One of her tasks was to ring up each county for their accounts figures and enter them into the system and Bridie says she was fairly confident with technology in that role.

Currently Bridie has a cordless phone and a mobile phone with an emergency button. When asked about social media Bridie said she would not mind learning about Facebook. Bridie has a tablet computer and is connected to the internet and does a big shop on-line fortnightly with Kate, but does not use the tablet by herself. Bridie also has a Careline/Telecare link that the Carers ensure she wears every day, Bridie is confident to use this in an emergency, however Careline only works in the house.

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Intervention

Aims for the Client and Circle of Care.

Given the large and varied circle of care around Bridie the potential benefits were identified as assisting Kate to Co-ordinate Bridie's Care and keep people up to date with situations without having to make numerous phone calls, emails etc. and to be able to do this from a distance. This would also enable Kate's husband and Anna and Ginny to be more aware of Bridie's situation and able to support Bridie and each other better as a family.

Bridie's dizziness and falls can be supported with sensors that also work outside the home (Buddi) to enable Bridie to continue to walk to the shop independently and with confidence. Access to the App in the shop would act as a welfare check each time Bridie is served and they can communicate issues to Kate and Tamsin if concerned. Tamsin will be able to keep track of Bridies wellbeing, record blood sugar and inform Kate of any visits and outcomes without having to contact her specifically.

Within the community access to the app would let the church warden record when Bridie went to coffee morning on Friday. Technology in the home would then allow formal visits from the care agency and meals on wheels to record their visits. This would act as another welfare check and allow concerns to be flagged clearly and to the relevant parties.

Potential solutions planned through the project

The plan was to build a timeline for Bridie with all interactions and events that take place in her day, issue Bridie with appropriate sensors for herself (buddi) and her home (movement sensor) that will populate the timeline including integrating with her Careline. Give Bridie a personal login so she can use the app herself it she wishes. Share the timeline with the circle of care by giving logins to everyone involved and issue Kate, Catherine and Tamsin with project phones or tablets to maximize access and interaction to the timeline. In addition to this leave a project phone in Bridie's home for Bridie and visitors to use.

Intervention

Bridie and her family were interviewed to establish the care routine for Bridie. Due to the early phase of the project Bridie's timeline was built in the Beta area of the app. This was challenging for the pilot team as the basis for the new app was the Nourish Care Home system so it appeared quite inflexible and took some time to learn ways in which this needed to be changed or ways we could adapt existing functions away from time and task and towards a record of daily activity and interactions.

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Bridie, Kate and her family were given individual logins and the project team met with Kate and her husband to download the beta app onto their devices and establish logins and train them on the basic functions. The learning from the requirements of this formed the basis of the 'how to use' factsheet. This included where to find the app, how to download and open it, setting up logins and entering tasks and alerts. Kate and her husband were easily able to access the app and put entries on there, however without the secure timeline sharing no other parties were able to enter information so any benefit was unclear to them. A couple of months later the organisation element for Bridie's timeline was replicated and moved to the new IntegrAAL app version. However this was not communicated clearly so no support was available and Kate and her husband could no longer login as they had a different version of the app stored on their phone and tablet.

Once this was identified attempt to rectify this were made, however the profile copied over from Bridie only included profile and care plan elements. The timeline that had been so time consuming and complicated to setup had not been replicated. A request for this to be replicated was submitted but this did not seem to be possible to achieve. Some months later this was rebuilt manually but this impacted on the continuity of the use of the app and has not been used yet.

Bridie was issued with a Buddi and wristband falls detector and this was set up in the home. Several meetings had taken place with Buddi and Nourish and in theory the timeline was able to integrate with the Buddi unit, however this did not happen on this occasion. This meant the Buddi unit was essentially a stand alone piece of technology without the ability of remote review by a project member to give extra support. Only on completion of the questionnaires was it discovered the issues that had been experienced by the family using a Buddi unsupported by the project. The associated wrist worn falls detector was too sensitive resulting in many many false alarms including when family were on holiday. It went off when Bridie was into hospital and family had a call saying the falls detector had gone off.

"Given that there were phone calls we found that reassuring even though they were false alarms.it was good having that information relayed to us." Kate

Kate had to ring Bridie on each alarm raised and if she didn't answer assume she had fallen so it took a lot of time and NHS personnel to check the false alarms. Bridie was panicked by an alarm, she called Kate and said the thing is flashing at me. She did not know what to do. She couldn't work out where the voice on the unit was coming from as it was so quiet. With the phone it kept dropping out of broadband as it is so poor in the area so the GPS location is not sent and the 2 way voice on the unit was unclear. The battery often went flat as Bridie turns it off at the mains each evening then she would phone Kate

and say, “That thing doesn't work, that thing is flashing at me”. It did detect one fall correctly, Kate was away but was able to call Tamsin to go round. Bridie was on the floor unable to get up.

Eventually Bridie decided she did not want the Buddi anymore and her granddaughter Ginny requested that it be removed. The Buddi was collected however Ginny called the council directly and ironically we do not know where the Buddi is or who collected it. This also raises consideration given to asset marking and processes to follow on management of hardware, these relatively small, mobile and expensive items must be maintained more closely than other aids or equipment.

Tamsin was also given a login and training from the project team during a couple of sessions, Tamsin was open and supportive to the project but not at all confident with the technology, one of the training sessions required how to use the smart phone, this included how to turn it off and on and the various screen locks and screen swipes. This limited experience and the developmental stage of the app meant there were barriers to Tamsin feeling comfortable and confident enough to start using the app independently.

This situation replicated with Catherine at the local shop. The project spoke at length to Catherine who was very open and willing to be involved the login was set up and a project phone was left behind the counter to log whenever Bridie had visited. The phone was not accessed at all, not one visit was logged, it simply did not factor in the daily routine of the staff that were behind the counter. A consideration here was did each staff member need a different login or would a global login for the shop be sufficient? Having to log in each time was another barrier to using the app in this situation. Many professionals are used to secure systems to record notes in some way; this simply is not applicable in community settings. The secure timeline sharing element of the app was required for this to be used with confidence, with various levels of privacy; this could have mitigated the need for a formal login requirement.

The project was discussed with Brenda from the Church who was very reticent, she was unable to understand the concept of what we were trying to achieve and not sure that it was something they would be able to be involved in, she would be happy to support Bridie but was not confident in becoming part of the project.

The project showed the app to the private Carers that came to visit Bridie, they were very positive about the potential for it to help them communicate any issues to the family but they were unable to complete any tasks not on their task list in Bridie’s care plan and suggested we would need to contact the office. The office was phoned a couple of times and finally a discussion took place about the project; we were informed that the registered Manager would have to approve this and we left various messages but our calls were not returned.

One of the most promising responses from the community was from the meals on wheels service who agreed to meet with the project in the evening after the working day. The project was explained and Norma although unsure of the part they could play given the very little time they spent in each client's home was very open to trying something, although could see no long term benefit or any way this could be expanded out into the community or how we could work with the drivers to populate the app. This would involve the driver on Bridie's route to either carry a smartphone or use the smartphone in Bridie's house, neither of which were popular. Many of the Drivers were retired and doing this as a part time job to get them out of the house. Most had never owned a mobile phone never mind a smart phone, the poor signal in the area had not only affected the function of mobile phones it had affected the culture and the community who had not yet evolved to rely on them. They actually were quite well connected already; the app did not offer them anything they did not have, they phoned, visited and spoke to each other on a regular basis. Introducing technology to make this more efficient would introduce a lot of stress for people because they were not used to using technology and because it remains unreliable in that area due to poor signal.

A group of Reablement Workers (RW) began to use the app to record their care notes, they began to use this to populate the timeline and began feeding back their experiences of using the app and the true impact of the lack of signal and the behaviour of the app in poor signal areas came to light.

The RW were using the App on Dorset County Council tablets, best practice for the app was to remain logged in all day. However this was counter to Dorset County Council advice that RW only log into the tablets to check their rota and enter mileage and then log off to save data charges and battery. This logging off behaviour had the impact of losing any unsaved notes in the app when there was poor signal in the area; the other issue of poor signal was it caused the app to stall when in areas of poor signal, making it impossible to add notes in the first place.

This led to the RW creating a 'work around' where they would write up notes on the app at home or later in their shift and having to log on and log off at home or within a good signal or wifi area. It took considerable time to identify there were 2 different issues and to resolve to impact of the signal. The stalling was only identified when a developer came to the UK and went on a field visit to witness the impact, he immediately knew that the app was identifying a signal present and automatically tried to refresh, however the app was not able to discern sufficient strength of data signal. Hence it was trying to refresh in areas with insufficient or no data signal causing the app to run very slowly and impacting on the usability. This experience was frustrating for the RW and remains a shadow over their experience on the project, is yet to be fully resolved.

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Impact

There was a lot of support and enthusiasm in the community for the potential that the app could provide at the start of the project and this was tempered by the very early developmental stages of the software, giving limited functionality. The RW and families can clearly see the benefit and would wish to remain engaged with some form of technology if the improvements such as the timeline sharing and the integration with Careline and Buddi were available. Older adults had a more passive acceptance of the technology, seeing that it could be of use to others who are supporting them but not wanting to have anything to do with it themselves, thinking that you need to be clever to use it or brave.

Halfway through the study the need for on-going support, advice and review of technology became evident and the realisation that this could not be the role of one person, illustrated by the absence of a lead in Nourish for almost a year and of the pilot lead for several months due to illness. Even in pilot of this size the requirement for hand holding and on-going support to use technology had been massively underestimated.

Towards the end we still found people were optimistic and open, keen to see the developments promised come to fruition, even with all the issues above the concept remains well received. Given the rocky path that the UK pilot took it has left a remarkably positive impact on those that have been involved.

Very little happened as planned yet so much experience and learning came out of that; of things going wrong and of the challenges. These are gems that can be mined to create a far superior user experience in the future. Much more work has to be done in the community to raise skills in using devices that in turn will offer more choice.

Case study feedback quotes

Would you like to continue using the technology?

Given a fair wind yes, the expansion would be that everyone would use it. But we were the only ones putting comments in.

Mum thought it was a phone but forgot to charge it so it was often dead when we got there. I don't know how you would get around that.

With greater flexibility I think it could [support people at home]. Adding things onto it but it needs to be very flexible rather than rigid tasks. It would be better on a tablet and needs to be responsive rather than didactic. Rather than tick boxes it needs to be …This is what happened…

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Just to give it a go as anything is better than nothing and it steers itself in the right direction with things like this.

It would have been really good if it had worked… I expect the first version of the iPhone was not much cop...

The response of everyone involved was good, the support from buddi and the response was good.

The idea is good and I struggle to see how it could be designed differently. The number of times I hit my watch in a day. It is the same for the falls detector. [Buddi]

The last word…

I think the project is really good and needs to be supported. The issue of people living to a great age is going to define the century. And we need to find ways of supporting them and their families as we grow old together!

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