Developing awareness and understanding amongst mental health nursing students of the lived experience of dementia with the aid of selected first-person media resources

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Abstract
This study examines the influence that first-person media products (film, television, internet, books and newspapers) have upon promoting empathic understanding of the dementia experience amongst mental health nursing students. A designated mental health nursing learning group \( n = 36 \) was provided with a series of media products where personal dementia narratives were expressed. A grounded theory approach was used with focus group interviews conducted following each of the five designated media activities. This generated a variety of themes and concepts which were analysed in conjunction with responses from a subsequently distributed questionnaire and module evaluation. The first-person narratives were viewed as having a strong emotive impact upon students as well as promoting a broader understanding of how dementia impacts upon a person’s day-to-day life and the experience of family and carers. This facilitated the reframing of behaviours commonly considered ‘challenging’ with more of a person’s internal experience being recognised. A common concern, despite the stated value of these resources regarded the potential in becoming overwhelmed by informational and emotional content. This study highlighted the need for facilitators to carefully select first-person products with consideration shown to the expressiveness of narrators and the range and type of experience recounted. It also indicated the importance of adequately preparing students for what they were accessing and subsequently assisting them in processing the lived dementia experience. Whilst only accessing a small sample of narratives, all students expressed feeling better prepared for practice and having a more questioning and reflective approach towards the internal experience of those they were engaged with. This approach has much to offer.
from an attitudinal perspective and could form the base for training packages involved with
dementia learning, especially given the current drive towards person-centred, compassionate
and ‘caring’ practice. Further study in this area is required.

Keywords
cognitive impairment, dementia, grounded theory, nursing education, older people

Introduction

Each individual’s experience of dementia is unique and can be contextualised within their
personal frame of reference. What a person with dementia might be thinking and feeling
though can be very hard for others to comprehend, especially when communicative and
cognitive abilities are declining. This gives rise in practice to the potential for
misunderstanding and for care needs to be insufficiently met. The need for health care
practitioners to be more mindful about the needs and experiences of those they are
working with is strongly advocated within the Department of Health’s National Dementia
Strategy (Department of Health, 2009). It is the intention of this study to examine the
influence that first-person media products have upon promoting empathic understanding
of the dementia experience amongst mental health nursing students. Whilst a broad
spectrum of media types is involved, those featured in this study relate specifically to film,
television, internet, books and newspapers. The media products used were purposely chosen
for the breadth of personal experience and the types of narrative/‘story’ being related. They
illustrate the fluid states that can exist between vulnerability and resilience as well as ways in
which individuals and families are impacted upon. The examples listed below were selected
because of the range of experience being recounted, quality of discussions generated with
previous student groups and comments within module evaluations about their positive
influence upon learning.

- Feature film – *Iris* (British Broadcasting Company and Eyre, 2001). Based upon John
Bayley’s autobiographical account concerning his wife Iris Murdoch’s Alzheimer’s disease
and the impact it had upon them individually and as a couple. This film has a particularly
strong person-centred feel featuring a number of scenes exploring their lives pre- and
post-dementia.
- TV documentary – *My Life on a Post it Note* (Clough, 2006). Featured an articulate
woman with early-onset Alzheimer’s disease trying to maintain her independence in the
face of her steady deterioration and the concerns of her daughter and health care
professionals. It is a thought provoking and very emotionally impactful resource.
‘The Abnormal Changes so Far’ focuses upon the narrator’s day-to-day experiences and
contextual experience of dementia. This was chosen because of the clarity with which the
author contrasts his internal experience (thoughts and feelings) with his subsequent
behaviour and responses to others.
- Internet site – *Living with Dementia/Talking Point Forum* (Alzheimer’s Society). Guided
study offering students a range of personal accounts from individuals with dementia and
carers. This site contains a wealth of first-person narratives and discussion threads concerning day-to-day experiences.

- Newspaper article (Metro) *So near and yet so far* (Stevenson, 2007). Outlines a young woman’s experience and feelings about her father’s dementia. The important feature concerning this article is the broadening of the dementia experience to consider impact upon the wider family.

**Empathic learning and media resources**

The recent findings of the Francis inquiry report (Mid Staffordshire NHS Foundation Trust Inquiry, 2010) identified widespread institutional deficiencies and a poor caring culture being demonstrated in the services examined. We can also consider the Department of Health’s (2012) *Compassion in Practice* which advocates examination of what is meant by *caring*. The need for empathic, person-centred care for individuals with dementia is recommended by the National Dementia Strategy *Living Well with Dementia* (Department of Health, 2009). This reflects the work of Tom Kitwood (1997) and Naomi Feil (1997) concerning the importance of *tuning in* to an individual’s world and recognising something of their internal, *felt* experience. It illustrates the concept of ‘mindfulness’, a counter to the predominant medicalised perspective with which dementia care still endures. Students who are being trained within health care disciplines need to be aware of the reductive interpretations that can be associated with the medical model where pathology takes precedence to the person. Holistic care or approaches such as the social model encompass a wider range of issues and enhance the degree of person-centeredness applied to those being worked with. The importance of fostering mindfulness amongst mental health students concerns the development of a reflective care approach and the delivery of effective individualised care. This can be regarded through frameworks such as O’Connor and Seymour’s (1990) interpersonal model which illustrates the dynamics operating between two parties, in this instance health care practitioner and person with dementia. The importance of this is in being able to contextualise a person’s internal experience and better understand their external behaviour, for example reframing ‘aggressive’ behaviour as stemming from feelings of powerlessness, frustration or fear. Mindfulness in this instance means acknowledging their internal experience and conveying an understanding of this back to them. Compassionate care will only flourish when the whole person (rather than merely their pathology) is recognised.

The media provide a multitude of opportunities for individuals to learn about direct mental health experience with engaging and informative products to be found across all source types (Morris, 2006). Sieff (2003) outlines the media’s importance as a primary communicating agent with regard to mental health issues. This is supported by McQuail (2005) who outlines the potency of the mass media as a force for public enlightenment. The internet in particular offers individuals a range of resources for sharing experience and information through social networking sites such as Facebook and Twitter or online discussion forums which include the Alzheimer’s Society’s *Talking Point Forum*. Neil Hunt from the Alzheimer’s Society asserts that media products offer a valuable resource in helping to change attitudes and awareness about dementia (Coventry Telegraph, 2008). Media resources outlining experience from a first-person perspective provide us with
examples which can be impactful and enhance understanding and awareness about the lived and felt experience of dementia.

The use of media products complement what is learnt from other core sources including clinical practice, personal experience and related research. These other sources offer valuable learning potential although have their limitations. Students’ practice learning can be restricted to what is individually encountered during a defined timescale. It is also dependent upon the type of placement a student is allocated to (i.e. community, day service or residential care), available learning opportunities, the level of cognitive impairment/communicative ability encountered and the quality of reflective supervision offered by the clinical team. As a consequence, what is experienced and learnt will differ greatly from one student to another. Using media narratives allows experiences to be accessed collectively and reflected upon and discussed within the group, thereby facilitating the quality of learning being taken away (Morris, 2011). It has been noted that students commencing the dementia care component of their training relate varying levels of prior personal experience with some sharing very insightful comments concerning the dementia experience and its impact upon the family. It is notable that others report little or no personal experience. There is a wide range of research available documenting the dementia experience and with regard to the person with dementia includes aspects such as loss (Robinson et al., 2005), worthlessness (Steeman et al., 2007) and anxiety and depression (Bird and Blair, 2010). For the carer, it incorporates elements such as guilt and anger (Davis et al., 2011), stress/burden (Etters et al., 2008) and anticipatory grief (Holley and Mast, 2009). Whilst research articles and text books expound upon many facets of the dementia experience, it can sometimes be difficult to fully appreciate the emotional component or the contextual issues of actually living with this condition. When considering the felt experience of dementia, it becomes more clearly understood when placed in context and personalised through biographical narratives.

Methods

Developing person-centred, empathic approaches to working with individuals with dementia requires practitioners to have exposure to phenomenological, auto-ethnographic and other forms of personal lived experience evidence. This study provided mental health students with access to a range of first-person media narratives recounting aspects of a person’s lived dementia experience. Narrative communication allows service users and health professionals to understand and constitute illness experiences (Gray, 2009). This reflects Bruner’s (1991) view of narratives representing individuals’ personal and collaborative construction of reality. Narrative research utilises a range of qualitative methods including that of grounded theory. An example of this relating to media narratives involves Fleischmann’s (2005) thematic analysis through grounded theory of websites for parents of children with autism. A grounded theory approach was used with this study, concerning first-person narratives of the dementia experience, generating data through focus group interviews, questionnaires and module evaluations. Grounded theory provides opportunities to see beyond what seems obvious and progress towards more open and imaginative interpretations (Charmaz, 2006). Initial engagement and understanding amongst students was captured through a series of short focus group discussions which followed the accessing of each media product. This inductive phase generated a variety of themes and concepts which were analysed in conjunction with the questionnaire responses.
There was an initial open coding and categorisation of data following the focus group interviews with a selective coding and refining of categories after the questionnaires had been completed (Holloway and Todres, 2010). Further reflections were collected through specific responses from students in their evaluative feedback concerning the learning module.

A designated mental health nursing group containing 36 students was involved in this study. They were all at the time of the study in the second year of their training, on dementia care placements and undertaking a corresponding taught module. They had since the start of their programme been required by clinical placement availability to be divided into two sub-groups comprising 18 students each and taught separately. All students were deemed eligible and there were no exclusion criteria. This was felt to be a representative sample with students in these sub-groups matching the background and mix found in previous cohorts. It was a convenience sample utilising the most readily accessible participants for this study (Haber, 2010). Theoretical sampling was signified as no further variation was noted with the second sub-group of students (Wuest, 2007). Focus group interviews and completion of questionnaires occurred at the same point within the module for each sub-group, and no changes to content and design were made. Consent was sought from all participants. Full details about the study were provided, and anonymity and confidentiality were assured. Students were prepared for each of the five media activities through the provision of verbal instructions and opportunities for questions allowed. A corresponding worksheet was given in each instance to help guide reflection. A short focus group discussion followed each activity where engagement with the personal narrative was shared. The media products were evenly spaced and offered at two-week intervals. After all media products had been accessed, a more detailed evaluation was covered through the completion of a questionnaire and later module evaluation (for timeline, see Figure 1). Approval for this study was obtained through the University’s School of Healthcare Research and Ethics Committee. As a study it has a strong ethical orientation, encouraging students to see the person and not merely their condition. Information sheets detailing this study were given to all students and consent sought concerning inclusion with the questionnaires. All students were required to be included with the activities, focus groups and module evaluations as part of the learning programme. Anonymity within this study was assured.

The focus groups utilised a semi-structured interview process with questions contained in a guide outlining areas to be considered (see Appendix 1). A benefit of interviewing is the freedom offered to prompt for more information (Holloway and Wheeler, 2010). Questions covered the sub-types identified by Patton (2002) concerning experience, feeling and knowledge. Whilst Goodman and Evans (2010) recommend group sizes of between five and 12 members, in this instance the total group \( n = 36 \) were divided into two smaller groups with 18 students each. The students had already been together in these sub-groups for over a year and therefore were felt to be able to participate appropriately. As Holloway and Wheeler (2010) state, focus group interviews differ from individual interviews as members respond to the interviewer and fellow participants, stimulating debate about the topic. This was observed within the focus groups with some thought-provoking data collected.

A questionnaire to gather further data was offered at the end of the teaching module (see Appendix 2). This questionnaire was designed in collaboration with colleagues from both research and education backgrounds. Questions were then checked for readability and clarity with other tutorial staff. The use of questionnaires is regarded as a useful data collection method providing respondents with anonymity and enabling a wide range of
information to be gathered quickly (Bowling, 2002; Polit and Beck, 2010; Sullivan-Bolyai and Bova, 2010). The questionnaire design utilised a range of question types with some open and others using Likert scales. These focused upon respondents’ perceptions concerning the media resources accessed. Close attention was given to the questions which were structured along with colleagues’ comments. As Fain (2009) outlines, designing good questions that are easy to answer while focusing on the issues and information to be collected is essential to developing a good questionnaire. The questionnaire was completed by 32 respondents (four were absent on the day it was distributed) who are numbered (R1–R32) and listed anonymously. Strauss and Corbin (1998) outline the process whereby researchers differentiate between significant and less important data through developing provisional ideas and themes which are examined over time and confirmed by the data. This was carried out with the assistance of field notes and memo writing, a process outlined by Charmaz (2006) as enabling researchers to create robust categories through moving back and forth between emerging categories and data. Further feedback was gathered through module evaluation, with responses made to specific questions around the first-person narrative activities. These were broad questions aimed at ascertaining students’ thoughts about their exposure to these resources as well as what they found helpful and recommendations for further use.

**Results**

The two audio visual media types of TV and film featured most prominently (see Figure 2), concerning the emotional intensity of these products and the enhanced level of understanding promoted. The added components of spoken dialogue and music were highlighted by students as helping to engage them with individuals featured on screen.
The film Iris was very moving and sad. However it helped me to develop an understanding and appreciation of the experience of individuals with dementia. (R7)

The importance of emotive engagement is that it evokes the psychotherapeutic concept of ‘here and now’ (Inskipp, 2000), illustrating the immediacy of what is experienced and a real feeling of involvement with those featured. This demonstrates Horton and Wohl’s (1956) parasocial relations with recipients feeling emotively connected with those featured. In this study, the majority of students noted an enhanced appreciation of the person residing within the condition of dementia and their changing relationships. It reflects Kitwood’s (1997) concept of personhood and acknowledges the wider context of dementia as a societal problem (embedded in social relations) rather than a condition that merely affects individuals. This was an important connection for students to consider concerning influences from family, carers and the social environment.

A frequently commented upon theme related to a person’s ability to cope, with polarised aspects such as struggling and coping well both featuring strongly. Media examples featuring people living positively with dementia were seen as thought provoking with attention directed more towards what individuals can do as opposed to the more frequently considered can’t do.

I found this documentary both humorous and sad as it showed how dementia can affect somebody positively. It was refreshing to get a more positive insight into the lived experience.
experience, whilst taking into account the more challenging effects on family and independence. (R11)

The personal ‘story’ recounted in examples such as this refocuses the dementia experience away from the more commonly depicted tragic narrative. In other words, life can be good sometimes even with dementia. This perspective was developed further through the identification of strong personal characteristics being held by some people with dementia. Comments in particular centred upon the woman in the documentary with terms such as ‘resilient’, ‘humorous’ and ‘engaging’ being used. Likewise, students reading Robert Davis’ book chapter admired his firm determination to cope positively with life despite facing increasing limitations. Examples such as these bring to life the National Dementia Strategy’s (Department of Health, 2009) and the Alzheimer’s Society’s notion of *Living Well with Dementia*.

The written narratives in particular were acknowledged by students as containing depth of expressiveness concerning personal thoughts and feelings. This was valued as helping to appreciate more fully the person’s internal world.

It was good learning from someone with the disease and how they felt and dealt with it. (R15) Showed feelings and emotions surrounding early onset dementia, including anger towards the illness and people’s concepts towards it. (R1)

There was a sense conveyed by students about having greater insight about the impact that dementia has upon a person’s life. This helps to contextualise theoretical aspects by relating them more meaningfully to individuals’ felt experience. There was a broad consensus amongst students that ‘challenging behaviours’ need reframing and acknowledging from a person’s internal perspective which supports Feil’s (1993) assertions of there being reasons behind all disoriented behaviour. There are many practice implications here with feelings such as frustration, fear and helplessness being recognised and responded to instead of merely a person’s observed behaviour (Morris and Morris, 2010). This was recognised by students in the need to attend more fully to the internal ‘drivers’ behind a person’s behaviour.

A further issue of importance concerning the variety of narrative perspectives featured was the hearing of relatives’ ‘stories’.

This article was an eye-opener. It was refreshing to see the frustration and guilt the family were feeling as well as the person with dementia. (R23)

Many other responses supported this statement illustrating the need to broaden understanding to encompass the impact that dementia has upon the whole family group. Whilst breadth of experience was valued, an interesting problem identified by students concerned levels of saturation with information and emotional overload being reached. The internet in particular with its vast array of resources was regarded by some students as daunting concerning the amount of material available.

Although insightful I did find this a lot to digest in one session. As a point of reference though it is excellent. (R12)

Was really good but too much information to be read at once. (R22)

These responses highlighted the need to carefully structure the students’ experience, as whilst they were directed towards specific discussion threads the temptation to browse further was...
Media resources accessed on this module have made you more appreciative of a person’s internal experience (thoughts and feelings) with regard to people you have been engaged with in clinical practice.

![Bar graph](https://example.com/bar-graph.png)

**Figure 3. Understanding internal experience.**

The feeling of overload also concerned prolonged exposure to distressing narratives.

It is always sad to read someone’s personal experiences of any illness, but with reading I just get to the point of saturation. (R5)

Whilst the thoughts and feelings within personal narratives can be enormously thought provoking, consideration clearly needs to be given to students’ overall experience of immersion within content which is distressing. Potential problems here would involve becoming detached and distant from individuals’ internal experiences.

A particular point of interest concerned students’ deeper levels of critical reflection as dementia learning progressed. This related to their progressive exposure to the first-person media products during the course of this study as well as those they had accessed before.

I had watched this film before knowing about dementia and it didn’t make sense then. Very educative, informative and eye-opener. (R8)

This reflects Kolb’s (1984) experiential learning cycle with deeper levels of understanding being generated through successive reflective episodes. The notion of interpretative recipient is reflected here illustrating how perceptions can be modified in light of on-going learning and experience. It also acknowledges the quality of the facilitated learning experience which enabled students to become ‘tuned in’ to specific elements. The process of accessing the selected media narratives was regarded as helpful with all participants agreeing that it had made them more appreciative of a person’s internal experience of dementia (see Figure 3), with specific comments reflecting the need to recognise the person within the condition.
Discussion

A key aspect concerns the emotive impact that personal narratives can have upon those accessing them. This relates particularly to the audio-visual media types (film and television) which appear from students’ feedback to have been the most influential. It can be regarded through Gestalt theory which illustrates a process of figure and ground whereby certain components from our perceptual field stand out and become more noticeable (King and Wertheimer, 2005). This can be related to the influence of emotive learning upon memory which is enhanced for central details and impaired for peripheral ones (Shafer et al., 2011). It operates at various stages of the retention and consolidation process, with emotive arousal increasing what is retained (Christianson and Engelberg, 2006; Laney et al., 2004). From this, we can reflect upon the process of exposing learners to material which is rich in expressive and emotive content. This was commented upon as impacting upon and helping to shape their resultant understanding. Whilst this claim would warrant further testing, the heightened attention upon lived experience offers students a valuable point of reference when engaging in practice. This was indicated in subsequent discussions when processing and reflecting upon media examples with students. The television documentary for example challenged a number of previously held ideas and understanding about ‘dementia sufferers’. What they witnessed was a multi-faceted view of a woman’s dementia experience. Whilst she had periods of despair (including thoughts of suicide), she also expressed herself with a great deal of warmth and humour and demonstrated on the whole a sense of living positively with her deteriorating condition. This prompted further thoughts and discussion amongst students around the theme Living with Dementia which is notably addressed by the Alzheimer’s Society and the National Dementia Strategy (Department of Health, 2009).

Students commented upon enhancements in awareness and learning concerning a person’s internal dementia experience. This reflected a development of insight whereby a range of ‘challenging’ behaviours were newly reframed and understood. What became evident during this process was the need for guidance, helping students to prepare for the media products accessed and subsequently to reflect upon and process new learning generated. Ausubel’s (1968) assimilation theory highlights the importance of initial input in helping to prepare learners for accessing new material. This was facilitated through the provision of introductory input (classroom tutorials and reading material) concerning the dementia experience. Worksheets were provided for use with each media resource helping students to tune in to salient aspects and acknowledge the significance of what they were looking at. This was followed by opportunities for personal reflection and classroom discussion. This approach relates to Kolb’s (1984) experiential learning cycle where reflection upon experience allows new concepts to be formed which can subsequently be tested out in practice. The reflection upon media products (experience) promoted discussion around a range of themes, a core aspect concerning the appreciation of internal experience and its influence upon external behaviour (O’Connor and Seymour, 1990). This enabled students to begin reframing some of the commonly observed ‘challenging’ behaviours. The biographical narrative (book chapter) accessed was cited as being particularly helpful in enabling underlying emotions and thoughts to be glimpsed. It highlights a particular strength of this media type whereby first-person narratives offer readers a view of a person’s inner world through the perspective of inside looking out (Morris, 2006). This reflects Lothe’s (2000) assertion of the reader becoming active within the body of writing. We can also regard Genette’s (1995) concept of internal focalisation where narrative is recounted through the consciousness of a character (factual or fictional). This enables a degree of identification and helps to promote empathic learning. The
importance here is the ability of learners to subsequently question what they are encountering in practice, including the observed behaviours of those with dementia and their family/carers. This would help decrease the use of less appropriate interventions, i.e. automatically offering sedative medication for agitated behaviour and instead promote responses which meet the internal needs and well-being aspects of those concerned.

A potential difficulty with accessing personal narratives involves becoming overwhelmed and needing to withdraw from what is being accessed. It concerns two particular components, informational and emotional content. With regard to the latter, there were some very clear comments from students stating how sad certain media products made them feel. Whilst this can promote impactful learning, feeling oversaturated is likely to evoke distancing responses or dissuade engagement with further examples. The process of empathy requires individuals to ‘connect’ and engage with another’s felt experience. The problem though relates to the degree of distress that individuals can remain with before becoming emotionally overloaded and needing to psychologically distance selves (Gladstein, 1983; Haugh and Merry, 2001). Saturation also related to informational content with internet resources being specifically commented upon. The proliferation and scope of available material on the internet can easily cause information overload (Cooke, 2001; Scrivener, 2002). Particular mention was made about the Alzheimer’s Society’s Talking Point Forum to which students were directed. This has over 25,000 discussion threads and 300,000 individual posts. The problem of overload was minimised in this instance by offering clear guidance restricting them to designated examples and asking them to comment solely upon the experiences posted. What is evident is that students can quickly become overwhelmed by both informational and emotive components. The need is to facilitate what is being accessed and learning that can be taken away. Over saturation will mean the impact factor becomes diluted and the process can become stressful and wearisome. There is a need therefore to attend to the amount of first-person narrative material offered to students as well as the available timeframe for accessing it. Guidance and support is needed to prevent feelings of saturation.

Given the above discussion points of emotive impact, learning potential and saturation concerns, there is a significant issue concerning that of media selection. One factor clearly related to is that of the expressive ability or charismatic appeal of the narrator. Other issues concern source types with some more captivating and engaging than others. Audio-visual resources were clearly seen as being the most emotively impactful with comments about the realness of the experience and the opportunity to live the moment along with the narrator adding potency. Written narratives offered depth in terms of expression concerning the person’s thoughts and feelings. This helped reframe and appreciate experience from another’s internal frame of reference. It is essential to recognise though that each first-person media example is unique, reflecting Kitwood’s (1997) assertion that there are as many types of dementia as there are people with dementia. What appears to be particularly significant with regard to first-person dementia narratives is the difference in the types of experience recounted. ‘Stories’ reflect an ever-changing view with both resilience and vulnerability featured. Narratives might feature heroic figures coping valiantly or overburdened individuals struggling to cope. Each person has their own unique story to relate with the totality of narratives representing an ever-changing plateau featuring both highs and lows. There is a need therefore to help students appreciate this point and to not ‘fix’ their understanding based upon a restricted sample of experiences. Therefore, sufficient breadth of narratives is needed featuring experiences of coping and struggling, different stages of the condition, as well as the perspective of the person with dementia and...
family members. Different types of media source offer further variety and examples other than those used in this study can certainly be considered, i.e. works of art/paintings, poetry, radio programmes, songs and plays. This is all complemented through opportunities for reflection and processing of what is being accessed to maximise learning potential.

**Conclusion**

The results of this study highlight the value of accessing first-person narratives in terms of broadening understanding and heightening appreciation of the lived dementia experience. Whilst individual narratives cannot simply be generalised to fit a wider range of experience, accessing first-person accounts can help those involved in health care to become more questioning and mindful when working in practice. The study being reported here is only based upon a small number of mental health nursing students although indicates a valuable learning potential of using first-person media accounts within dementia care learning. Its use in practice could also be considered by students and clinicians across a wide range of educational and service establishments forming a core component of dementia care training. There are a number of issues for educationalists to bear in mind though when selecting such resources including type and range of examples. These can be chosen for their expressive potential, range of perspectives and content. It is important to sufficiently prepare students for what they are being exposed to with opportunities to reflect upon what is being learnt and experienced. The potential problem from saturation needs to be considered with adequate opportunities for students to break off and process what they accessing. Appropriate levels of support and supervision from teaching personnel are needed given the acute level of emotional resonance such resources can have. It is not intended for this approach to be carried out in isolation but to be offered as a complementary learning resource, alongside related clinical practice placements. As well as helping to develop understanding, this approach has much to offer from an attitudinal perspective. With the current drive towards person-centred learning and service-user involvement, it is essential that practitioners are more mindful and aware about the internal world of those they are working with. This helps us more effectively develop partnerships with individuals experiencing dementia and carers. Further study in this area is clearly needed with a larger number of students accessed as well as continued evaluation of the learning impact from using these resources.

**Key points for policy, practice and/or research**

- Audio-visual resources have the potential to engage recipients very powerfully on an emotive level.
- Written narratives offer a deep level of engagement with narrator’s thoughts and feelings.
- First-person narratives help recipients better understand internal experience and reframe observed external behaviours.
- Facilitators need to be mindful of the potential for over saturation amongst students of lived experience material.
- Support for students is needed before, during and after the accessing of first-person narratives.
Declaration of conflicting interest

None declared.

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References


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Appendix 1 – Focus group questions

(1) How did you feel about accessing this media product?
(2) What did you like about this media product?
(3) What did you not like about this media product?
(4) How was your understanding about the lived experience of dementia enhanced through accessing this product?
(5) Do you have any further comments about this experience?

Appendix 2 – Questionnaire

Developing awareness and understanding of the lived experience of dementia with the aid of selected first-person media resources

(1) Please comment upon how your understanding of the lived experience of dementia has been influenced through your exposure to the following media sources:

- Film – Iris
- TV documentary – My Life on a Post it Note
- Book Chapter – My Journey into Alzheimer’s Disease (Robert Davis)
- Internet guided study (Alzheimer’s Society)
- Newspaper article (Metro)
(2) Please indicate in rank order, your most impactful media example, putting 1 next to the most impactful through to 5 for the least impactful

(1 = highest; 2 = second highest; 3 = third highest; 4 = fourth highest; 5 = lowest)

<table>
<thead>
<tr>
<th>Media source</th>
<th>Allocated rating</th>
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<tbody>
<tr>
<td>Film – Iris</td>
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<tr>
<td>TV documentary – <em>My Life on a Post it Note</em></td>
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<tr>
<td>Book Chapter – <em>My Journey into Alzheimer’s Disease</em> (Robert Davis)</td>
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<tr>
<td>Internet guided study ([Alzheimer’s Society])</td>
<td></td>
</tr>
<tr>
<td>Newspaper article (Metro)</td>
<td></td>
</tr>
</tbody>
</table>

(3) Please comment on what made your highest rated choice the most impactful for you

(4) Media resources accessed on this module have made you more appreciative of a person’s internal experience (thoughts and feelings) with regard to people you have been engaged within clinical practice?

PLEASE CIRCLE THE TERM WHICH MOST APPLIES

Strongly agree  Agree  Neither agree nor disagree  Disagree  Strongly disagree

(5) With regards to your response in question 4, can you give an example from practice

(6) What else, besides the selected media resources accessed on this module, has influenced your understanding of the lived experience of dementia

Many thanks for taking the time to complete these questions