

**In their words: how television and visual media can raise awareness of dementia and other health conditions that carry stigma, including disabilities.**

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**Abstract:** This article explores the mutual contribution of television and disability studies, focusing on the role of television and visual media in raising awareness and challenging gaps in understanding of dementia, a health condition that carries stigma and is framed as a disability. The Living Well with Dementia, Dorset: Video project, demonstrates the duality of how creating and disseminating a video featuring people with dementia and carers talking about what it means to live well with the condition, provides a way to use media to raise awareness of dementia. Portraying real-life experiences of people affected by dementia was crucial, and enabled these often marginalized voices to be heard. Participants discussed experiences of diagnosis, post-diagnostic support, adjustments to lifestyle, social activities and family relationships. The video was disseminated through YouTube, and the impact on understandings of dementia was established through a questionnaire. Findings indicate personal stories are a powerful way to raise awareness of dementia, an approach that could improve awareness of other health conditions that carry stigma, including disabilities. Video provides researchers with novel ways to disseminate findings that extend to new and wide-ranging audiences. The fields of television and disability studies can therefore make a valuable mutual contribution.

**Key words:** Dementia; personal stories; awareness raising; stigma; television studies; disability studies.

Globally, the number of people living with dementia is increasing rapidly, aligned with healthcare improvements and the associated rise in life expectancy worldwide (World Health Organization 2012). This demographic trend is expected to continue well into the future. In the United Kingdom (UK) alone, the number of people living with dementia is expected to increase from 850,000 in 2015 to 1 million by 2025 (Alzheimer's Society 2015). The World Health Organization outlined the importance of raising awareness of dementia as a public health priority in 2012, calling for dementia to become a worldwide health priority with action required at international and national levels (World Health Organization 2012).

Dementia is a national health priority in the UK, which has led to a groundswell of national and local policies aimed at improving quality of life and care for those affected by the condition (for example: Department of Health 2009; 2012; 2013). Alongside this political impetus, there has also been a drive to increase public awareness and understanding about dementia, to help reduce negative stigma and increase low diagnosis rates nationally. This includes the Alzheimer's Society Dementia Friends Campaign, which is a social movement designed to raise awareness of dementia, enabling members of the public to understand more about dementia and the things that they, themselves, could do to help people with the condition (Dementia Friends 2014). Despite these positive drivers for change, people with dementia still report that they are not living as well as they could be, reporting loneliness and a fear of going out and engaging in their local community (Alzheimer's Society 2014a).

### **The power of stories**

Within the field of disability studies storytelling is an established approach used to empower people with disabilities (Atkinson 1993; 2004; Atkinson and Williams 1990; Goodley 1996; 1998; Grove 2015; Meininger 2006). Grove (2015) examined the power of the story as one

approach to empowering people with intellectual disabilities. She found that the ability to tell a story enabled people with intellectual disabilities to develop an increased sense of identity/purpose, confidence, communication and value (Grove 2015). Others have found that storytelling provides participants with an opportunity to bring together insight and empathy (Goodley 1996). By affirming the subjective meanings the story teller enables others, whether in similar circumstances or not, to make connections and take strength (Goodley 1996). Storytelling can then enable people with disabilities to develop social relationships and active community participation (Grove 2015). Oral and life history approaches have also been used within disability studies as part of an empowerment ideology, enabling people that participate to tell their stories, reflect on them, and develop new insights into their meaning by considering them in a wider social and political context (Atkinson 2004). The enabling factors are time, space, support and practice, and the inclusion of other people to share the experience and reflections (Atkinson 2004). Life history approaches allow us to capture people's life stories in a range of different ways (Hatch and Wisniewski 1995; Victor 2005), and for those with dementia this has included life storybooks, collages, memory boxes, and electronic formats (Thompson 2011). Life history approaches are particularly valuable when working with people with dementia, as they can be individualized to ensure that the format that best fits the person and their situation is used (Thompson 2011). This promotes understanding about the individual, relationships and person-centred care (Thompson 2011).

Characters with disabilities are increasingly being featured in the media; although there has been some critique of the authenticity of the stories due to the lack of actual performers with disabilities playing these roles (GLADD 2014). On our television screens, though, we are seeing an increase in documentaries about the day to day lives of people with disabilities, which some argue has developed out of the coverage of the Paralympics (Rose 2012). Such

documentaries are often light-hearted by nature and focus on a particular aspect of someone's life, a prime example being the recent series about love and dating, *The Undateables* (2012 - , UK: Channel Four). However, they captivate an audience in a different way to more traditional educational films (such as, Lovett 2015). These kinds of documentaries have a positive approach to involved people with disabilities, often using humour, warmth and affection to enable the audience get to know the characters and live their lives with them, through the medium of the television screen (Rose 2012). This is a powerful way for the audience to see the person rather than the disability, which in turn contributes towards reducing negative stereotypes associated with disability (ITC 2003). Perhaps then we can learn from their approach? There are also many examples of public health campaigns that have used the media as a channel to disseminate key messages and influence healthy decision making. Public Health England recently reported that since the launch of their Act F.A.S.T stroke awareness campaign in 2009, an additional 38,600 people arrived at hospital for medical treatment within a three hour timeframe, with over 4,000 fewer people left with a disability as a result of a stroke (Public Health England 2015). The development of social media (such as YouTube, Facebook, and Twitter) and associated increase in publication and viewing of short video clips provides a platform to disseminate public health messages that are cost effective, instant and interactive, and support high levels of audience engagement. Personal stories are freely accessible through social media. In a book about stories told in social media, Page (2012: 1) argues that 'stories are important discursive and social resources that create identities for their story tellers and audience'. Experiences that were once private are now being publicly shared (Page 2012). Stories are being (re)shaped in different contexts online, and public intrigue and hype is leading to mass audience attention and open discussion, often albeit for a short temporary spell (Page 2012). Recent examples of this include: the 'ice bucket challenge' which raised money and awareness for the Amyotrophic

Lateral Sclerosis Association; and the ‘no make-up selfie’ which raised money and awareness for Cancer Research UK. The internet has also led to the emergence of citizen journalism, where members of the public are starting to take on the role of professional reporters, communicating information via the internet (Bulkley 2012).

### **Media portrayal of dementia**

Public awareness of health issues is constructed and reflected by the media (Lupton 1999; Peel 2014). The media is therefore one of the most important public sources of information about health (Lupton 1999; Peel 2014). As Lupton (1999: 260) states:

...media portrayals contribute to the creation or reproduction of knowledge's about illness and disease ... they work to portray ill people in certain lights (for example, as ‘innocent victims’ or ‘deserving of their fate’).

Thus, it is widely accepted that knowledge and understanding about diseases (such as dementia), and the people that are affected by them, is socially constructed and influenced by the common discourse used and disseminated by the media (Clarke 2006; Collin and Hughes 2011; Lyons 2000; Seale 2002; Williamson et al. 2011). Lyons (2000) suggests that the way that people behave with regards to their own, and others health, is affected by the ‘dominant constructions’ of health and illness in the media. Understanding how the media portray dementia is then vital, but could the impact on the audience also be examined? Within the media dementia is often negatively associated with age old stereotypes of ‘demented’ people and derogatory terms such as ‘dementia sufferers’. In a study designed to understand how talking about dementia and talking to people living with dementia is constructed, Peel (2014) discovered a ‘panic-blame’ framework apparent in print media coverage of dementia.

Drawing on analysis of 350 UK national newspaper articles, Peel (2014) found that dementia was represented negatively using terms such as ‘tsunami’ and ‘worse than death’, and this was combined with reporting of ‘individualistic behavioural change’ as well as lifestyle recommendations to ‘stave off’ the condition. In opposition to this media discourse, Peel (2014) found, little use of ‘hyperbolic metaphor’ or ‘reference to individual responsibility for dementia, and any corresponding blame and accountability’ in the language used by informal carers of people with dementia gathered during 12 interviews. Therefore, Peel (2014) argues that, the existence of ‘individualistic dementia ‘preventative’ behaviour in media discourse is problematic’, in contrast to other more ‘controllable’ and treatable chronic health conditions such as type 2 diabetes. In order to ensure positive social change for people diagnosed with dementia, Peel (2014) suggests engaging with, and critiquing, the panic-blame cultural context that is developing within print media coverage of dementia. Undeniably this is a relevant and important point; however we take this argument a stage further, specifying that the fundamental role of the media is to continually challenge negative stigma and stereotypes associated with dementia, and other health conditions that carry stigma, including disabilities. This, we argue, can be achieved through using the words, faces, voices and stories of real people who are affected by such conditions. In this article we demonstrate the value of this approach in raising awareness of dementia and challenging gaps in understandings of dementia, by drawing on the Living Well with Dementia, Dorset: Video (LWDDV) project as an exemplar (LWDDV 2014). This is indicative of the positive contribution that television and disability studies can make to one another.

### **The Living Well with Dementia, Dorset: Video project**

The aim of the LWDDV project was first to create an awareness raising video featuring people with dementia and carers talking about what it means to live well with dementia, and second to disseminate this video through YouTube and measure the impact after viewing with a self-complete questionnaire. The LWDDV project was developed as an exemplar to measure the impact of using personal stories to raise public awareness of dementia. Part of the rationale for developing this video was the juxtaposition of demographic figures within Dorset, on the one hand reporting population figures with one of the highest numbers of older people across the UK, and on the other some of the lowest dementia diagnosis rates (Dorset County Council 2012). The aim of the video was to challenge stereotypes about what it is like to live with dementia, and stimulate discussion about dementia to contribute to reducing the associated stigma, encouraging people to live well with dementia by accessing the right support and services for them and their family. Obtaining the views of people with dementia and carers was considered crucial in terms of portraying the real-life experiences of living with the condition, and enabling these, often marginalized, voices to be heard. The target audience for the video was the general public, although it was envisaged that given the Dorset focus, people in Dorset would be more inclined to view it.

### **The use of video**

Social Science researchers use video to record the experiences of people with dementia for a number of reasons. Most commonly video has been used as a way to record experiences, as an alternative to audio recording, and utilized by researchers during analysis (for example: Ragneskog et al. [2001] video-recorded participants with dementia to explore whether music could be used as a nursing intervention to reduce symptoms of agitation in a nursing home). Others have found video useful in enabling them to include the experiences, and involvement of people with dementia in the research process (Cook 2003). Video has also been used as a

way to help those caring for people with dementia to reflect on their interactions, enabling them to learn through lived experience, thus facilitating understanding and developing their own nursing skills (Hansebo and Kihlgren 2001). A number of videos aimed at raising awareness of dementia have been published on YouTube recently. For example, in Ireland the Dementia Elevator General Awareness Video (Dementia Elevator 2014)), in Austria MAS Alzheimerhilfe released an awareness raising video (MAS Alzheimerhilfe 2014), and in the UK the Right to Know campaign by the Alzheimer's Society (Alzheimer's Society 2014b). In this project however, we wanted to use personal stories to raise awareness of what it is like to live with dementia, using video as a tool to record the stories. We were also concerned with how we could measure the impact of the LWDDV, and if so how accurate this would be.

### **Ethics, filming and editing**

Including the views of people with dementia is an important empowerment principle (Trevisan and Reilly 2014). People with dementia are considered a vulnerable group (Safeguarding Vulnerable Groups Act 2006); however their level of vulnerability varies according to the extent of their cognitive impairment (Dewing 2008; Johannesen and Logiudice 2013). This can have ethical implications particularly when obtaining informed consent. The video would ultimately become a public document and therefore it was crucial that the consent of all participants, about both their participation and how the video would be used, was obtained. Prior to filming ethical approval was granted by the University Ethics Committee (BU Ethics 2014) Local ethics and governance processes were followed, including operating in an ethical manner with due regard to the relevant ethical considerations and challenges; ensuring data is stored securely and retained or destroyed in accordance with the Data Protection Act 1998; and making sure that the findings are disseminated appropriate in terms of anonymity and confidentiality (full ethics and

governance processes in: BU Ethics 2014). Participants were accessed through gatekeepers at established support groups for people with dementia. Gatekeepers, in this case, Leaders of Support Group, were sent information sheets outlining the details of the project, which they then shared with the people that attend the group. Individual members of the group were free to decide whether or not they wished to participate in the project. Those who wished to participate 'opted in' and were called by a member of the research team to talk through what their participation would involve. On the day of filming, participants were given another opportunity to discuss the project, and what their participation would involve, prior to the videos being recorded. Potential participants were provided with an information sheet that explained the purpose of the video, how the video would be recorded, how the participants would be able to view and comment on it, how and when participation could be withdrawn until, and where it would be located once it became publicly available. Individuals who decided to take part were then asked to confirm their participation by signing a consent form. These measures were taken to ensure that all participants based their decision to participate on full information about the project, and felt under no pressure to take part.

Interviews were conducting in a seminar room at the University and were video recorded by an external video production company. To ensure that participants were certain about their participation, they were given space and time to prepare. The seminar room was booked out for a whole day and participants were invited to attend at set time slots throughout the day. A relaxation room was located next door to the seminar room, and provided participants with refreshments and opportunities to discuss what their participation would involve, go through the information sheets and sign the consent forms. Once the final draft of the video was available, participants were given two weeks to watch the video and request any changes, such as shots that they did not wish to be included to be removed. Participants were also free

to withdraw their participation entirely up until this point. Once the draft version of the video was available, participants were asked to view the video and, if happy with it, sign a further consent form that gave their permission for the video to be published and in the public domain. To ensure as much confidentiality and anonymity as possible, the names of participants were not attached to the video. As a data collection method, interviews allow a reciprocal bond to develop between the researcher and the participant, and are a suitable way to explore the views and experiences of people with dementia and their carers. Five semi-structured interviews were conducted with people living within Dorset; three in dyads (formed of one person with dementia and their carers) and two with carers of people with dementia. . Following an inductive approach, the number of interviews undertaken was not limited, but continued until a point of data saturation was reached (Tuckett 2004). Each interview lasted between 10 and 35 minutes and was recorded on video. Participants were asked one open ended question: ‘What is your experience of living with dementia?’ Responses drew upon diagnosis, treatment, lifestyle, social activities and family relationships. Analysis was undertaken during the interviews, as the researcher was able to press a button on the camera when participants mentioned something they felt could be included in the video. Following the interviews the researcher also noted down any comments they felt should be included in the video and gave this to the video production company. The video production company then used this to edit the recordings into a five minute draft version of the video. This was reviewed by the research team who asked for some minor edits to be made. The video production company made the edits and then sent this second draft back to the research team. The research team then asked the participants to view and suggest any changes. None of the participants suggested any changes and all signed a further consent form, confirming they were happy for the video to be publicly available.

## **Measuring impact**

The video (LWDDV 2014), became publicly available in May 2014, through the BU Equality and Diversity YouTube Channel (BU Equality and Diversity 2015). A Survey Monkey questionnaire was designed to be disseminated alongside the video to measure its impact. After viewing the video, the public were invited to complete a questionnaire to establish the impact on their understandings of dementia. The video description contained a hyperlink to the questionnaire and information inviting members of the public to complete the questionnaire after viewing the video. The video and link to the questionnaire were disseminated through BU social media channels, and existing networks and mailing lists. Results were analysed in January 2015 using Excel. Closed ended responses were analysed in terms of frequency and percentage of the total number of respondents, whilst open ended responses were grouped thematically. To help achieve a higher response rate, the questionnaire was purposefully kept short, consisting of fifteen questions (five closed ended, two open ended and eight collecting demographic information).

## **Respondents**

Between May 2014 and January 2015 the video was viewed 1883 times, with 153 people responding to the questionnaire. This equates to a 12% response rate considered low for questionnaires (Mitchell 1985), giving rise to the risk of bias, unless it is can be proved that those who did not respond, did not differ from those who did (Bryman 2012). The low response rate may be for a number of reasons. Response rates to online questionnaires can vary in comparison to those sent in the post, as less time has gone into developing the 'motivational tools' to increase response, such as personalized introductory letters and follow

up postcards, and respondents might be concerned about the security of the data they provide over the internet (Kaplowitz, Hadlock and Levine 2004). We note that the link to our questionnaire was not clearly visible to people watching the video, due to the layout of the YouTube website. On reflection this may have hindered the response rate rather than bias.

The demographic characteristics of respondents are outlined in Table 1. Respondent's age group category ranged from 16-24 to 75+; however the majority (59.5%) were in the age group category 45-64, suggesting that this is an effective way to reach younger and older people. More females (81.7%) completed the questionnaire in comparison to males (15.0%), and most respondents were of White ethnic origin (83.7%). We anticipated that the locality focus would mean more people from Dorset would view the video, however the majority (77.8%) of respondents stated that they did not live, work or study in Dorset. This shows that the potential reach of social media is beyond geographical boundaries. It is therefore evident that a range of people with different demographic characteristics viewed the video and then completed the questionnaire. What will remain unknown are the demographic characteristics of the other 88% of people that viewed the video and did not complete the questionnaire. Ensuring that videos and other media are accessible to the population in general is therefore essential.

< Insert Table 1 about here >

### **Perceptions of dementia**

The findings suggest that respondents changed their perception of dementia after watching the video. When asked 'would you find it hard to talk to someone with dementia about their

personal experiences of living with the condition', 24.2% (n=37) of respondent's stated they would. After watching the video this number decreased to 14.4% (n=22) as shown in Table 2. Respondents with previous experience of dementia (either themselves or through someone else) were asked 'would you find it easier to talk about this experience to other people after watching the video', more than two thirds of the 130 respondents that answered this question stated that they would (68.5% or 89). When asked 'after watching the video would you be encouraged to access support from the wider community or BU, if you felt you needed that support', 88.9% (n=136) stated they would. Respondents were asked, if they felt portraying personal stories in a video format is a useful tool to raise awareness of dementia issues, 96.1% (n=147) stated they did, whilst the remaining 3.9% (n=6) did not respond.

< Insert Table 2 about here >

Respondents were asked: 'if you could use two or three words or a phrase to describe someone with dementia what would it be?' Responses to this question varied greatly, 39.2% (n=49) were positive, 45.6% (n=57) neutral, 13.6% (n=17) negative, whilst 1.6% did not respond. 19.2% (n=24) used positive words or phrases making an association between putting the person before their condition: 'the person is still inside'; 'an individual person with a life altering condition'; and 'remember the person'. A further 9.6% (n=12) gave other positive responses that emphasized the need for understanding more about dementia: 'it's not their fault'; 'in need of understanding'; and 'it affects everyone differently'. Whilst another 10.4% (n=13) responded positively that people with dementia are living for today: 'still alive/living'; 'focus on living'; and 'living in the moment'. Neutral responses, from 45.6% (n=57) of respondents, described typical characteristics of dementia: 'confusion, loss of memory'; 'lost and confused'; and 'challenging, misunderstood, changed'. Negative responses focusing on time were received from 4.8% (n=6) of respondents: 'running out of

time'; and 'fading away'. Whilst a further 8.8% (n=11) used negative descriptions such as: 'child like & confused'; 'lost soul'; 'vulnerable and trapped'.

### **Challenging stigma through personal stories**

The findings show that 96.1% of respondents feel that personal stories in a video format are a powerful way to raise awareness of dementia issues. Respondents who made additional comments about the video also stated:

'Great to have people expressing and sharing their views and experiences, really powerful and engaging way to put subjects over.'

'Enjoyed hearing the people talk about their own experiences.'

'The video was very effective simple honest and true. The video may be of great benefit with any courses or education relating to dementia training.'

This demonstrates that personal stories in a video format are a powerful way to challenge stigma that exists about dementia, through more open discussion about the condition:

'Very positive. Demystifies the condition.'

'Being more open makes it a lot less scary.'

'Encouraging! Particularly last phrase - all about the person not the condition.'

'I agree - it needs to be more open. More discussed and treated respectfully. It could be anyone of us!'

We therefore argue that this is a powerful way to raise awareness and challenge gaps in understanding about other health conditions that carry stigma, including disabilities.

Naturally this project has limitations. Not all responses were positive, as a minority used negative language to describe dementia. Some constructive criticism was also noted in the additional comments:

‘I’d like to see a video of each couple as they enter the next stages of dementia.’

‘Not all dementia patients will accept help or support as I have experienced I am my Fathers carer and he refuses any outside help.’

A limitation of this article is that we can only report on the responses we received to the survey, 153 people but a low response rate of 12% of the 1883 people that viewed the video in total. However, this data represents a first step towards evaluating the impact of using personal stories as a way to raise awareness of dementia, and other health conditions that carry stigma, including disabilities.

### **Television and disability studies: Making a difference together**

In summary, our analysis reveals that the public feel personal stories in a video format are a powerful way to raise awareness of dementia issues, and shows that members of the public changed their perception of dementia after watching the LWDDV (2014). This demonstrates the powerful impact of utilising the words, faces, voices and stories of people who are affected by conditions such as dementia or disabilities. There is of course a need to be sensitive and cautious of ethical issues when using personal stories. However, utilising the words, faces, voices and stories of people who are affected by conditions such as dementia or disabilities, can have a positive impact by enabling the public to understand what it is really like to live with these conditions. Without this kind of insight it is more difficult to see the

person before their disease or disability. The media therefore has a fundamental role to play in challenging negative stigma and stereotypes associated with dementia, or in fact any other health conditions that carries stigma, including disabilities. It is then, essential that professionals working within the media and television industry facilitate positive environments and attitudes to ensure that people with dementia or other health conditions feel they can participate as contributors and employees. The mutual contribution of television and disability studies is to enhance understanding about health conditions that carry stigma, helping to create diverse, equal, inclusive communities for all. Social media provides further opportunities for researchers to think outside of traditional academic approaches and use novel ways to disseminate research that extend to new and wide-ranging audiences (Lupton 2014). We therefore look forward to seeing how use of personal stories within the fields of television and disability studies continues to develop.

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**Table 1: Demographic characteristics of questionnaire respondents.**

<b>Variable</b>	<b>Frequency (N = 153)</b>
Age	
16 - 24	2
25 - 44	20
45- 64	91
65 - 74	28
75+	7
Non response	5
Gender	
Female	125
Male	23
Prefer not to say	2
Non response	3
Live, work or study in Dorset	
Yes	30
No	119
Non response	4
Ethnicity	
Asian or Asian British – Indian	1
Asian or Asian British – Pakistani	1
Black or Black British – Caribbean	1
Mixed Ethnic Background - White and Asian	1
Mixed Ethnic Background - any other mixed background	4
Any other Ethnic group - Any other group	6
White - British	60
White – Irish	11
White - Irish Traveller	1
White – Other	56
Non response	11

**Table 2: Talking to others about their personal experiences of living with dementia.**

<b>Would you find it hard to talk to someone with dementia about their personal experiences of living with the condition?</b>		<b>Response Frequency</b>	<b>Response Percentage</b>
Before watching the video	Yes	37	24.2%
	No	113	73.9%
	Non response	3	2.0%
	Total	153	100.0%
After watching the video	Yes	22	14.4%
	No	127	83.0%
	Non response	4	2.6%
	Total	153	100.0%