

**Title:** Understanding Blogging Motivations in Palliative Care Using Maslow's Hierarchy of Needs.

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**Abstract**

The pervasive use and potential of weblogs has increased the field of social health informatics and is becoming increasingly difficult to ignore. The prevalence of these technologies for narrative use brings about the fusion of diverse schools of thought on motivation. One proven model is that of Maslow, whose theory of needs has an intuitive appeal in understanding bloggers' needs and motivations. This paper considers theoretical and practical blogging experiences for palliative care users through the embracement of Maslow's hierarchy of needs. Palliative care patients, carers and clinicians were interviewed about their weblogs and data qualitatively analysed. The results indicate that the experience of maintaining a weblog is therapeutic for individuals and fulfils needs hierarchically from the lowest to the highest as outlined in Maslow's theory.

**Keywords:** - Weblogs; Maslow's hierarchy of needs; CyberPsychology; End of life; Motivation; Computer Mediated Communication

Authors:

## 1 Introduction

The way people use technology is constantly changing and it is becoming increasingly difficult to ignore the web culture and its impact on health and the practice of medicine (Giustini, 2006; Kovic, Lulic and Brumini, 2008). Patients and healthcare professionals use these web technologies for varying purposes and outcomes. One medium that has gained popularity over the years is a weblog where users, including patients publicise and share their experiences (Lowney and O'Brien, 2012; Ngwenya and Mills, 2014). Weblogs are defined as personal webpages with content displayed in reverse chronological order. They differ from other social networking sites due to the diverse and multiple forms of media content and genres used to produce weblogs. The majority of research on weblogs in health has focused more on the perspectives of the doctors and technical aspects of how this technology fits in the medical

world (Giustini, 2006; Coombes, 2007)). To date, literature on health-related weblogs maintained by patients and other healthcare users has been limited whilst the actual existence of these weblogs has increased (Forster, 2009). Furthermore, little work has been done to evaluate the motivation for using a weblog amongst users within palliative and end of life care.

The goal of this study is to gain insight into why palliative care service users blog and how this technology can give a better understanding of patients, carers and healthcare professionals' needs. Specifically, we addressed this goal using the following procedure: first, motivations for maintaining a weblog are explored, secondly, Maslow's hierarchy is situated within a blogging environment and thirdly, from the gathered data, a modified hierarchical structure restricted to blogging within end of life care is proposed.

## **2 Characteristic needs of palliative care users**

In order for appropriate interventions to be developed for users, it is important to be aware of their characteristics or needs, symptoms and also to understand the psychosocial issues they may experience (Vachon, 2005). With a better understanding of these elements, their needs can be identified and appropriately addressed in the most efficient way.

### *2.1 Palliative care patients*

Description of palliative care users is vague and usually guided by a description of a disease, prognosis or symptoms (Van Mechelen *et al.*, 2013). Even though this field has grown exponentially over the years, the description of the patient population varies across studies with a lack on consensus. The World Health Organisation describes the palliative care patient as someone that has a non-curative or life-threatening condition (WHO, 2002). Literature focuses on the theoretical principles and goals of palliative care, which are mainly to relieve suffering and improve quality of life for patients (Pastrana *et al.*, 2008).

The characteristics of palliative care patients as depicted within the literature are evidence to the need of interventions that assist and support service users. One such self-directed intervention is the weblog. Within palliative care, individuals are using weblogs to communicate their needs for social and emotional support; to inform other people about their illness or that of their loved one thus creating a community; to increase their sense of empowerment (Ngwenya, Mills and Kingston, 2009); and overall as a coping strategy (Van de Velde *et al.*, 2011). These aspects make this area ripe for research on motivations of using a weblog and impacts on service users' health.

### *2.2 Needs of Personal Carers of palliative care patients*

An informal carer in palliative care is a family member or friend who takes the role of caring for the patient. It has been suggested that the role of a family care-giver can be stressful and is most often associated with negative effects including social isolation, negative health impact, negative emotional experiences and time burdens (Strang, 2001). Although there are positive experiences shared about caring for a family member with palliative care needs, including the close relationship developed. However, research has mostly focused on identifying perceived support needs of informal carers that can be appropriately addressed by interventions (Payne, Smith and Dean, 1999) as well as the negative impacts of caring (Payne and EAPC, 2010). These close relationships are also developed within a highly charged emotional environment which necessitates emotional, informational and at times physical support for carers (Chelagat and Kulei, 2013). Previous research findings identify other problems associated with being an informal carer including exhaustion, sleeplessness, anxiety and depression (Harding *et al.*, 2012).

These service users can benefit from the internet which makes it possible for people to build relationships anonymously without any stigmas and obligations attached. A weblog is a way that some carers have found to keep in touch with the outside world during their busy role. The internet provides a web of self-support, mutual support and information that may not be available to family members through the doctor. In their research of weblogs of parents with a child treated for cancer, Van de Velde and colleagues (2011) reported that participants stated that the writing helped them cope with their situation, thus, illustrating the relevance of using a weblog within palliative care.

### 2.3 *Palliative care health professionals' needs*

There are many different health care professionals who care for palliative patients including nurses, doctors and healthcare assistants. Working in a hospice and caring for terminally ill patients is valuable work but is capable of being an immensely stressful profession. Some issues identified by Doyle *et al* (2005) that palliative care professionals come across in the course of their work that can contribute to their own stress include, not possessing the necessary skills to help them carry out their job effectively. Sometimes healthcare professionals themselves may be distressed due to the emotional challenges of their roles and the care demands required (Chelagat and Kulei, 2013). Health professionals may struggle with the death of a patient and not have a chance to grieve (Funk, Peters and Roger, 2017). This environment can arouse unresolved personal conflicts within oneself in terms of dealing with issues of their own mortality.

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Maintaining the mental health of palliative care professionals is an important aspect of ensuring the quality of care they provide to users and also their wellbeing. The internet can be used to implement and facilitate strategies to improve health care professionals' mental health and provide other necessary support. Research on the use of social media by health professionals reported that users found social networking sites to be very useful (George, 2011). These technologies have the potential to promote

sharing, transparency, and interaction amongst professionals as a way of coping with stressors experienced within the work environment.

We now move on to contextualise these different aspects of users' needs within Maslow's hierarchy.

### 3 Maslow's Hierarchy of Needs

One of the most significant and widely used theories of motivation is Maslow's hierarchy of needs. This theory is based on an individual's biological, cultural and situational circumstances which generate a need that influences that person's motivation (Maslow, 1943). These needs are ranked hierarchically, from lowest to highest; according to the level of influence they have on human behaviour as shown in Table 1.

**Table 1: Maslow's Hierarchy of Needs with Examples (Adapted from Weiner, 1980)**

| Needs              | Example of Deficiency                           | Example of Fulfilment   |
|--------------------|---|---|
| Physiological      | Hunger, thirst, fatigue, illness, homelessness  | Physical well-being, comfort, relaxation                            |
| Safety             | Insecurity, fear, sense of loss, obsession      | Security, balance, calm, tranquillity                               |
| Social             | Emptiness, isolation, loneliness                | Free expression of emotions, sense of warmth, renewed sense of life |
| Self-esteem        | Inferiority feelings, negativism                | Self-respect, Self-esteem, Confidence                               |
| Self-actualisation | Boredom, limited activities, no meaning in life | Pleasurable work, Creative living, having potentials                |

#### 3.1 Maslow in Computing

Within the computing and information technology disciplines, Maslow's hierarchy has been used to explore adoption rates and use of technologies. Lin (1998) used this hierarchy to explain adoption dynamics amongst individuals who chose to use personal computers for more advanced functions. (Lin, 1998) went on to portray a link between "motivation" and "action" and how Maslow's self-actualisation level could be a possible explanation for this link. Thielke and colleagues (2012) used the hierarchy to draw attention to specific needs of older people and how some assistive technologies may undermine self-esteem and thus become an adoption barrier. Another interesting utilisation of Maslow's hierarchy

in the field of computing has been in the development of e-commerce user experience strategies (Yu and Wu, 2010) where an understanding of individuals' personalised needs can be beneficial in offering customers specific products.

### 3.2 Maslow in palliative care

According to literature (Zalenski and Raspa, 2006) the use of Maslow's hierarchy within palliative care is growing. Higginson *et al* (2007) rightfully postulated that Maslow's hierarchy of needs is very useful in palliative care as it gives an understanding that higher level aspects such as mental health may not be wanted or appreciated by individuals unless lower level needs such as pain relief are met. Following Maslow's original schema, Zalenski and Raspa (2006) identified certain needs in palliative care that match Maslow's model as shown in Table 2.

**Table 2: Maslow's Hierarchy of Needs with Examples of Needs in Palliative Care (summarised from Zalenski and Raspa, 2006).**

| Needs              | Example of Deficiency  |
|--------------------|--|
| Physiological      | Experience of pain, dyspnea  |
| Safety             | Fear of physical safety in case of death   |
| Social             | Need for affection and love as individuals approach or are faced with imminent death |
| Self-Esteem        | Need for respect despite the person's illness and physical appearance                |
| Self-actualisation | Need for a higher sense of purpose and motivation, lack of self-fulfilment           |

Herbst (2006) explored the hierarchy of needs by applying it in practice in a large hospice programme in the United States. Maslow's hierarchy of needs as used by Zalenski and Raspa (2006) and Herbst (2006) show the importance of understanding and treating the patient holistically and not just focusing on physical symptom control. It is also important to be aware of the complexity and fluidity of palliative care patients' needs and the subjective nature of people's needs. Integration of Maslow's theory within care planning can be successful and is a useful model in palliative care to address physiological, security/safety, love/belonging and self-esteem needs.

### 3.3 Changes and adaptations of Maslow's Hierarchy

Maslow's hierarchy has several criticisms that have led to its adaptation and change over time. Kenrick and colleagues (2010) suggested that the needs do not exist hierarchically but are rather overlapping which suggests that earlier needs are not fully replaced but continue to exist throughout a

person's life. This idea collaborates with the notion suggested by Maslow that a human being never gets to a stage of complete satisfaction.

Another adaptation done by Maslow (1999), was the addition of another construct, one of motivational self-transcendence, as being at the top of the hierarchy of needs. According to Maslow, transcendence is the highest sense of self-awareness that a person can have reaching an extent of depersonalisation. Research in Computer Mediated Communication (CMC) corroborates this, stating that the anonymity of the internet can increase an individual's personal self-awareness and encouraging them to disclose more (Mills, 2011). This has implications on the understanding of motivation as the later model suggests that the highest level of development goes farther than a fulfilled individuals' self (self-actualisation) to a stage where these ego needs are transcended.

Self-transcendence can help people get a better understanding of the meaning and purpose of their life, which would seem very relevant within the field of palliative care as Coward and Reed (1996) explained how self-transcendence can be like an out of body experience where an individual extends beyond their personal boundaries to help others and promote their wellbeing. The work of Zalenski and Raspa (2006) especially lays a foundation for the model proposed in this paper and indicates how Maslow's hierarchy can be used to address and meet palliative care needs. However, to date, no research resting on Maslow's developed motivation theory has explored the motivation factors of palliative care users for blogging. Thus, this research extends further work identified by Zalenski and Raspa (2006) by assessing palliative care users' needs and how blogging as an intervention has the potential to address those needs.

#### **4 Research Methods**

The broad principles of grounded theory (Braun and Clarke, 2006) were employed to provide structure to the research process whilst the data was analysed thematically. Semi-structured interviews were used for data collection August 2008 and April 2009. Semi-structured interviews are a commonly used tool in Human Computer Interaction (HCI) and also within medical research where the role and perspectives of patients are being investigated. Interviews were found to be a suitable method of data collection as the goal of the study was to enhance understanding of phenomena rather than produce objective facts that are generalizable to the population. This gave participants the opportunity to express themselves in a less demanding environment with less missing data compared to questionnaires.

Online interview methods allow flexibility in that they can utilise a mixed method of synchronous and asynchronous ways of data collection. One major drawback of this approach is the lack of nonverbal cues, although there is also the possibility that the anonymity and lack of non-verbal cues may have enhanced the data collected through higher levels of self-disclosure from interviewees (Mills, 2011)

Ethical approval for this research was sought and gained from Staffordshire University, UK as well as the UK NHS Local Research Ethics Committee.

#### *4.1 Recruitment*

Internet search engines and other weblog directories like technorati (<http://technorati.com/>) and weblog catalog (<http://www.blogcatalog.com/>) were used to search for weblogs of palliative care patients, carers and palliative care healthcare providers. The search terms used included a variation (with synonyms) of the following “cancer weblogs, palliative weblog, end of life care”. This could potentially have led to a sampling bias as the accessibility of weblogs would depend on the subject tagging assigned by the user or the software. Authors of the potential weblogs were checked against the inclusion criteria and then an invitation to participate in the research was initiated. The inclusion criteria were that someone was either a palliative care patient, a carer of someone receiving palliative care, or a staff member of a palliative care service provider; all participants were 18 years or over. After a two week period a follow up e-mail was sent to those who had not responded. When participants agreed for their weblogs to be used, an interview invitation with the information and consent sheets was sent out to them including ethical and administrative details of the study. The participants were also asked to indicate which method they preferred for the interview (telephone, e-mail, instant messenger, or Voice over Internet Protocol (VoIP) phone e.g. Skype) and their time zone as they were all in different states in North America. The interviews were then set up and conducted as arranged.

#### *4.2 Participants*

Twenty seven potential participants were approached through their weblog. Four of these potential participants were found not to meet the inclusion criteria, one refused to participate, and six did not respond. From the remaining 16 weblogs, 4 participants did not respond to the interview request and 12 participants agreed to take part in the interviews. All participants were native English speakers and maintained their weblog in English. The participants were selected on the basis of a degree of homogeneity of their experience. This sample size was considered adequate by the authors given that it is a purposive sample with people specifically interviewed on their knowledge or experience relating to a specific topic (Guest, Bunce and Johnson, 2006) and considering the challenges of recruitment within palliative care studies (Aktas and Walsh, 2011). The sample was also one of convenience, including participants who were accessible to the researchers and willing to take part in the study. Table 3 below shows the biographics of the 12 participants. These included participants from the three categories of users and providers of palliative care: patients, carers and staff. These three groups of people were selected as they are the main users and providers of palliative care and, as the literature has portrayed, they all need some form of support

within their roles. The authors felt that involving all three user groups would give a multi-perspective view of the use of weblogs within this care setting as is now encouraged within healthcare research (Kendall *et al.*, 2009).

**Table 3: Participants' Biographics**

| Participant number | User group | Gender | Age         | Profession              |
|--------------------|------------|--------|-------------|-------------------------|
| P1                 | Patient    | Male   | 40s         | Artist                  |
| P2                 | Patient    | Female | 64          | Undisclosed             |
| P3                 | Patient    | Male   | 50s         | Former newspaper editor |
| P4                 | Patient    | Female | 35          | Undisclosed             |
| S5                 | Clinician  | Female | undisclosed | Hospice nurse           |
| S6                 | Clinician  | Male   | undisclosed | Hospice director        |
| S7                 | Clinician  | Male   | undisclosed | Hospice social worker   |
| S8                 | Clinician  | Male   | undisclosed | Physician               |
| S9                 | Clinician  | Male   | undisclosed | Physician               |
| C10                | Carer      | Male   | undisclosed | Undisclosed             |
| C11                | Carer      | Female | undisclosed | Undisclosed             |
| C12                | Carer      | Female | undisclosed | Undisclosed             |

#### 4.3 Data Collection and Analysis

Three participants opted to have the interview questions sent through e-mail, 2 opted for telephone interviews, 3 opted for VOIP, but due to technical difficulties only 1 was conducted through Skype. Six interviews were conducted using instant messenger. Participants were asked about their experience of using the weblog and what they used their blog for. They were then asked about the purpose and the initial reason for starting a weblog and why they have continued to use a weblog. Lastly, participants were asked what they felt they achieved from using a weblog. Detailed notes were also taken during the interviews by the researcher. Telephone interviews were audio taped and transcribed verbatim immediately after the event and the instant messenger interviews produced an electronic transcript of the conversation as it occurred. Telephone interviews took approximately 30 – 40 minutes and instant messenger interviews lasted between 1 – 3 hours. The e-mail interviews involved multiple e-mail exchanges with the participants to elicit information, unlike e-mail surveys (Meho, 2006). Considering the time difference and distance of the participants, this method of data collection was appropriate as well as effective in answering the research questions. All the interview transcriptions including the e-mails were imported into Nvivo, a data management program. A multi-step data analysis technique informed by



Glaser & Strauss (1967) was employed. In-vivo coding was carried out on the transcript by using each participant's own words to develop categories. This was done by using a constant comparison technique where codes are compared against each other to seek out similarities, possible differences and relationships. The categories were further refined, integrated and cross-referenced with the data and from this further analysis emerged common themes. For the purpose of data validation, the results were discussed with other researchers with expertise in grounded theory and thematic analysis methods. This abductive research strategy was preferred as it emphasises the importance of the participants' subjective world. Pseudonym initials were used to refer to the respondents in the results.

## **5 Results**

From the analysis of the interview transcripts, 24 categories emerged. Further analysis conducted on the data made it possible to sort and synthesise these categories according to their correspondence with Maslow's needs hierarchy making a coherent interpretation of the data. The user's' perceptions and experiences of using a weblog complemented the levels of need identified by Maslow in his theory of motivation as shown in Table 4.

**Table 4: Results' correspondence with Maslow's needs hierarchy.**

| <b>Maslow's Hierarchy</b> | <b>Supporting Quotations<br/>(Recorded and transcribed verbatim with punctuation added were applicable)</b>   | <b>Corresponding Categories</b>  | <b>Participants mentioning actions in each element of the hierarchy; frequency count of theme is given in brackets</b> |
|---------------------------|---|--|--|
| Physiological Needs       | <p><i>"I felt it would provide a useful dimension to the experience of having and coping with chronic lymphocytic leukaemia. Many discussion forums are restrictive in subject matter, don't allow for a range of topics, including more personal and opinionated thoughts" [P1]</i></p> <p><i>"I began doing research... after I learned that I was terminal... I had heard something on the NBC Today Show about blogging as it was a fairly new concept... felt it might be a good way for me to express what and why I was feeling"[P3]</i></p> | Therapeutic Device<br>Lack of information  | P1 (4), P4(2), S5, S7, S8, C10(2), C11(22), C12(2)   |
| Safety/Security Needs     | <p><i>"I do keep a separate ... e-mail account for the blog and do not post or give out my main e-mail address, just to protect myself from spammers, etc."[C11]</i></p> <p><i>"Privacy is an important issue to me, confidentiality, not so much. I don't care if people know the details of my blogging experience or my wife's, or are directed to her blog, but I don't want people told any information that cannot be found on the blog regarding contacting me, etc..."[C10]</i></p>   | Privacy and confidentiality  | P1, P2(3), P3, P4(2), S5, S6(2), S7, S8(3), S9(2), C10(2), C11, C12  |
| Social Needs              | <p><i>"Because one of my goals since I became so ill has to been to be in better touch with my very far flung network of friends and acquaintances and ....this is one more way of really being in touch with people"[P2]</i></p> <p><i>"the blog .....it has also helped to create community. i have found much support online and am now read by many who have never met me but find something in my blog to which they can relate."[C12]</i></p>   | Family and friends<br>Target audience<br>Easy access for everyone<br>Chronic and terminal<br>Talking about dying and death<br>Seeking and giving support | P1(5), P2(9), P4(9), S5(3), S6(5), S7(2), S8(4), C10(4), C11(6), C12(2)  |

|                    |  | Venue for Connecting   |   |
|--------------------|--|--|---|
| Esteem Needs       | <p><i>"It is useful to fellow patients and their caregivers and also to me. It helps me network with others who may have useful ideas, and it helps me focus and organize my thoughts."</i>[P3]</p> <p><i>"over the years the blog has become important for many people, and a small community of readers has formed around it who comment and discuss issues."</i>[S9]</p>  | <p>I enjoy blogging<br/>Control the message<br/>Empowering<br/>Academic discussion<br/>Raising awareness</p> | <p>P1(3), P2, P3, P4(2), S5, S6(2), S9(2), C11(2), C12(3)</p> |
| Self-Actualisation | <p><i>"I have received some attention because of it. It was written up in CR, a national cancer magazine....eventually I would like to fashion the blog material into a book"</i>[P3]</p> <p><i>"i have been blogging for three years. it has provided a record of my journey ...and also empowered me as a writer. i would say that it has been entirely positive for me - and become important in a way that i would never have envisaged."</i> [P1]</p>   | <p>Creative outlet<br/>Record of my journey<br/>Personal self</p>  | <p>P1(11), P2, P3(2), P4(2), S5, S7(2), S8, C12</p>           |
| Self-Transcendence | <p><i>"I decided that I needed to give something back. And being an artist and always enjoying the visual and written word, I thought the best gift I could give and possibly leave anyone was a series of my thoughts, a blog, whereby the reader would have the ability to interpret what I wrote in his/her own way and comment as she/he felt fit or simply read"</i>[P1]</p> <p><i>"our focus for it was, is really educating other professionals about hospices and palliative care issues"</i>[C10]</p> | <p>Educating others</p>  | <p>P3, C10(2), P1</p>   |

In particular, Table 4 shows that all the participants in this study had safety needs and all except one patient and one staff user also had social needs. Interestingly, only two patients had physiological needs, although all carers had such needs as well as all but one staff member. Three participants, (two staff members and one carer) did not have esteem needs, although both staff did have self-actualisation needs. Only two patients and one staff member realised self-transcendence needs.

In summary, Table 4 clearly shows that patients (P1-P4) all found blogging satisfied their higher needs with less focus on the lower, basic needs. On the other hand, carers,(C10 –C12), used blogging for satisfying lower needs, in particular, social needs and, to a lesser extent, esteem needs. The staff group (S5-S9), spanned all categories of needs, with four of the five participants having self-actualisation needs; interestingly, only three had physiological needs in terms of blogging.

Other categories that emerged from the data did not seem relevant to Maslow’s hierarchy. These categories raise important questions and highlight the importance and experience of using a weblog. Table 5 below summarises these categories.

**Table 5: Outstanding results not applied to Maslow’s Hierarchy of Needs (with summarised explanations of categories)**

Although using Maslow’s model was useful in understanding the data of service user’s experiences, there were other data that did not apply which are of interest to users of weblogs.

| Category                                   | Summarised findings   | Supporting quotations   |
|--|---|---|
| Good release and thought processing avenue | Participants expressed how using the weblog as a good release which gave them space to think and process their thoughts. During their diagnosis, patients found that they needed personal space to process the implications of their illness and the weblog afforded them that place. | <p>“...it has been an enjoyable creative outlet...I can’t stop myself from writing, so it is a creative outlet...” [P4]</p> <p>“...there have been difficult cases I’ve had and by picking a topic related to that but not necessarily talking exactly about that case I have been able to sort of type out my frustrations, now I don’t put the emotions and the frustrations on the</p> |

|                                     |   |  |
|-------------------------------------|---|--|
|                                     |   | <p><i>page but just by typing about the subject and thinking through it I feel that I might have a better understanding or I have just released it and it's not a weight on my shoulders anymore."</i> [S6].</p>   |
| <p>Research in end of life care</p> | <p>The majority of participants reported that they used the weblogs to research into end of life care. This was a place where they could discuss their experience and get more information that they would not necessarily have received from the doctor. Healthcare professionals found a place to exchange good practice and to contribute to research.</p> | <p><i>"...It has made me better at the business of hospice for sure, and has probably made my team better because I can look at issues from the perspective of many different hospice professionals and pass those thoughts and ideas on to the team."</i> [S7]</p> <p><i>"...So I am trying now to get readers beyond my circle of people who know me... I want people to think about it. You know there is this kind of last taboo you know, people don't want to talk about death and dying and I think it is important for people to talk about and think about."</i> [P1]</p> |
| <p>Technology</p>                   | <p>One unanticipated finding of interest that is not reported in the literature was that the latest technologies, most of which use Web 2.0 applications, may never be appropriate for hospice patients especially those who are elderly due to their functional abilities and working experience of computers (Hanson, 2009).</p>                            | <p><i>"...I mean again this is just a generalisation but the majority of patients who come to us, tend to be elderly people, just in day care and I think they have not got that culture about technology."</i> [S7]</p> <p><i>"I think the younger you are the more likely you know you will use it..."</i> [C11],</p>  |

|                                  |   |   |
|----------------------------------|---|---|
|                                  | <p>This is an important issue for future research in technology in palliative care. Web 2.0 technology refers to online technology that is more interactive and gives users the ability to input with more control on the content.</p>  |   |
| <p>Ramifications of blogging</p> | <p>Participants expressed concern about the negative sides of maintaining a weblog. There was a great emphasis on the burden and pressure to keep posting interesting features. Another pertinent issue was the ramifications of publishing publicly. Participants felt that sometimes people misinterpreted what they had written and reacted negatively towards them and this had a negative impact on their blogging experience.</p> | <p><i>"...It's actually a bit of a burden... some people actually started reading the thing and that's put on some pressure that I wasn't expecting...I found a certain amount of appreciation from the readers. I feel both flattered and pressured to keep the stories coming." [S5]</i></p> <p><i>"...On the negative side, I have been bashed by anonymous commenters and have even been accused of exploiting my son . I have NEVER asked for money or anything from anyone except prayer, so that comment REALLY hurt me..." [C10].</i></p> |
|                                  |   |   |

## 6 Discussion

This study provides a detailed description of palliative care users' needs on blogging using Maslow's hierarchy but the findings have important implications for service providers and developers. The key results of this study show that Maslow's hierarchy of needs can be an important tool in enabling an in-depth analysis of the users' perceptions.

The results of Table 4 are important as they indicate that carers are blogging to meet social and esteem needs with little evidence of higher needs being met; there are many possible reasons for this, including lack of technical familiarity or, more importantly, physical tiredness which reduces personal esteem and which may lead to depression (Mills, 2006). In addition, in this sample of participants, at least, patients found blogging helpful in meeting all needs up to self-actualisation, with one participant, possibly using his creative talent as an artist to satisfy self-actualisation needs.

Figure 1 shows the model of blogging motivation emerging from this study. It illustrates the needs of the participants in this sample as expressed in Table 4. The model developed in this study is informed by Maslow's theory of needs and therefore acknowledges and supports the hierarchical nature of needs that individuals might have. However, the findings of the current study do not support the traditional pyramid structure of Maslow's hierarchy and so this model is portrayed as a diamond following the interpretation of the results. This model is an inverted hierarchy of the traditional representation of Maslow's model, which shows and corresponds to the growth in needs that bloggers experience with an increase of use of the weblog. As the individual's needs are met through blogging, they move through the hierarchy and their needs increase from one level to the next from low level needs to higher level needs. The diamond shape of the model corresponds to the results of the study highlighting the levels of needs that are frequently prevalent during blogging.

*{Insert Figure Here}*

Figure 1: Blogging motivation based on Satisfaction of Needs

Each of Maslow's needs has implications and manifestation in the blogging motivations that the users experienced and reported in this study. The needs of participants are highly situated within the context of palliative care and their experience within the environment as a patient, carer or staff.

### *Physiological needs*

This finding is in accordance with prior literature which (Norwood, 1999) labelled as coping information. At the lowest level individuals seek 'coping information' in order to meet their basic needs. The results of this study show that participants used their weblog to seek information to help them cope with their illness or with the situation as a carer or staff. Simple activities such as asking other people online how to prepare or serve food or what foods can be used to repress nausea, offered satisfaction to the user at this basic level of need. This study produced results which corroborate previous literature that states that people can and do satisfy their physiological needs with help from other people (Backer, Hannon and Russell, 1994) and in this case the users employed weblogs to facilitate the satisfaction of these needs.

### *Safety and security needs*

The most interesting finding was that safety and security as the second stage of Maslow's hierarchy seemed to be portrayed by all three user groups as a need that was fulfilled. Although the theme was not mentioned as frequently, all three user groups reported this need. This finding has important implications within palliative care as it shows the significance of the need for safety within this care setting and how this need should always be reviewed in accordance to the individual's perspective. Palliative care users need to feel safe and secure whether physically or psychologically and according to the sample in this study, a weblog offered them that environment. This also accords with literature that states how the internet removes barriers such as stigmas allowing people freedom to disclose (Walther and Boyd, 2002). Their weblogs were their safe haven where they could disclose, felt uninhibited, and found safety in the comfort of finding people with a shared experience. Their insecurities and concerns about their illness or methods of caring were addressed as they interacted through their weblogs.

### *Social needs*

On the question of the third level in the hierarchy of needs, this study found that all except two users viewed their weblog as fulfilling the need to belong to a group. Participants expressed a desire to share their stories and form friendships and attachments with similar people or individuals who have a similar experience which is consistent with findings by Kim and Chung (2007) on characteristics of cancer bloggers. Social and esteem needs appeared more frequently in the interviews and weblogs as participants expressed how blogging helped them construct and define their identity thus realising the personal meaning of their life and illness/situation. As people/audience commented on the blog this fulfilled the individual's need of contributing to society and being a valuable member. This also widens the social circle and community that a person belongs to fulfilling the social needs and developing a community that is focused on the needs of the individual. These findings further support previous research (Kaye, 2012; Sundar *et al.*, 2012) that states that online



social interaction and enjoyment of the blogging experience developed users' virtual identity, promoted an expansion of their online social network and increased their life satisfaction and well-being.

#### *Esteem needs*

As the third level of needs was satisfied, users continued to blog and began to strengthen the bonds between members of their weblog community. Within this stage, users reported how the weblog was not a part of their lives and expressed how valuable it was for them. It became an empowering activity and was very important in their perceived autonomy as they realised how many people they could reach and had the potential to change lives including their own. A strong relationship between autonomy and self-esteem has been reported in literature (Deci and Ryan, 1995) which, interestingly, the participants in this study referred to within this level of needs. These results are also consistent with those of other studies (Valkenburg, Peter and Schouten, 2006) and suggest that using the weblog had a positive effect on users' self-esteem and wellbeing.

#### *Self-Actualisation needs*

This level of needs is a stage where an individual seeks self-fulfilment through creativity with an acceptance of their situation and determination to do the best they can. According to Norwood (1999), individuals in this stage seek information that is edifying which is in line with the participants' reported experience. By definition, self-actualisation means being involved in an activity that is of great importance and varying selfless activities can meet this need (Thielke *et al.*, 2012). Using a weblog to share and help other people can be classed as an altruistic activity which facilitates a sense of worth associated with healing. This is consistent with the definition of self-actualisation where an individual is more concerned with fulfilling their potential. Self-actualisation has been found in other studies, for example that of Gurak & Antonijevic (2008) where weblogs helped individuals to express their identity and develop meaning to their experiences thus fulfilling some aspects of human desire.

#### *Self-transcendence needs*

Contrary to expectations, although self-transcendence is very important and essential within end of life care this level did not seem to manifest broadly within the blogosphere in this study. Only three participants (two patients, and one clinician) stated that they no longer had anything to gain from blogging but wanted to share and give back to society in a form of education thus showing self-transcendence. It is encouraging to compare the perspectives of these three bloggers with literature which states that individuals at this stage seek for ways to edify others (Huitt, 2007) thus reaching beyond personal fulfilment observed in self-actualisation.

The results of this study confirm the relevance of Maslow's hierarchy within the hospice framework (Zalenski and Raspa, 2006) even though it would seem that the highest needs are only represented after some usage

of the weblog. This would be consistent with literature that has shown how more benefits of blogging occur as time passes. According to Van de Velde (2011) the triggering motives for blogging changed over time from informing friends to higher level social needs. Kim and Chung (2007) also showed how cancer bloggers who had used their weblog for longer periods of time moved on to use their blog to express themselves as well as to encourage others which are also features of higher level needs.

There are some themes of interest that emerged from the data that did not necessarily fit within Maslow's hierarchy of needs. What is surprising is that although the users enjoyed the experience of using the weblog, they also expressed some concerns over the suitability of this technology in palliative care. Some of the healthcare professionals highlighted some potential barriers due to lack of adoption if this was implemented as an intervention. Issues raised included the impact on relationships between the healthcare providers and the patients. In comparison, carers expressed satisfaction with the technology which is in agreement with Whitten *et al* (2006) who reported how due to the role of informal caregivers, they are ready to embrace the use of technology even more so than patients. These were the main differences between the user groups within this study. . First of all, the negative aspects of using weblogs or social media was raised as a point of concern. All three user groups expressed a concern of sharing private information with the public at such a vulnerable time in their life. The negative and unhelpful comments from the public who do not know the context around the situation that the user is blogging including trolling was described as demotivating with the potential of having a negative mental impact (Bach, 2008). Research has evidence of the negative impact of social media including using a weblog (Abdulahi *et al.*, 2014), however most of this research is conducted on and about young users. This explains an interesting concern raised about the unsuitability of web 2.0 technology for current palliative care patients that are elderly. Research shows how the older generation at present exhibit difficulties in the use of web technology (Hanson and L., 2009) and evidence from blog distribution over age shows that younger people use weblogs more (Schler *et al.*, 2006). Although the age digital divide is shrinking, with older people using the web (Jones and Fox, 2009) the number is still less than that of the young technology-savvy generation. Although there is an increasing urgency for e-Inclusion as the population ages, research indicates a growing number of elderly people that use the internet. An explanation for the numbers that are still lower than that of younger people online, is that the elderly people are most consistent in their use of their internet and can take a longer time to adopt technology (Niehaves and Plattfaut, 2014). The digital divide is also explained by the usage of technology with younger people using social media, online communication including weblogs while older people use the internet for shopping and information seeking (Jam Van Deursen and Agm Van Dijk, 2014).

Another concern and potential negative aspect using a weblog include the pressure of maintaining a certain image when updating or maintaining a weblog. This 'impression management' is a psychological factor that

may influence an individual 'self-concept and reading other people's comments may invalidate one's constructed self, and promote social comparison leading to discontent (Jung, Song and Vorderer, 2012).

However due to the sample size a full comparison of the different views amongst carers, patients and healthcare professionals was not conducted and this would be an interesting aspect for further research. All user groups however did express an awareness of the negative effects and impacts of blogging including unwarranted comments and the burden of meeting readers' expectations. Nonetheless, this did not deter the bloggers from using their weblog as they felt that the positive benefits outweighed the negative.

### **7 Limitations and future work**

As this study was exploratory and preliminary research, it employed qualitative strategies, and therefore it is recognised that the findings may not be considered to be generalizable. However the authors argue and hold the premise that representational generalisations about the nature of the phenomenon under investigation and not the statistical distribution can be drawn from these findings. Another limitation is the date that these data were collected as the pace at which technology is developed and utilised is fast. This has implications on our conclusion as we are aware that issues linked to the digital divide based on age has decreased as more elderly patients use the internet for health purposes. Recent electronic and mobile health developments has increased the acceptance as well as adoption of these technologies compared to the time this study was conducted. A limited sample of participants was included due to the convenience sampling technique used which can often be considered as a less rigorous method. A more thoughtful approach to selection was done based on people with the experience of blogging. Future research efforts should focus on testing the applicability of this model in a larger research design. For further practical and theoretical development, an intervention trial is highly recommended to measure the direct beneficial health outcomes that can be attributed to blogging as well as the potential drawbacks. In addition, our study mainly dealt with all three user groups almost as one. Future research should distinguish more fully the patients, carers and staff taking into consideration their different needs. However, the findings have established an empirical foundation for understanding the needs which individuals within the hospice context have and how they seek fulfilment of those needs through blogging. Thus, this paper not only provides evidence as to how Maslow's hierarchy of needs can be used to explain blogging motivation but also shows how useful weblogs are to those who are within palliative and end of life care.

### **8 Conclusion**

There is tremendous potential for weblogs within palliative care as evidenced by the interview data collected from service users. Based on the study findings, it is concluded that social and esteem needs were the most prominent to be fulfilled by palliative care bloggers. The least prominent

were physiological and self-transcendence needs. Although Maslow's hierarchy is well-known and criticised for being overly simplistic, this study has shown that it is still a useful tool for social media motivation within palliative care. This model not only enhances the understanding of how users' motivation can be represented but, within the three categories of patients, staff and carers, the research has shown how using a weblog within the domain of palliative care can deepen the understanding of users' needs. It suggests how weblogs fulfil, and in some instances facilitate, the satisfaction of needs that are of importance to the individual. It is possible that this model may also be applicable to other health settings but further studies are needed to show this.

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**Figure 1: Blogging motivation based on Satisfaction of Needs**

