

e-Health Diaries for People at End-of-Life: “A crutch to lean on”

C. Wilson¹, P. Ormandy¹, C. Vasilica¹ and S. Ali²

¹School of Nursing, Midwifery, Social Work and Social Sciences, University of Salford, Salford, Greater Manchester, United Kingdom

²Health and Social Care, University of Salford, Salford, Greater Manchester, United Kingdom

Abstract – *The objective of this article is to explore the use of e-Health diaries in palliative care. 68 patients from three hospices in the UK were involved in the study. A sample of 14 patients was selected for diary analysis and focus groups. The qualitative data was examined using thematic analysis and findings exposed the different ways patients used their diaries, who they wrote for and what they revealed about their personalized care needs. e-Health diaries are invaluable at providing the patient with a voice and creating rich information for healthcare professionals.*

Keywords: e-Health diary, blogging, end-of-life care, personalized care, qualitative data.

1 Introduction

e-Health is an emerging term relating to the use of the Internet and other technologies to enhance health care services and the information delivered to stakeholders involved in healthcare practice.[1] Consequently, e-Health’s primary outcome is to improve patient well-being through communication and information technology.[2] An e-Health diary allows the patient to write a web or app based diary that is shared with their care team. The use of e-Health diaries is rare, although, they have been successful at improving the self-efficacy of patients with cardiovascular disease[3], Crohn’s disease[4] and diabetes.[5]

Technologies, such as e-Health, have emerged in end-of-life care to enhance the communication between healthcare professional’s (HCPs), patients and families, to expose and foster adherence to patients’ care wishes.[6] These technologies include informative websites,[7] videos and telemedicine. However, very few interventions are patient focused,[8] with the exception of patient held medical records.[9] Most are aimed at providing information for caregivers and HCPs.[8,10] No known e-Health interventions involve patients nearing the end-of-life writing an e-Health diary, however, there are accounts of patients writing blogs about their medical conditions.

Blogging is a proficient social media feature enabling users to express themselves through online entries in a chronological order.[11-12] An important characteristic of blogging is the stimulation of communication,[13] allowing users to reflect on personal experiences, share and seek opinions, and release emotional tension. Users’ blog for a

number of reasons; three prominent types of blogs include, individual created entries, a mashup of information curated from other sources and knowledge entries.[14] Individual blogs known as personal journals, diary entries and online diaries embody the blogger’s own experiences and views.[15]

In the health context, primarily blogs are used by patients to self-manage a health condition or achieve a specific health goal.[16] Patients also blog to communicate other issues rather than just health.[17] Evidence suggests that the therapeutic outcomes of blogging include being able to express emotion, decreased feeling of loneliness, emotions management and finding satisfactory information.[18-19] Furthermore, by sharing personal stories and reflecting on the process/services, users are able to support peers in decision-making practice[20], which in turn empowers people to actively be involved in their healthcare.[21]

Issues and concerns patients have regarding posting blogs range from a fear of being judged for their own opinions and behavior, maintaining their privacy, blogs being edited, receiving negative opinions and a lack of interest from HCPs.[22] However, blogs written by patients are often useful for physicians to gain a deeper understanding of their patients.[23] Additionally, clinicians can join their patient bloggers online to signpost users to information as a coping mechanism.[17]

e-Health diaries differ to blogs as they are not publically displayed on a website, instead they offer patients a platform to write a diary that can be shared with whomever the patient chooses. This can help patients overcome fears of being judged and loss of privacy.[22] Moreover, e-Health diaries ensure that HCPs take an interest in what the patient is writing by acting as a written communication between patient and HCP. Unlike most other e-Health interventions in end-of-life care, the diaries provide the patient with a means to express their wishes, fears, feelings and thoughts. This approach is innovative and as such, the qualitative research is exploratory in nature.

1.1 Research questions

This paper explores the use of an e-Health service, which provides patients with a diary writing function. The use of the diary by patients nearing the end-of-life will be analyzed by referring to the following research questions:

- 1) In what ways are end-of-life patients using e-Health dairies?

- 2) Who are the e-Health dairies being written for?
- 3) What do the dairies tell us about patients nearing the end-of-life?

2 Methodology

2.1 VitruCare™

The e-Health service that the patients were asked to trial is called VitruCare™. VitruCare™ is web and app based system that offers different patients different services, from action planning and goal setting for patients with long term conditions to well-being services for patients nearing the end-of-life. The diary forms one microapp available to patients in end-of-life care. It has a 3000 character allowance and can be written as often as the patient chooses. The diary is shared with the patients' chosen care team. The care team can include anyone the patient wishes from nurses, doctors, physiotherapists to family members and next door neighbors.

The patients were asked to trial VitruCare™ for three months, during which time they had access to a variety of microapps such as 'Introducing Me' and 'How I Feel Today'. The most popular microapp was 'How I Feel Today', which included the diary element of the service. The present paper explores the use of this online diary by patients and HCPs.

2.2 Sample

Sixty-eight patients were recruited from three different Sue Ryder hospices that offer palliative care in the United Kingdom (UK). These patients had been diagnosed as nearing the end-of-life according to the Gold Standard Framework, however, for the purpose of the trial they were perceived to have longer than three months to live by the clinician. A sample of 14 patients (7 male; 7 female) was selected to represent the use of the diary. This purposive sample was selected to represent a variety of ages, medical conditions, gender and type of diarist. The average age of the participants was 57 years with complex health conditions including neurological, cancer, and respiratory disease.

A group of 45 HCPs were involved with the 68 patients using VitruCare™, working for either the referral units or the hospices. Again a purposive sample of 11 HCPs were selected to take part in focus groups to gather qualitative data exploring their experiences of monitoring patients through online patient diary information entered on VitruCare™. The sample was selected to provide a range of HCPs from all three hospice sites, in a variety of roles such as day therapy nurses, clinical nurse specialists and consultants. They were aged between 31 and 62, with an average age of 49 and all were female as there were no male HCPs involved in the care of the patients.

2.3 Data collection

Following ethical approval from the UK National Research Ethics Committee and the Hospice research governance committee, qualitative data was collected from the sample of 14 patients through two different methods. Firstly, all patients

consented to the data they entered into VitruCare™ being used for research purposes. As such, each participant's diary entries, for the three months they took part in the trial, were collated and anonymized through the Microsoft CRM system. There were 899 separate entries, which average at 64 entries per participant. Secondly, four focus groups each with two or three participants (well enough to attend) were held with 10 patients on the trial. There was a focus group at each of the three hospice sites, and two focus groups at one of the hospices where there were a larger number of users. All participants provided consent to be part of a focus group and for the discussion to be recorded. Patients were asked about their use of VitruCare™; how often they used it, what they used it for and which function they used most. They were also asked about the impact, if any, that the online diary had on their lives.

In addition, rich qualitative data was collected from the sample of 11 HCPs through focus groups. Three focus groups, one at each of the three hospice sites, were held with three to four HCP participants. All of the HCPs involved consented to attending the focus group and the discussion being digitally recorded. Similarly, the HCPs were asked about their use of VitruCare™; how often they monitored patient entries, what information they reviewed or was of interest and how they used this information. They were also asked about what impact the online dairies had on patient care and their role as an HCP.

2.4 Data analysis

All focus groups were transcribed and patient diary entries collated into date/time ordered qualitative data narratives. The data were analyzed by three experienced qualitative researchers using thematic analysis. Initially the researchers independently familiarized themselves with the data and developed preliminary coded themes alongside detailed notes of thematic meaning. These preliminary codes and meanings were then discussed, agreed and developed into a comprehensive coding guide, ensuring consensus meaning and understanding across the three researchers. The data were then coded using Nvivo 10 for Windows and second coded for validity and reliability by another researcher. From the coding process, overarching themes were developed that depict the data collected and answer the research questions. Under the research questions, three core themes: *Type of diarist*, *Who do the patient write for?* and *About the patient* will be presented and discussed in the results section.

3 Results and Discussion

3.1 Type of diarist

It became evident from the patient diary data that there were two main types of diarists. Patients appeared to use the diary for different reasons. The first of which was to log symptoms, daily activities and health indicators as a record for the patient care team or self-management of health. The second included using the diary therapeutically and as a narrative to expel thoughts, feelings and emotions. These diarists wrote their

entries privately, excluding family and friends, but were still aware that their HCPs could read it. A number of patients also began using their diary as a simple log but over time increased the detail in their entries to include emotions, feelings and intricate stories. These types of diarists tended to warm towards using the diary in their end-of-life care.

Out of the sample of diary entries, nine patients utilized their diaries to log moments in their health and in their lives, similar to people who develop blogs to self-manage their health[16] and previous e-Health diaries used to tackle diabetes[5] and cardiovascular disease.[3] These moments included daily activity, general mood, symptoms, appointments, hospice treatment, hospital treatment, medication and any self-managed treatments and demonstrate the complexity of patients' treatments and interactions with their care team. Brenda wrote daily in her diary:

Brenda: "Ached a bit today after physio, especially neck and diaphragm. Blood sugar down to 2.2 today with what felt like a dumping syndrome episode. Social worker came today and she will be ringing the hospice about the drop in, and what care I may need. Weight 39.8 Ventilator 2 x 20 mins."

Patients would write about what had happened in the immediate past; for instance, that day or that week and very rarely would they recollect events from the distance past or write about what may happen in the future. There was only one patient (Philip) who thought about the future and even then it was merely fleeting comments and not in too much detail:

Philip: "I've got to get info on making a Will I've put it off too long."

Philip: "I wonder what's gonna be next."

The entries were usually regular and often daily, to the extent that if a patient missed an entry, they felt like they should justify why, demonstrating that the diary acted more as a regular log of moments related to the patients' health. Jane's entry indicated a sense of obligation to update her diary regularly:

Jane: "Had a very bad day, (14/07/2015), that's why I had NOT filled in my diary, thought I had till I checked it now."

In accordance to tele-medically augmented palliative care,[24] additional reasons that patients struggled to complete their diaries included illness, death, tiredness, going on holiday, being admitted to hospital and having technical difficulties. Illness, death and tiredness were difficult to overcome as barriers to usage, however, other obstacles could be reduced. For instance, as suggested by Nemecek et al.,[24] there was readily available technical support for patients and technical problems were continuously being improved by VitruCare™ to prevent issues stopping patients using the service. Moreover, five of the 14 patients in the sample had admissions to hospital, which prevented them from using

VitruCare™ due to poor connectivity issues. As digital health evolves and use of social media increases[25-26] certain web or app based systems will become paramount to patients' care plans. It is therefore important for the chosen e-Health service to be included in a patient's medical records and for hospitals and hospices to provide the necessary resources and appropriate internet access.

The second type of diarist is the patient who uses VitruCare™ as a reflective diary to record their ongoing thoughts and feelings. This emotion management has been previously adopted by people with cancer[18] and young adults with depression who blog about their experiences.[19] Five out of the sample of 14 diarists, were patients who utilized the diaries in this way. For these patients, the diary became less of a log of symptoms and treatments and more of a release of emotions about what was happening to them. Stephen in a patient focus group spoke about how he used the diary as an emotional outlet:

Stephen: "I'm using it as a sort of crutch to lean on...I kind of treat it as somewhere I can write down some of this stuff at the same time, just reading it, where I'm at and so on because I can't discuss it with my family at the moment."

These patients, through the recollection of stories[21] from the immediate past and the distant past develop a narrative that expresses: their fear of their illness and dying, frustrations at changes in lifestyle, feelings of guilt, sadness of being alone and happiness when interacting with others. Charlotte, who struggled with chemotherapy, felt too young to be dying and often expressed fears of what was going to happen:

Charlotte: "Feel sad that mobility is so impaired and frightened at the thought of going into hospital in the poor condition that I am currently in"

These emotive narratives tell us less about the daily symptoms and record of treatment but more importantly provide an invaluable insight of the emotions and mental well-being of people approaching the end-of-life. Chung and Kim[18] discovered that cancer patients and companions write blogs for four main reasons; prevention and care, problem-solving, emotion management and information sharing. Innovators and designers of e-Health for end-of-life care should consider these patient requirements when developing their software, especially as VitruCare™ has been used for similar reasons; to share their information with HCPs, friends and family and to manage emotions by writing emotive narratives. The system also provides a secure messaging facility for patients to ask about care and solve any health related problems.

3.2 Who do the patients write for?

Diaries are usually entirely private, written by the individual to reflect on moments in their life. They are therefore written for the person doing the writing however, a diary in an e-Health context is different. These diaries are completed by

individuals as patients and as part of their healthcare.[4] The patients are aware that their care team can see the information that is being written and so their diary is not just written for themselves but also for others. The following section explores who the patients are writing for and the themes connected with these interactions by exploring the focus group data.

All diarists can choose who they share their diary with by selecting people to be part of their extended care team. The patients who log symptoms, treatments, mood and activity tend to write their diaries for a mixed audience of HCPs, family and friends. These diarists are similar to bloggers and they use their diary to inform their care team of what is going on, mostly so that they do not have to constantly repeat information.[21] In a focus group, James spoke about the reasons he started using VitruCare™:

James: "I started using it because I was thinking of doing a blog just to get thoughts down somewhere, maybe share them and so what I was finding was that I was telling people things and some would say, how are you, and I couldn't remember who I had told what, who I needed to update. So it would have been a way to get the basic facts down somewhere."

For these diarists, the main difference between writing a blog and using VitruCare™, is that a variety of HCPs are looking at their information and would be able to see if any emerging problems and be able to act on these issues. This level of interaction that the online system provides, reassures patients:

Brenda: "I feel more secure in my health because of it. That you've got someone there, day by day rather than having to wait between appointments, which can be a bit scary"

Similar to previous studies on palliative care[27] and hospice volunteering,[28] HCPs describe the care they are providing their patients as giving time, not saving time. Therefore, even though learning the intricacies of a new IT system can be challenging and time consuming, nurses and clinicians were aware of how the information that the patient is providing can enhance the face to face interaction:

Clinical Nurse Specialist: "It's preparation isn't it, it's that enhanced communication because we may not have seen them for two weeks previously...you know if they've had an uneventful two weeks or whether they've had a rough weekend, so at least you're well prepared."

HCPs did, however, raise concerns about whether the service was being used correctly by patients. They did not want patients to enter emergency information in case the system was not regularly and immediately checked by the care team. These concerns were around whether the interactive nature of the diary function would prevent the patient from contacting the correct emergency channels, whether the patient would know it was an emergency and how the HCP would feel if they had missed something. Patients, did seem to be aware that VitruCare™ was not for emergencies:

Brenda: "I see the diaries as your day to day, this is how I am, there's nothing urgent, no real problems but this is a log."

Also from the diary entries it was clear that patients were only reporting emergency episodes after they had happened and as a log for their extended care team. In these recollections, it was evident that patients were still following the correct emergency procedures despite the communicative nature of VitruCare™:

Paul: "Woke from afternoon sleep, unable to move off the bed luckily phone to hand, phoned Judith at work, unable to communicate properly. Judith came straight home after calling ambulance, had managed to crawl into hallway where I was laid on floor when Judith & paramedics found me."

The patients who use their diaries to therapeutically express thoughts, feelings and memories, write for different reasons to patients who use their diary as a log. Although they are aware that HCPs can see what they write, they are writing the diary to help themselves come to terms with their situations, similar to people writing blogs about health conditions.[18-19,21] These diarists do not want to share their diary with friends or family:

Stephen: "I wouldn't want my family reading what I was putting down"

The e-Health diary, unlike blogs, provides a platform for patients who wish to express concerns and emotions about their illnesses privately, away from family and friends. These diarists do write, however, knowing that HCPs can read the information and often if a patient is low in mood or is experiencing depressive symptoms, they express this by reaching out to their HCP:

Doris: "feeling shitty, most of my life has being so hard, now I'm having a hard time dying, no I don't want to die like this, don't want to die at all yet, but in this pain is evil, but I will not kill myself I promised my kids last year I would not."

Knowing this information, which is not always verbalized by patients, HCPs can help make the right decision concerning a patient's care. Previously blogs by terminally ill patients have provided valuable information for HCPs, especially the nursing community, but often from past reflection on the written material.[13] These, e-Health diaries place HCPs in a unique position where they can see a live snapshot into a patient's life and can personalize healthcare accordingly. From having access to the diaries the hospice care team have been able to diagnose patients with depression and anxiety and effectively treat mental health alongside physical health.

3.3 About the patient

Throughout the diaries, whether used as logs or self-reflective narratives, it became apparent how important social interactions were for the patients. The patients who had difficult family circumstances or struggled to accept help from others, often expressed how alone they felt, finding symptoms and lifestyle management more difficult. Stephen had been diagnosed with bowel cancer and because of his fear of hospitals, he postponed his treatment and surgery until it was too late. He was consequently given a terminal diagnosis. He writes in his diary about the pressures that this decision has put his family relationships, especially his wife. When he is alone, his mood and symptoms are worse and he finds it challenging to care for himself:

Stephen: "A little bit of reality hit home today... after an argument with my wife I spent the night in my own home only to discover that preparing a hot meal was stretching my abilities... I got tired just standing in the kitchen and out of breath walking to and fro to sit in the living room about 10 steps away to sit down. In the end I swallowed what little pride I had left and asked her to pick me up."

Doris, suffering from Congestive Obstructive Pulmonary Disease (COPD) and anxiety found it difficult to accept help from her relatives. Her daughter would regularly visit but Doris was aware of how she was taking her frustrations, of not being able to do things for herself, out on her daughter. She therefore felt a tremendous guilt, but was reliant on help. When her daughter was not with her and other family members had not contacted her, she felt alone and scared:

Doris: "...feel so alone, no one to tell about how I feel, scared, don't know why."

Patients, even if their symptoms and pain were bad, had improved mood and feelings of happiness if they had contact with another person. For Doris, her reassurance came from a positive experience of HCPs at the hospice and how 'lovely' there were to her:

Doris: "I am in the hospice at mo, everyone is so very nice, there all so lovely and caring...just had a foot massage from carol it was very nice and relaxing she is so good with it, she is such a nice person anyway, she's smashing."

Mood and emotions were also dramatically improved for all patients who had had contact with family members, whether this had been a phone call or a face-to-face visit. Jane mentioned how her symptoms and energy were still low but her mood was lifted by the visit from her daughter:

Jane: "My daughter, Naomi, staying with me for a few days & we are REALLY close & miss each other. So even though my symptoms and energy are RED, I am happier cos she's here and she looks after me so much, my pain levels are lower, (can't do anything), pampered by my loving daughter."

HCPs, family and friends of patients with a terminal diagnosis cannot underestimate the importance of social interaction. A positive social interaction with minimal effort can hugely improve a patient's quality of life.[29] Kubler-Ross[30] convey that the communication of people with a serious illness depends on which stage of the grief cycle the patient is at (denial, anger, bargaining, depression and acceptance). Patients at different stages often need more or less social interaction from loved ones either through technology or face to face.[31] The e-Health diaries have revealed that mood, depression, symptoms and treatments can prevent patients from socializing but when interactions with HCPs or family and friends do occur, the patient's mood is uplifted.

The diary data, particularly the patient logs, indicated the level of individual patient activity. It was evident, as time progressed, how a patients' ability to be active and social reduced as their illness and bodily function[32] deteriorated:

Charlotte: "Frank decided to take me to the local town for different scenery...disaster as I was unable to walk any significant distance...felt very insecure in an unfamiliar environment."

Even though social interactions and activities were important for patients, many were frustrated at not being able to do what they used to. The activities that patients could no longer do included baking, cooking, working, running errands, going out for lunch and coffee. Both James and Cheryl expressed their frustration and disappointment at not having the same level of freedom as they used to:

James: "Very moody and snappy on Sunday...probably a mixture of worry about work, finances and lack of independence."

Cheryl: "My friends are coming for lunch so that will be nice...we are not going out for lunch because I have backache. I feel bad about letting them down because they were looking forward to it."

The frustration that patients' felt towards losing physical and cognitive function coupled with how influential social interaction was on patient mood, highlighted the importance of providing patients with the means to be dignified and independent for as long as possible.[33] Treatments for independence could be as simple as efficiently providing the right painkillers and assistive technologies. James was frustrated at not being able to drive, not being independent, having to wait for his power chair. Once he was given his power chair, he found a new feeling of freedom:

James: "Good day. First trip out in my power chair with Lorraine. Went well if not a little cold...it felt great to be able to get up to the shops without any trouble."

There were, however, still problems as James found that not many areas had wheelchair access including the entrance to his own home and his doctor's surgery. When treating patients nearing the end-of-life, these diaries reveal how essential it is to provide personalized care tailored to the individual. There needs to be an awareness of the daily problems that people face so that independence[33] and social interactions[31] can be maintained for as long as possible. Web and app based digital services, can help HCPs understand the individual needs of the patient by providing a window into their lives.[13] This does not hinder the face to face interaction but enhances the quality of care provided.

4 Conclusions

VitruCare™ developed an e-Health service for people nearing the end-of-life. It was used by 68 terminally ill patients from three different UK based hospices. The most popular function of the e-Health service was the 3000 character diary, which could be shared with HCPs, family and friends. This phenomenon, alongside the literature on blogging, indicates the desire of patients who have been diagnosed as end-of-life to write about their situation.

Two different type of diarists emerged from the qualitative analysis. The first writes for information sharing and self-management of health[21] whilst the other writes for emotion management by creating a rich narrative.[18] Innovators of e-Health should consider these two different styles when developing online diaries or blogs for patients in palliative care. Designs would need to incorporate the needs of both by providing enough character space for storytellers but also providing tools for patients to log symptoms, activity, patient reported outcome measures and health indicators.[4] Additionally, the level of privacy of the diary would need to be controlled by the patient as information sharers would want more people to read their entries whilst therapeutic diarists would want to keep their entries private.

Both types of diarist wrote their information for HCPs to read, providing a feeling of reassurance that HCPs would be able to see any changes in the mental and physical health of the patients and plan care accordingly. This information can also prove invaluable to HCPs, as an insight into the lives of people nearing the end-of-life, similar to information from patient blogs.[13] The difference being that the 'real-time' entries allow HCPs to action according to patients' needs. e-Health could therefore be paramount in understanding the patient and developing personalized healthcare[34] for people in palliative care.

Insights provided by the analysis in this paper reveal that patients, however low they are feeling, place significant value in social interaction and relationships. Often low mood is connected with being alone and good mood is related with positive interactions with HCPs, family or friends. This finding has powerful implications for innovators of connective technologies[31] such as video calling, social media and web-based communities. It also supports the work of befriending schemes, volunteer[28] and therapeutic services in hospices.

There is limited research on the use of e-Health diaries and blogs by patients nearing end-of-life. These mediums offer therapeutic services for patients whilst delivering valuable information for HCPs. Consequently, future research should encourage the use of e-Health in palliative care to give the patient a voice and improve personalized patient-led care.

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