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Unsolicited Written Narratives as a Methodological Genre in Terminal Illness:

Challenges and Limitations

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Abstract

Stories about illness have proved invaluable in helping health professionals to understand illness experiences. Such narratives have traditionally been solicited by researchers through interviews and the collection of personal writings, including diaries. These approaches are, however, researcher driven; the impetus for the creation of the story comes from the researcher and not the narrator. In recent years there has been exponential growth in illness narratives created by individuals, of their own volition, and made available for others to read in print or as Internet accounts. We sought to determine whether it was possible to identify such material for use as research data to explore the subject of living with the terminal illness amyotrophic lateral sclerosis/motor neuron disease. The contention being that these accounts are narrator driven and therefore focus on issues of greatest importance to the affected person. We encountered and sought to overcome a number of methodological and ethical challenges, which is our focus here.

Keywords

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The ability to tell stories is a human trait which starts in childhood and subsequently continues to develop throughout life. Creating and telling personal narratives provides the means for individuals to make sense of their experiences, including illness. It could be argued that in order to arrive at an understanding of the personal experiences of living with serious illness it would be necessary to conduct in-depth interviews with people so affected, such as in the seminal studies by Williams (1984) and Bury (1982). More recently, however, researchers have explored the social context and meaning contained within autobiographical narratives, about a variety of conditions, obtained from both solicited written accounts (Robinson, 1990; Salander & Hamberg, 2005) and unsolicited written accounts (Hayne & Yonge, 1997; Bingley et al., 2006; Bengs, Johansson, Danielsson, Lehti, & Hammarström 2008; Ryan, Bannister & Anas, 2009; Page & Keady, 2010). Although each approach clearly has its place in the study of illness experiences, it is the use of unsolicited written illness narratives which is our focus here. Working in this way offers the potential to collect stories of illness, in particular those of a controversial or sensitive nature, without the usual interaction that exists between researcher and participant (Salander & Hamberg 2005); as such it is the narrator who determines the content of their story and not the researcher. Our intention here is to explore, and discuss, the challenges and limitations we encountered and the strategies we employed when using this method for a study exploring the personal experiences of living with the terminal illness amyotrophic lateral sclerosis/motor neuron disease (ALS/MND).

ALS/MND

ALS/MND is an often-rapidly progressive terminal neurodegenerative condition of unknown etiology which results in weakness and wasting of muscles, loss of mobility and difficulty with speech, swallowing and respiration, often compounded by psychological effects. The disease follows a continuously progressive course; although periods of stability might occur,

once a function or ability has been lost, it is not regained. Consequently those diagnosed with ALS/MND can very rapidly become dependent on other people for even the most basic of needs. More than 50% of people die within three years of the onset of their first symptom and average survival from diagnosis is around fourteen months (Motor Neuron Disease Association (MNDA), 2009). The involvement of people with terminal illnesses in long term studies is fraught with methodological and ethical difficulties. In ALS/MND this is due in no small part to the progressive nature of the condition, with the result that it can be impractical to obtain vital information regarding personal experiences as the disease progresses. Innovative methodological approaches are therefore required to ensure that the full illness experience in ALS/MND, and other terminal illnesses, can be studied, but without imposing additional demands on the dying person.

Illness Narratives

For hundreds of years individuals have used a variety of approaches, including letters and diaries, to write about their illnesses (Wiltshire, 2005; McLellan, 1997). More recently, published and book length accounts of illness, sometimes called pathographies, have become more common (Hawkins, 1993; Bingley, et al., 2006) and the latter years of the 20th century witnessed an exponential proliferation in illness narratives on the Internet (Bingley, et al., 2006). It has been claimed that this recent explosion in the availability of illness narratives was related to patients' needs to be experts in their own condition and to reclaim their illnesses from an increasingly technological, hospital based system, which regards all disease within a biomedical model (Hellman, 2005). However, personal accounts of illness have tended to be regarded more as anecdotal and idiosyncratic commentaries, rather than as raw material suitable for careful analysis (Robinson, 1990). The expansion of freely available illness stories goes some way to address the need for patients to be heard publicly within biomedical discourse (McKay & Bonner, 1999). Writing many decades before the present

popularity of the genre, Allport (as cited in Taylor, Robinson, & McCormick, 1986, p.198), endorsed the usefulness of written illness accounts as a research method;

> If the language of personal documents can be shown to enhance understanding, power of prediction and power of control (. . .) then these documents must be admitted as a valid scientific method.

Studying such illness narratives provides researchers with an invaluable opportunity to understand patients' endeavors to comprehend what is happening to them; others are enabled to share the illness experience through the dissemination of the narrative (Hydén, 1997).

Search Strategy

Because this was such a new methodological approach we found no definitive guidance for how narratives should be identified and collated for research purposes. We therefore sought insight from the available published articles regarding a suitable strategy. We carried out a systematic review of papers adopting this approach which revealed that relatively few published studies have used unsolicited written narratives as research data (O'Brien & Clark, 2010). With the exception of Bingley et al. (2006) who included both types, these studies concentrated on either published or Internet material. The information within these papers was frequently of limited value because authors often failed to adopt a comprehensive approach, with some focused on single Web sites (Stone, 2007; Headland, 2006) or specific journals (Hayne & Yonge, 1997).

We wanted to understand how prevalent these writings were and to contextualise the findings through answering a number of supplementary questions including who has written about living with the disease, where were these writings located, and what was the focus of the narratives? We were anxious therefore to obtain a broad range of experiences, written within a variety of contexts, to incorporate present day and historical accounts within the analysis, to understand how living with the illness might have changed during modern times.

Consequently we thought it important to do this without imposing constraints on the amount of material collected.   Therefore our intention was to identify as many published and Internet ALS/MND narratives as possible, available at the time of our search (January-March 2005). To achieve this, we incorporated elements of systematic review (SR) methodology to help shape the initial search strategy. There is a clear distinction however between our approach, to locate illness narratives, and that of systematic reviewers who seek out all research studies on a specific topic. Whereas this could be interpreted as being incongruent with a qualitative methodology, we believe it was justified as a means of imposing an element of order on the search for narratives, especially because we were effectively faced with a sample of unknown size. Additionally, we did not want to introduce a sampling bias, as other researchers adopting similar approaches have, by restricting sampling to specific journals (Wisdom, Bruce, Saedi, Weis, & Green, 2008) or single Web sites (Headland, 2006).

We used a range of terms including personal narratives, experiences, writing, and stories. Confusion exists regarding nomenclature relating to the illness (Swash & Desai, 2000), we therefore thought it important to incorporate the most frequently used terminology into the search to avoid any selection bias and to ensure that a comprehensive sample was obtained. Each search was therefore repeated to incorporate MND and Motor Neuron Disease, ALS and Amyotrophic Lateral Sclerosis and Lou Gehrig's disease. We used a varied strategy to locate material including trawls of Internet search and Meta search engines (Google, Dogpile), electronic searches of ALS/MND association Web sites, database searches (Web of Science, CINAHL, Medline, Care Data, Lexis Nexis), electronic/hand searches of library collections and electronic searches of online bookstores (Amazon.co.uk, Amazon.com, Alibris).

This strategy returned an overwhelming number of hits, most of which proved inappropriate on further investigation. This alerted us to the often erratic nature of electronic

searching and the need for careful consideration when entering search terms. The second

phase of the search strategy involved narrowing the focus through a detailed meticulous and

laborious investigation.

The Search for Internet Narratives

The systematic identification, inclusion or exclusion of personal Web sites was ultimately

conducted through a four-stage process.

Stage One: Snowballing. Internet search engines displayed the search results in order of their

likely relevance to the search term. Given the large number of hits returned during some

searches, only the first five pages of results were scanned because it was unlikely that Web

sites containing relevant material would be identified beyond this. We also accessed, and

scanned for inclusion, any onward links from relevant Web sites which appeared appropriate.

This snowballing was also adopted in some of the published studies using online narratives

(Jones, Zahl & Huws, 2001; Hardey, 2002; Pitts, 2004; Jones, 2005; Mohammed & Thombre,

2005; Suzuki & Beale, 2006; Bingley et al., 2006). Snowballing in this manner meant that

numerous relevant Web sites were identified from one source; however, it also became

apparent that sites were continually revisited through links from a number of different Web

sites. This had the potential to engulf us, so to impose an element of order on the search we

maintained a log of activity for our Internet searches as suggested by Robinson (2001). We

recorded details of each site, together with a hyperlink to the Web address; this was important

because many sites were accessed through complicated routes which would be difficult to

retrace.

We continued with this process until all links were checked. During this time an

element of saturation became apparent, as more and more Web sites identified with each

search were already noted from previous searches. This view of saturation, which differs

slightly from the established convention, was used to demonstrate our confidence that our

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sample contained as broad a range of experiences as was possible at that time and so assist in the contextualization of the narratives.

At this stage we also identified a number of ALS/MND Internet chat rooms and fora, some of which contained links to personal Web sites. We limited our searches to Internet sites with open access as a key criterion was to include only material which was available, within the public domain, without any form of gatekeeper control. We will address this issue further when we discuss ethical considerations in the use of this material. Our attempts to locate Internet based narratives therefore pursued a systematic pathway approach which ultimately identified 1363 Web sites each of which had the potential to contain ALS/MND illness narratives

Stage Two: Removal of duplicate/inappropriate Web site content. We became aware that our snowballing activity resulted in some Web sites being accessed from a number of different Internet locations and considerable duplication was evident. Systematically checking all Web sites revealed not only the extent of this duplication, but also the extent of unrelated Web site content. At this stage a substantial number of Web sites (988) were discarded because of duplication or inappropriate content which was not focused on the personal experience of living with ALS/MND.

Stage Three: Removal of defunct links/sites. The dynamic nature of the construction of the Internet means that Web sites can easily be set up, moved and discontinued. We were not surprised, then, to find that many identified sites were no longer functioning and as a result a further 278 sites were eliminated at this stage.

Stage Four: Application of inclusion/exclusion criteria. The remaining 97 Web sites were then subjected to our inclusion/exclusion criteria during which a further 33 sites were eliminated because their content did not meet our requirements (Table 1). Following this we were left with 64 Web sites which were again accessed so that a copy of the narrative could be

downloaded and retained. The importance of archiving such material cannot be under-estimated. The potentially erratic availability of some Internet sites represents a challenge for researchers who must ensure that material from the site is secured before it is lost forever (Hardey, 2002; Robinson, 2001).

INSERT TABLE 1 ABOUT HERE

A decision was made at this point to limit the extent of the downloaded material to that which was available on the date the site was accessed. Our reasoning here was to ensure that data collection was manageable within the time constraints of the study. In addition, we thought that continually revisiting Web sites over a period of time to download updates could potentially overwhelm the study with material from a small number of contributors, some of whom updated their journal entries almost on a daily basis.

The Search for Print Narratives

The search for print narratives (books, chapters, journal and newspaper articles) was conducted alongside the search for Internet narratives, between January and March 2005. The initial scoping exercise described earlier was applied to both genres. The search for print narratives then followed conventional bibliographic searching and included key word searches of the electronic databases alluded to earlier (i.e. Web of Science, CINAHL, Medline, Care Data, Lexis Nexis) before progressing to Internet based search activity. Searches of the first four of these databases yielded very little of relevance to the study because their focus was concerned with academic work and reporting research. We had hoped to identify newspaper articles written by people with ALS/MND; on investigation however we found that most articles in newspapers appeared to have been written about people with the disease and not by them and so they did not meet our inclusion criteria. Online bookstores, library collections and official ALS/MND association Web sites were the most useful sources of information regarding print material. Some personal Web sites included

lists of books. Our approach was similar to that adopted in a search for autobiographies

written by people with dementia (Page & Keady, 2010). The search for print narratives also

followed a four stage process similar, but not identical, to the search for Internet material.

Stage One: Scoping exercise and bibliographic search. The initial search identified 277 potential

narratives. Wherever possible, personal details of the author and publication information

were obtained. This was often taken from reviews written by people who had read them and

from publishers' publicity material available through online bookstores and ALS/MND

association Web sites. This information included the title, author(s), date of publication,

publisher and ISBN, where available.

Stage Two: Application of inclusion/exclusion criteria. The known details of the 277 potential

narratives were subjected to the same inclusion/exclusion criteria as the Internet narratives

(see Table 1). At this stage we excluded 149 narratives, for one of two reasons. First, we

determined that the narrative had not been written by or with a person with ALS/MND; and

second we found some to be fictional accounts of living with illness contained in novels.

Stage Three: Removal of inappropriate material. A number of short narratives (12) were

eliminated at this point either because they contained minimal information about living with

ALS/MND or the experiences reported concerned extremely atypical variants of the illness.

Additionally, anonymous narratives were rejected because it was impossible to verify their

authenticity.

Stage Four: Removal of duplicated narratives. On obtaining copies of some print narratives we

became aware that a number of stories were available in different locations. Once the

duplicated entries were removed we were left with narratives by 107 authors, which

comprised 38 books, 30 chapters, 33 short narratives, four journal and two newspaper

articles. A number of books were produced through small independent publishers and despite

a concerted effort copies of 10 out of print publications could not be located. Hence our analysis was restricted to narratives by 97 authors.

With reference to the principles inherent within SR methodology, our search could be said to show high sensitivity, because we were confident of having identified many relevant narratives from our exhaustive searches. However, as is usual with highly sensitive searches, we identified many more sources that were not relevant to the study and consequently the search had a low specificity. In addition to the logistical problems we encountered in the identification of our material, we also had to address a number of other methodological and ethical issues regarding the use of this data.

Methodological issues

Is the Material Genuine?

There are issues relating to the authenticity of written narratives (Salander & Hamberg, 2005), which perhaps apply more to Internet than print accounts; how could we be sure that the narratives were genuine and written by a person diagnosed with the illness? Hookman (2008), in his study of blogs, argued that depending on the context of the study, it does not matter if bloggers do not always tell the 'truth'. Pitts (2004), in a study of breast cancer narratives found on personal Web sites, highlighted difficulties in assuring the veracity of such material in relation to the narrators themselves, and consequently made no explicit claims regarding the off line identities of her authors. The Internet is a medium for self publishing without regulation and although we did not expect that hoax sites would have been created within the area under scrutiny, it was necessary to search for elements of truth and authenticity within the identified sites to assure ourselves regarding the content. We regarded sites as verifiable if they were Web sites of official ALS/MND organizations or contained links to, or from, these official Web sites; it could be argued that such links would not be present if the ALS/MND organization had any doubts about the validity of what was

reported. Some authors provided links to other ALS/MND stories which we regarded as providing an element of authentication; these authors sometimes commented on similarities in each others' experiences which helped to validate the content of the Web site. It could be contended that authors of personal Web sites would not provide links into other sites unless they regarded those sites as authentic.

The situation regarding the veracity of published material is perhaps less contentious. We assumed that publishers of personal stories of lives affected by illness would assure themselves of the legitimacy of the accounts prior to publication. A number of print accounts identified within this study were self published; these were taken at face value because we believed it unlikely that individuals would create fictitious accounts of living with a condition such as ALS/MND. Many of these stories were also referred to on ALS/MND Web sites, which provided additional reassurance of their authenticity. We do acknowledge, however, that these measures are not perfect and even though we introduced a range of checks, they are no guarantee of authenticity.

We must emphasize that the process undertaken to identify the narratives described here was extremely time consuming. It should not be considered an easy option for data collection. If it is to be carried out in a systematic and meaningful way, this approach requires a thoroughly organized system with considerable attention to detail.

How Should a Narrative be Defined?

It is generally agreed that illness narratives follow an ordered chronology containing a beginning, middle and end and they detail the personal experience of undergoing change of some kind (McLellan, 1997; Hydén, 1997). This temporal sequencing reflects everyday life where what happens first affects and, to an extent, influences what then follows. This trajectory gives some coherence to the story without which it would be a jumbled collection of episodes without a logical storyline. However, placing such restrictions on what is

regarded as a narrative, and accepting only those stories which conform to the chronological format might deny those who are unable to comply with narrative coherence (Baldwin 2005). It is possible that some individuals with physical disabilities, such as those affected by ALS/MND, might be unable to articulate or document their stories in a recognized narrative format and so might also be narratively dispossessed (Baldwin, 2005). Unlike others therefore, who restricted their analysis to material of "sufficient depth and length" (Page & Keady, 2010, p.513), we adopted a flexible approach to narrative definition which ensured that it was not just those capable of producing a linear story that were heard. Some narratives contained within compilation volumes amounted to no more than a paragraph, focused on a specific matter. We decided that to exclude these shorter stories would be to silence those incapable of constructing a narrative with a temporal order and extended format.

Logistics of Preparing a Large Volume of Material for Analysis

A number of challenges were created by the sheer volume of data to be analyzed (161 narratives) which were exacerbated by the disparate modes of presentation reflecting Grinyer's (2006, p. 212) notion of "a range of styles and approaches to storytelling". The length of personal stories differed enormously; Internet narratives varied from a single page to many pages of text, with one comprising 45 chapters covering the twelve-month period from diagnosis until death (www.lutheroutloud.com). Print narratives comprised a mixture of book length, chapter length, short narratives and newspaper or journal articles.

Organization of the data by means of data reduction is regarded as the first step in the analytic process (Miles & Huberman, 1994). We employed an anticipatory reduction through our decision to limit the downloaded material to that available at the time each Web site was accessed. Initial processing of material, in preparation for analysis, was relatively straightforward for Internet narratives. Each narrative was read through and content not related to the study was edited out; relevant material was copied and pasted into NVivo 7

(Bazeley, 2007) which was used to assist in the management of the data during analysis. Print narratives were handled in the same manner; however the relevant material had to be transcribed into individual word documents which was extremely time consuming, especially for the lengthier texts. We regarded this approach as essential, despite being labor intensive, because it was important to ensure that all units of text, both print and Internet, were analyzed using the same approach. However this process, akin to the transcribing required following data collection using interviews, did serve the function of facilitating immersion in the data which was of prime importance in our thematic analysis (Braun & Clarke, 2006).

Ethical Challenges

In all research involving human subjects obtaining informed consent and taking measures to ensure privacy and confidentiality are viewed as basic ethical principles. The advent of research conducted on the Internet has raised questions regarding the extent to which this avenue for research can be governed by such established principles. Grinyer (2007), among others, pointed out that existing codes of ethical practice might not adequately address key areas of concern in the use of Internet data. We recognized that the use of material from the Internet could raise ethical concerns, specifically regarding the issues of informed consent and anonymity. To assure ourselves that our approach was ethically sound we sought guidance from the limited available literature.

Ethical Guidelines for Internet research

A number of guidelines and suggestions for ethical decision making for Internet research have been published (Frankel & Siang, 1999; Ess & the Association of Internet Researchers (Ess & the AoIR), 2002; National Committee for Research Ethics in the Social Sciences and the Humanities (NESH), 2003; Bruckman, 2002), but none have provided a specific ethical framework for Internet research. It is possible that the distinction between public or private communication on the Internet is the most important issue with regard to

ethical decision making in this area. The NESH (2003) guidelines acknowledged that this distinction can be difficult to establish in some cases. They did however point out, as a general rule, that material contained within open fora, obtainable by anyone with Internet access, could be freely used for research purposes. Researchers using other data sources on the Internet, such as blogs, have concluded similarly; blogs might contain personal information, but unless they are made 'friends only' they are not private and can therefore be used as research data (Hookman 2008).

The AoIR guidelines (Ess & the AoIR, 2002) raised the question of whether participants in Internet research were best understood as subjects taking part in a defined activity, i.e. communicating in a specific chat room which allowed for private exchanges, or as authors intent on publicizing their work through freely accessible Web pages. This distinction would oblige research involving subjects to obtain consent and ensure greater levels of protection for privacy and confidentiality than would be required in research involving authors. However, the guidelines referred only to material from group activities, such as chat rooms and bulletin boards, and did not include personal Web sites, intended to publicize the owner's views.

Robinson (2001), in her model for decision making regarding the use of Internet data, concluded that material freely available in a public place, without gatekeeper control, was posted in the knowledge that others unknown to the author might access it and make comments about it without having to seek consent. Unfortunately, she omitted to include narratives contained within personal Web sites in her ethical deliberations. A further distinction was made by Eysenbach and Wyatt (2002), who stated that informed consent would be required if Internet based data were collected through active intervention, interaction or communication by the researcher. In keeping with this notion of publicly available data, we therefore confined ourselves to the use of material obtained from personal

Web sites which, at the time accessed, were publicly available without constraint. Thus, we considered our study to be a form of passive analysis (Eysenbach & Wyatt 2002) in that it involved the study of information obtained from Web sites and published sources; we had no active involvement with narrators and so therefore required no informed consent to use the material.

Anonymity

Our second main ethical concern focused on the issue of anonymity for narrators. When exploring the personal Web pages of women with breast cancer, Pitts (2004) referred to them as creative works which the authors intended others to read, and as such she pointed out, they should be properly cited as authored works. Decisions regarding anonymity for creators of material on the Internet must take account of where the material is located. That which is available within the public domain and is regarded as a creative work should not be subjected to anonymity. Findings from our systematic review revealed that few researchers adopting this approach have considered this issue in sufficient depth; many took a confused stance and referred to authors while advocating anonymity but included quotations which could be traced using Internet search engines (O'Brien & Clark 2010). Researchers ought to be aware that failure, properly, to credit the source of material taken from a Web site should be seen in the same light as a copyright infringement. Many of the Web sites identified in our study contained a Creative Commons Deed, the Internet equivalent of copyright, which implies that the owner of a Web site expects to be regarded as the originator of a creative work. As such, our commitment to ascribe the sources of our electronic material was the same as that for any print medium accounts included within the study.

Requirement for Ethical Approval

Seale, Charteris-Black, MacFarlane and McPherson (2010) highlighted the complexity surrounding not only the need for informed consent, but also whether ethical

review was required for studies using publicly available data. Some authorities have suggested that researchers should not be required to seek review by an ethics committee or Institutional Review Board (IRB) when using material posted by individuals seeking public visibility (Frankel & Siang, 1999). Miles (2009) and Wisdom et al. (2008) pointed out that their studies, using unsolicited narratives, were approved as exempt from institutional human subject protection requirements because they involved only the use of published or open source data. Robinson (2001) included a model for decision making regarding the need to pursue ethical approval when researching unsolicited narratives obtained from the Internet, but she omitted material obtained from personal Web sites. We surmised that the lack of appropriate guidance in the literature regarding the ethical implications of using data from personal Web sites and the question of whether formal ethical approval was required needed to be addressed. An adapted version of Robinson's model was therefore developed during this study, which addressed previous omissions and, we contend, will allow researchers to follow an algorithm to guide their decision making (see Figure 1).

INSERT FIGURE 1 ABOUT HERE

Ethical Considerations with the use of Print Material

The study of print narratives, although perhaps less challenging with regard to ethical implications, does require consideration from an ethical perspective. It could be argued that the process of documenting and publishing details of one's life in print, with the intention of selling or distributing it, means that authors are deliberately seeking publicity for their story and as such would have no demand for anonymity. Many print narratives are protected by copyright, which like the Internet equivalent, Creative Commons Deed, demands that the work is acknowledged and properly attributed. A consideration of the reason for writing can also help to illuminate the situation for both print and Internet narratives. A number of authors in our study specified that their wish was to share their experiences with others,

thereby raising awareness of the disease. As such there was no demand for privacy, rather, the opposite applied. It cannot be known for certain what each author would think about their narrative being analyzed and included in the study. Many authors have since died, but because their purpose in writing was often to generate publicity, this study will enable their stories to be shared again, often many years after they were written, helping to move forward the wider understanding of the effects of the disease.

Limitations in the use of Unsolicited Written Narratives

Our search strategy was designed to gain an understanding of the amount of illness narratives available at the time of the search and to attempt to compile a wide-ranging sample of writings for in depth analysis. Mohammed and Thombre (2005) pointed out that sampling from the Internet was, in effect, sampling from a population of an unknown size. We are confident that the electronic sample we obtained contains a broad range of experiences and geographical spread (O'Brien & Clark, 2006) but, as is usual with qualitative research, we make no claims for the totality or completeness of the sample. Despite having introduced a range of checks to assure ourselves of the veracity of the narratives, we acknowledge that they are no guarantee of authenticity. The processes undertaken in searching for suitable narratives for inclusion inevitably introduced an element of selection bias as a result of the choice of search terms used and sources scrutinized. Such searches are based on particular labels, but those who do not use these terms to describe themselves or their experiences will inevitably be excluded. The need for a wide ranging search strategy was therefore paramount.

When utilizing written narratives, there is necessarily a bias toward literacy (Hayne & Yonge, 1997). Authors of pathographies tend to make their living in some way from writing, for example as journalists, lecturers or authors (Bingley et al., 2006; Aronson, 2000). Those unable to compose a written story will not do so, or will not adhere to the model of how a story should be. There are questions whether researchers miss, ignore or fail to notice aspects

within accounts which do not easily fit with their accepted notion of a storyline (Gilbert, 2002). We have addressed this by paying attention to the smaller stories, i.e. those which do not essentially conform to the idealized notion of a narrative (Baldwin, 2005). Additionally the Internet provides the means for those not normally associated with autobiographical writing to document their stories because it allows for a more natural style, often containing spelling and grammatical errors. This "stylistic unevenness" (McLellan, 1997, p. 1619) resulting from the literary inexperience of the authors, can be negated by the immediacy of the need to tell the story, the value of which overrides considerations of style and grammar.

Conclusion

Researchers generate considerable amounts of data, yet a substantial quantity of material already exists, much of which is in the public domain. There are ethical implications in the generation of research data where suitable material is already available; nowhere perhaps is this more apparent than in studies involving those affected by terminal illness, such as ALS/MND, where data collection might intrude into their limited life span. Furthermore, there is a dearth of longitudinal research in this area because of the progressive nature of the illness, whereby individuals become unable to continue to participate in studies as their condition worsens. Historically it has proved difficult, methodologically and ethically, to capture experiences throughout the disease trajectory. The availability of numerous print and Internet illness narratives provided access to pertinent stories from an infinitely more diverse sample than could be obtained using conventional interview techniques (Hookway, 2008). The authors came from a variety of demographic backgrounds, the narratives provide an international dimension and they will also allow us to include an historical perspective because the experiences written about span the time period from 1975 until 2005 (O'Brien & Clark 2006). We do recognize, however, that excluding foreign language narratives results in a bias toward English-speaking cultures.

This study is the first to explore ALS/MND illness experiences as they are documented in print and Internet formats. We have identified material which spans a 30 year period of key developments in the care and management of ALS/MND worldwide; as such this data is unique and the findings will contribute to a greater understanding of what it means to live with ALS/MND in modern times. The 161 narratives of life with ALS/MND identified in this study could not have been obtained through any other means, which only serves to emphasize the importance of this approach. They have been collected without imposing any additional impact on the lives of those involved and as such the method should be regarded as ethical because of its non-intrusive nature. There are clear advantages but also some limitations in the use of unsolicited narratives as research data. We have addressed, in a systematic and transparent fashion, the difficulties we encountered and in doing so have provided detailed guidance for others who might use this approach. Using this approach we have identified a broad range of material regarding the experience of living with ALS/MND and are confident that this method could equally be applied to study the impact of other terminal illnesses.

REFERENCES

Aronson, J. K., (2000) 'Autopathography: the patient's tale.' *British Medical Journal,* 321(7276), 1599-1602. doi: 10.1136/bmj.321.7276.1599

O'Brien, M.R., and Clark, D. (2006) Online illness narratives about living with motor neurone disease: a quantitative analysis. *British Journal of Neuroscience Nursing.* 2 (8) 410-414.

O'Brien, M.R. and Clark D. (2010) Use of unsolicited first-person written illness narratives in research: systematic review. *Journal of Advanced Nursing* 66(8), 1671–1682. doi: 10.1111/j.1365-2648.2010.05349.x

Baldwin, C., (2005) 'Narrative, ethics and people with severe mental illness.' *Australian and New Zealand Journal of Psychiatry,* **39**, 1022-1029.

Bazeley, P., (2007) *Qualitative Data Analysis with NVivo.*2nd edn, London, Sage Publications

Bengs, C., Johansson, E., Danielsson, U., Lehti, A., and Hammarström, A. (2008) 'Gendered portraits of depression in Swedish Newspapers.' *Qualitative Health Research* 18(7), 962-973 doi: 10.1177/1049732308319825

Bingley, A. F., McDermott, E., Thomas, C., Payne, S., Seymour, J. E. and Clark, D., (2006) 'Making sense of dying: a review of narratives written since 1950 by people facing death from cancer and other diseases.' *Palliative Medicine,* 20(3), 183-195. doi: 10.1191/0269216306pm1136oa

Braun, V. and Clarke, V., (2006) 'Using thematic analysis in Psychology.' *Qualitative Research in Psychology,* 3, 77-101. doi: 10.1191/1478088706qp063oa

Bruckman, A.(2002) Ethical Guidelines for Research Online. Available: http://www-static.cc.gatech.edu/~asb/ethics/

Bury, M. (1982) 'Chronic illness as biographical disruption.' *Sociology of Health and Illness,* 4(2), 167-182. doi:10.1016/j.socscimed.2007.03.007

Ess, C. and AOIR Ethics Working Committee, (2002) Ethical decision-making and Internet research: Recommendations from the aoir ethics working committee. Available: http://www.aoir.org/reports/ethics.pdf

Eysenbach, G. and Wyatt, J., (2002) *Using the Internet for Surveys and Health Research.* http://www.jmir.org/2002/2/e13/ edn. doi:10.2196/jmir.4.2.e13

Frankel, M. and Siang, S., (1999) Ethical and legal aspects of human subjects research on the Internet. Available: http://www.aaas.org/spp/sfrl/projects/intres/report.pdf

Gilbert, K. R., (2002) 'Taking a narrative approach to grief research: finding meaning in stories.' *Death Studies,* 26(3), 223-239. doi: 10.1080/07481180211274

Greenhalgh, T., (1997) 'Papers that summarize other papers (systematic reviews and meta-analyses).' *British Medical Journal,* 315, 672-675.

Grinyer, A., (2007) 'The ethics of Internet usage in health and personal narratives research.' *Social Research Update,* Spring(49).

Grinyer, A., (2006) 'Telling the story of illness and death.' *Auto/Biography,* 14, 206-222.

Hardey, M., (2002) ''The story of my illness': personal accounts of illness on the Internet.' *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine,* 6(1), 31-46. doi: 10.1177/136345930200600103

Hawkins, A. H., (1993) *Reconstructing Illness.* 1st edn. West Lafayette, Ind: Purdue University Press.

Hayne, Y. and Yonge, O., (1997) 'The lifeworld of the chronic mentally ill: Analysis of 40 written personal accounts.' *Archives of Psychiatric Nursing,* 11(6), 314-324. doi:10.1016/S0883-9417(97)80004-0

Headland, M., (2006) 'Using a Web site containing patient narratives to understand people's experiences of living with arthritis.' *Journal of Orthopedic Nursing,* 10(2), 106-112. doi:10.1016/j.joon.2006.03.007

Hellman, A. P., (2005) 'Narrative and illness: the death of a doctor's friend.' *The Medical Journal of Australia,* 182(1), 9.

Hookway, N., (2008) '`Entering the blogosphere': some strategies for using blogs in social research.' *Qualitative Research,* 8: 91. doi: 10.1177/1468794107085298

Hydén, L. C., (1997) 'Illness and narrative.' *Sociology of Health & Illness,* 19(1), 48-69.

doi: 10.1111/j.1467-9566.1997.tb00015.x

Jones, R., (2005) 'Identity commitments in personal stories of mental illness on the Internet.' *Narrative Inquiry,* 15(2), 293-322.

Jones, R., Zahl, A., and Huws, J. C. (2001) 'First-hand accounts of emotional experiences in Autism: a qualitative analysis.' *Disability and Society* 16 (3), 393-401 doi: 10.1080/09687590120045950

McKay, S., and Bonner, F. (1999) 'Telling stories: Breast cancer pathographies in Australian women's magazines.' *Women's Studies International Forum,* 22(5), 563-571. doi: 10.1016/S0277-5395(99)00055-2

McLellan, M. F., (1997) 'Literature and medicine: Narratives of physical illness.' *The Lancet,* 349(9065), 1618. doi:10.1016/S0140-6736(97)04429-2

Miles, A. (2009) 'Of butterflies and wolves: enacting lupus transformations on the Internet.' *Anthropology and Medicine* 16(1), 1-12 doi: 10.1080/13648470802425906

Miles, M. B. and Huberman, A. M., 1994. *Qualitative Data Analysis.* 2 edn. California: Sage.

MND Association (2009) *A rapid response to a rapidly degenerative disease* – The case for a National Strategy for Motor Neurone Disease. MND Association, Northampton.

Mohammed, S. N. and Thombre, A. (2005) 'HIV/AIDS stories on the World Wide Web and transformation perspective.' *Journal of Health Communication,* 10(4), 347-360. doi: 10.1080/10810730590950066

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National Committee for Research Ethics in the Social Sciences and the Humanities (NESH),
Research ethics guidelines for Internet research. Available:
http://www.etikkom.no/no/Forskningsetikk/Etiske-retningslinjer/Samfunnsvitenskap-
jus-og-humaniora/Internett-forsking/

Page, S., and Keady, J. (2010) 'Sharing stories: a meta-ethnographic analysis of 12
autobiographies written by people with dementia between 1989 and 2007.' *Ageing
and Society*, 30, 511-526. doi:10.1017/S0144686X09990365

Pitts, V.,(2004). 'Illness and Internet Empowerment: Writing and Reading Breast Cancer in
Cyberspace.' *Health:* 8(1), 33-59. doi: 10.1177/1363459304038794

Robinson, I., (1990) 'Personal narratives, social careers and medical courses: Analyzing life
trajectories in autobiographies of people with multiple sclerosis.' *Social Science &
Medicine,* 30(11), 1173-1186. doi:10.1016/0277-9536(90)90257-S

Robinson, K. M., (2001) 'Unsolicited Narratives from the Internet: A Rich Source of
Qualitative Data.' *Qualitative Health Research,* 11(5), 706-714.
doi: 10.1177/104973201129119398

Ryan, E. B., Bannister, K. A. and Anas, A. P. (2009) 'The dementia narrative: writing to
reclaim social identity.' *Journal of Aging Studies* 23, 145-157
doi:10.1016/j.jaging.2007.12.018

Salander, P. and Hamberg, K., (2005) 'Gender differences in patients' written narratives
about being diagnosed with cancer.' *Psycho-Oncology,* 14, 684-695.
doi: 10.1002/pon.895

Seale, C., Charteris-Black, J., MacFarlane, A., McPherson, A. (2010) 'Interviews and Internet
Forums: a comparison of two sources of qualitative data.' *Qualitative Health
Research* 20 (5) 595-606 doi: 10.1177/1049732309354094

Stone, S. D., (2007) 'Patient concerns posthaemorrhagic stroke: a study of the Internet narratives of patients with ruptured arteriovenous malformation.' *Journal of Clinical Nursing,* 16(2), 289-297. doi: 10.1111/j.1365-2702.2005.01490.x

Suzuki, L. K. and Beale, I. L., (2006) 'Personal Web home pages of adolescents with cancer: self-presentation, information dissemination, and interpersonal connection.' *Journal of Pediatric Oncology Nursing,* 23(3), 152-161. doi: 10.1177/1043454206287301

Swash, M. and Desai, J., (2000) 'Motor neuron disease: classification and nomenclature.' *Amyotrophic Lateral Sclerosis and other motor neuron disorders,* 1(2), 105-112.

Taylor, A., Robinson, R. and McCormick, I., (1986) 'Written personal narratives as research documents-the case for their restoration.' *International Review of Applied Psychology,* 35, 197-208. doi: 10.1111/j.1464-0597.1986.tb00915.x

Whitehead, L. C.,(2006) 'Quest, chaos and restitution: living with chronic fatigue syndrome/myalgic encephalomyelitis.' *Social Science & Medicine,* 62(9), 2236-2245. doi:10.1016/j.socscimed.2005.09.008

Williams, G., (1984) 'The genesis of chronic illness: narrative re-construction.' *Sociology of Health and Illness,* 6(2), 175-200. doi: 10.1111/1467-9566.ep10778250

Wiltshire, J., (2005) 'Medical history from the viewpoint of the patient.' *Internal Medicine Journal,* 35(3), 193-194. doi: 10.1111/j.1445-5994.2004.00792.x

Wisdom, J. P., Bruce, K., Saedi, G. A, Weis, T., and Green, C. A. (2008) ''Stealing from myself': identity and recovery in personal accounts of mental illness.*' Australian and New Zealand Journal of Psychiatry* 42, 489-495 doi:10.1080/00048670802050579

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Table 1. Inclusion/Exclusion Criteria Applied to all Narratives. Adapted from (O'Brien and Clark 2006). Copyright MA Healthcare Ltd. Reprinted with Permission

Inclusion criteria	Exclusion criteria
Literature [diaries, memoirs, Web site entries, newspaper/journal articles], as a personal narrative, documenting the experience of living with a diagnosis of ALS/MND whether in print or on the Internet, written by people with ALS/People with MND (PALS/PwMND)	Narratives in verbal or visual format i.e. plays, films, and radio performances. Literature containing personal opinion rather than personal experience; with a focus on fund raising, general ALS/MND information and carers' experiences. Literature not written by PALS/PwMND
Narratives written in English or with an English translation available	Narratives that are not available in English
Narratives containing personal demographic details about the author	Narratives without personal demographic details about the author
Narratives based on personal experiences of living with ALS/MND	Narratives based on imaginary experiences
Narratives originally written by PALS/PwMND but subsequently edited by others prior to publication	Narratives written by others on behalf of PALS/PwMND
Narratives which are verifiable as being the work of PALS/PwMND (i.e. publisher's copyright; link to/from recognized organization or appropriate Web site)	Narratives which cannot be verified as being the work of PALS/PwMND