The influence of sensory stimulation on leisure engagement by individuals with Neuropalliative Conditions

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Abstract

This article describes a multiple, single-case design study and uses an occupational science focus to explore engagement with a filmshow and an "Interactive Video" installation by participants with neuropalliative conditions. Data was collected using the Individual Child Engagement Record with 14 participants (who had Barthel scores averaging 7/100). The time-sampled observations of engagement showed a significant difference between the scores for the control condition, engagement in a passive spectator role at a filmshow and engagement in a potentially active role at an "Interactive Video" session. The Control condition involved doing nothing in a room with very limited sensory stimulation. The Passive video projection involved a group of residents watching a filmshow of their choosing, on a large screen in a cinema like atmosphere. The potentially active "Interactive Video" installation combined video and motion detection to enable participants to influence the projection, giving the sense that they are moving through the artwork and therefore part of it. The results showed a difference in the participants' engagement across the cases. Therefore, passive film watching role appears to be less engaging while the potentially active role offered by the "Interactive Video" installation appears to offer an engaging use of free time for participants with neuropalliative conditions.

Introduction

Neuropalliative conditions (Turner-Stokes et al 2007) include rare conditions such as Locked in Syndrome or Huntington's Disease. They also include common conditions in their advanced stages such as Parkinson's Disease or Multiple Sclerosis. These conditions may result in a combination of physical, cognitive, perceptual, communication, sensory and awareness limitations, resulting in profound levels of disability. The associated sensory gating deficits (Arciniegas et al 1999) may leave the individual unable to filter out irrelevant and excessive information. As a result the individual may experience sensory overload, which may impact upon their ability to engage (Howell 1999) in leisure. This may lead to living life through others (Hocking 2000), taking on a passive/ spectator role (Nelson & Gordon-Larson 2006), and to occupational deprivation (Wilcock 2006, Whiteford 2004); hence this study.

Human occupations include any activity in which a person is engaged i.e. looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (CAOT 2008). However, for individuals with neuropalliative conditions, opportunities for engaging in occupations are limited by their performance

capacity, motivation, or sense of well-being (Nilsson 2006). Occupational science postulates that occupational deprivation (Whiteford 2004) and its negative effects on health & well-being, are the opposite of (and arguably may be reversed by) engagement in occupations such as leisure (Wilcock 2006). Therefore, this study focuses on engagement in leisure occupations. The profound limitations experienced by the participants in this study rendered them unable to 'participate' and therefore occupationally deprived, by their profound and permanent or progressive disability.

The participants of this study were profoundly disabled individuals who were totally dependent on supporters for their self care; had limited opportunities for productivity and usually focused their engagement within the domain of leisure. They all attended each of the cases observed as a group. A lack of leisure engagement may limit the re-establishment of pre - disability quality of life. Therefore, the residential care facility studied provided opportunities for engagement through casual leisure opportunities (Fenech & Baker 2008, Stonier 2008) such as engagement in a potentially active role at an "Interactive Video" session and engagement in a passive spectator role at a filmshow. Casual leisure is enjoyed in the moment, being immediately and intrinsically rewarding and requiring little or no skill to enjoy (Stebbins 1997). However, individuals with neuropalliative conditions experience many barriers to leisure engagement (Fenech 2008).

This study gained ethical approval from the University of Roehampton and the Director of Clinical Services of the facility. Those who participated gave written consent; the protection of vulnerable adults (POVA) policy was adhered to including collecting the minimum data possible, using only one neuropalliative experienced observer at a time, without video usage. During both experimental cases the participants were accompanied by familiar supporters. Additionally, no individual was excluded from, or included in "Interactive Video" sessions because of the study.

Yin (2009) defined multiple, single-case studies as being made up of separate 'experiments', having a replication logic across a number of separate instances, giving a meta-perspective on an issue (Stewart, 2012). Case-based methodologies can explore a particular phenomenon in a case such as an individual, a group, a process, or an event, where the phenomenon and its context overlap (Yin, 2009). In this instance the research question addressed was "Does occupational engagement alter with different numbers of sensory modalities?". Multiple, single-case studies allow the researcher to consider variables (such as engagement), incorporated within a single case (a leisure occupation) engaged in by a group (n=14). In this instance each case varied in terms of its sensory components.

Method

Observations of engagement (using a single marginal participant observer and a structured observation format) were made in accordance with the facility's philosophy of non-intrusion and its POVA policy. The latter limited the number of observers, and precluded the use of video recording (where the individual could be identified) for research.

This study involved the comparison of a control condition with engagement in a potentially active role at an "Interactive Video" session and engagement in a passive spectator role at a filmshow (described in the cases section above table 1). Because the

observations were of casual leisure satisfaction, data were gathered during each single (non-replicable) short-term experience (Stebbins 1997). The uniquely profound nature of the participants' disabilities and the small sample size mean that the findings are unlikely to be generalisable beyond neuropalliative conditions. These data form part of a larger study comparing the control condition with 7 different casual leisure occupations with different numbers of sensory components (Fenech 2009, Fenech 2010, Fenech 2012). Each control to case comparison study will act as a pilot study for a multi-centre study.

Participants

The participants (n=14) were residents of a facility (none of whom were undergoing rehabilitation), with profoundly disabling neuropalliative conditions, who consented to participate in the study. They were aged between 22 and 74 ($\bar{x}$=47); 5 were men and 9 were women.

According to Gupta et al (2004), the categories of ability with regard to activities of daily living include:
Independent (modified Rankin Scale [mRS] 0–1; or Glasgow Outcome Scale [GOS] 5; Barthel Index [BI] 90);
Mild disability (mRS 2; or GOS 4; Barthel Index 85);
Moderate disability (mRS 3; or GOS 4; Barthel Index 60);
Severe disability (mRS 4–5; or GOS 2–3; Barthel Index < 60);

The modified Rankin Scale (mRS) is a scale for measuring the degree of ability in daily occupations of people with a neurological disability, and is therefore a clinical outcome measure for stroke clinical trials.

The 'Glasgow Outcome Score' (GOS) is a scale measuring the degree of recovery after brain injury.

The Barthel index measures performance in activities of daily living, with the score achieved being assigned to a level descriptor.

The Katz Index of Independence in Activities of Daily Living, measures occupational performance, among older adults in a variety of care settings. The Index ranks performance in six domains of ADL.

The average mRS score of the study participants was 6, Barthel score was 7/100, whilst the average Katz score was 1/6 and thus was lower than Gupta *et al's* description of severe disability. Therefore, the term used throughout the article is that they experienced profound levels of disability.

Data Collection

The study was carried out using momentary time sampling (for 1 minute, every 5 minutes). This involved observations of engagement using the Individual Child Engagement Record (ICER) (Kishida & Kemp 2006) for each of the 14 participants, for 45 minutes per case. Data collection was conducted by a single marginal participant observer and with the same participants in all 3 cases.

The small sample size and the use of a single observer without video recording backup compromised the reliability of the data whilst complying with the facility's POVA policy. The reliability of the data was improved by ensuring that the observer understood the definitions of engagement provided in the ICER, and had used the measure of observed engagement with other leisure opportunities (Fenech 2009, and 2010) previously.

Data collection tool

The Individual Child Engagement Record (ICER) (Kishida & Kemp 2006) measures engagement of profound and multiple learning disability of persons who cannot report their own experience and so ideal for use with a population with such complex needs. The participants' engagement was observed during a control condition, engagement in a potentially active role at an "Interactive Video" session and engagement in a passive spectator role at a filmshow. This produced 140 data points per case (see table 2a & 2b & 2c). The ICER includes five engagement codes:

Active engagement - **participates actively** by **interacting** with the environment **appropriately/ manipulating materials or vocalising**.

Passive engagement - **interacts** with the environment **without manipulation** or vocalisation.

Undifferentiated engagement - **interacts** with the environment **automatically** i.e. in a repetitive manner.

Passive non-engagement - **does not interact with the environment/** do what is expected during the activity.

Active non-engagement - **interacts** with the environment in an **inappropriate manner** by manipulation/ movement and/or vocalisation.

The Cases

Table 1 presents the sensory modalities which were present in each case.

Table 1: Comparison of the sensory content of the occupations observed

Occupation	Control Group	Watching a Film	Video Interactive installation
Smell			
Hearing	?	✓	✓
Taste			
Touch/ temperature			
Seeing	?	✓	✓
Proprioceptive			?
Vestibular			✓
Minimum senses	0	2	3
Maximum senses	2	2	4

Note: (key ✓ =definitely/ for all, ? = possibly/ for some)

Each case will now be described:

The Control condition was set in a large first floor day room in the early afternoon, with the curtains closed, before a live performance was due to start, and with no staff present. There was no background noise coming from other rooms or from outside the windows. The only person present other than the residents was the researcher who was purposefully moving very slowly and quietly so as not to disturb the residents. None of the residents was moving; many could not move or eat and drink without assistance, which was not offered, due to aspiration risks. Despite the low engagement from staff, special consideration was given to those who were at risk of fitting, choking or respiratory distress, even when doing nothing. There were no novel or unusual olfactory stimulations. The participants could have habituated to the touch from clothing or equipment. Occasionally a resident would move their head to look around if they were able and this would offer some vestibular stimulation. Proprioceptive stimulation was

limited due to poor motor control. The room was not in total darkness and so residents with good eyesight would have been able to make out items in the room.

The participants had no performance demands made of them. This "waiting mode" was a state of occupational vacuum experienced on a regular basis due to their inability to seek stimulation without assistance. No resources, tools, materials or equipment were required during the control condition. To collect the data during this activity the researcher sat where each participant was observable unobtrusively. Table 2a shows the level of engagement of participants (rows) at time intervals (columns) of 5 minutes.

The Passive video projection: watching a filmshow occurred in a large public space, with no discernible odours, and which had a large screen at one end and low lighting. Participants had voted for which film to watch as a group the month before. Supporters accompanied participants to facilitate their engagement with the film. The case offered hearing and visual stimulation. The occupational performance demands of the case included tolerating and maintaining a sitting position, watching and listening to the film, understanding the film and following the plot, and non-disturbance of others. The precautions and contraindications for the case included selecting films that did not have the potential to cause epileptic fits. The "cinema" door was closed to reduce external stimulation. Therefore, the only noise and sights were from the film, which was played at a comfortable level for participants, but without being audible outside. Each participant was sitting in his or her own chair. They were probably aware of furniture and clothing prior to habituation. For this study, participants sat further apart than usual to isolate them. Most of the participants remained stationary while watching the filmshow, thus they experienced very little vestibular or proprioceptive stimulation.

The filmshow occurred against a background of habits, routines, and roles. The participants' role during the film was that of a physically passive absorber of stimulation, linking interests and roles, e.g. continuing an interest in classical music. The participant could have attended the filmshow routinely, or be continuing to watch part of a series of films, and so what they experienced could continue from the past and into the future. The data was collected from each participant in turn, during the same performance. The film could orientate or disorientate participants, depending on the topic and their ability to distinguish fact from fiction. Each participant watching the film varied in his or her personal, cultural, spiritual and clinical context.

The occupational demands placed upon a participant included having sufficient sitting tolerance for the duration of the film. Participants generally tried not to talk during the film so as not to disturb each other, but communication was required to discuss the film with others, or if they needed assistance. Socially acceptable behaviour in this context, involved sitting still and quiet whilst watching the film. Participants required sufficient cognitive ability, attention and concentration to be able to understand the film and follow the plot. The spatial demands of a filmshow included having space for attendants to manoeuvre wheelchairs or for participants to manoeuvre their own wheelchairs if possible. The room was at a comfortable temperature for non-mobile participants. Their choices and informal discussions of the film (afterwards) could have enhanced the participant's knowledge. The film lasted for two hours and

ten minutes, so the observations ceased after forty-five minutes. On the occasion that the observations were conducted the researcher was seated, facing the group and able to see them all. Table 2b shows the level of engagement of participants (rows) at time intervals (columns) of 5 minutes.

The potentially active "Interactive Video" Installation detected movement, enabling participants to interact with images projected on the floor and wall. There were two layers to each projection, the lower layer being a static image and the upper layer being a selection of small images that responded to movement. The projections used led to a trail of sparks in the participant's wake, autumn leaves scattering when touched, or ripples which move as if in a pool of water. On arriving, participants became aware of the reaction of the projection to movement. This installation offered participants the potential for auditory, visual and vestibular stimulation, and for some, proprioceptive stimulation. The case occurred in a big public space but with the door closed to reduce stimulation from outside. The participants could hear the sounds and music generated by the video projection in response to their movements. The participants were without food and drink during the case, and so may not have been experiencing any tastes at this time. There were no ambient smells, or noises and the room was at a comfortable temperature for non-mobile participants. Furthermore, the likelihood of detecting touch sensation in response to movement with in wheelchairs and clothes was reduced by the participant's limited mobility. The "Interactive Video" projection occurred in a darkened environment. The projection of their movements, special effects and patterns was shown on the wall and floor screens. Some participants could move their arms and legs to experience proprioceptive or vestibular stimulation. This case encouraged intergenerational leisure (Downs, 2008) since it appeared to also interest their visitors, which could have influenced engagement, although visitors would have been welcome at all the cases. Because this was a novel case, removing the social element to this case could have greatly influenced engagement.

The performance components required included the participant moving across the screen or mat, watching the floor or wall screen and making suggestions about how to move the wheelchair. The precautions and contraindications for the case included selecting a projection that used no strobe lighting effects, and therefore would not cause a participant to fit. The floor mat was large enough to allow several participants sufficient turning area to avoid collisions. The selected projections were age and gender neutral. The behavioural demands of the case included behaving in a socially acceptable but playful manner. The cognitive demands of the case included realising that their movements caused the alterations to the projection. Supporters, projection equipment and software, screen/mats and an audio system were required for the case to run smoothly. All the participants observed were able to influence the installation e.g. by directing supporters about how to move the wheelchair. Attention to the projection assisted the maintenance of concentration throughout the case. Their choices and discussion of the case could have enhanced the participant's knowledge. Communication could be required to direct wheelchair attendants or discuss the case. The participants' role was to stimulate the projection to react to their movements. For some, the installation stimulated their interest in or experience of other large celebratory events, computers, fireworks, autumn leaves, and/or water.

The installation was available to participants for ninety minutes in total, on a drop-in basis. Observations took place for the first forty-five minutes once the participant had understood how to engage with the case. The rejection of data from participants who used the installation for fewer than forty-five minutes enabled comparison of occupations and engagement of equal durations. On the occasion that the observations were conducted the researcher was seated, facing the group and able to see them all. Table 2c shows the level of engagement of participants (rows) at time intervals (columns) of 5 minutes.

Results

Table 2a: Data from the control condition

	Minute 1-2	Minute 5-6	Minute 10-11	Minute 15-16	Minute 20-21	Minute 25-26	Minute 30-31	Minute 35-36	Minute 40-41	Minute 45-46	Median	Average for each participant
	2	2	2	2	2	2	2	2	2	2	2	2
	2	2	2	2	2	2	2	2	2	2	2	2
	2	2	2	2	2	2	2	2	2	2	2	2
	2	2	2	2	2	2	2	2	2	2	2	2
	2	2	2	2	2	2	2	2	2	2	2	2
	2	2	2	2	2	2	2	2	2	2	2	2
	2	2	2	2	2	2	2	2	2	2	2	2
	2	2	2	2	2	2	2	2	2	2	2	2
	2	2	2	2	2	2	2	2	2	2	2	2
	2	2	2	2	2	2	2	2	2	2	2	2
	2	2	1	2	2	2	1	2	2	2	2	1.8
	2	2	2	2	2	2	2	2	2	2	2	2
	2	2	1	2	2	2	2	1	2	2	2	1.8
	2	2	2	2	2	2	2	2	2	2	2	2
Time sample average	2	2	1.9	2	2	2	1.9	1.9	2	2		

Table 2b: Data from Watching a Filmshow

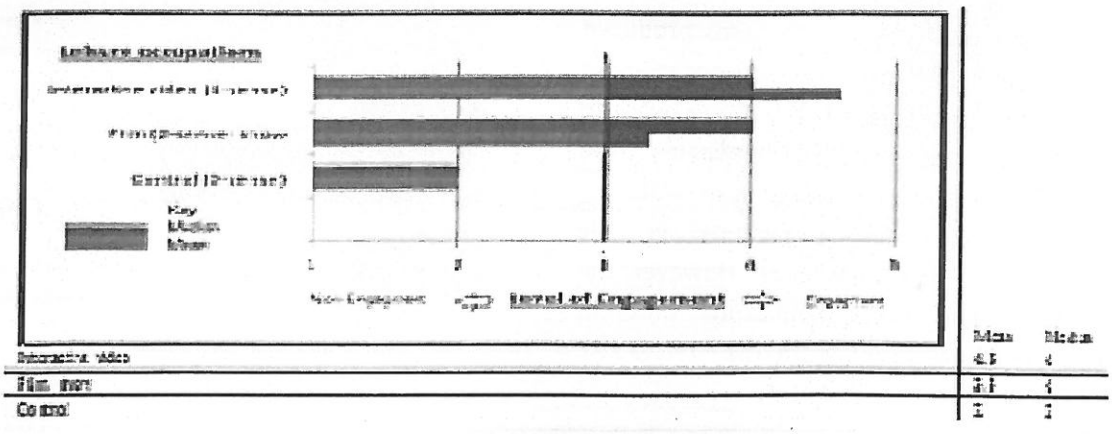
	Minute 1-2	Minute 5-6	Minute 10-11	Minute 15-16	Minute 20-21	Minute 25-26	Minute 30-31	Minute 35-36	Minute 40-41	Minute 45-46	Median	Average for each participant
	4	4	4	4	4	4	4	3	3	3	4	3.7
	4	4	4	4	4	4	4	4	4	4	4	4
	4	4	4	4	4	4	4	4	4	4	4	4
	4	4	4	4	4	4	4	4	4	4	4	4
	4	4	4	4	4	4	4	4	4	4	4	4
	4	4	4	4	4	4	4	4	4	4	4	4
	4	4	4	4	4	4	4	4	4	4	4	4
	4	4	4	4	4	4	4	4	4	4	4	4
	4	4	4	4	4	4	4	4	4	4	4	4
	4	4	4	4	4	4	4	4	4	4	4	4
	4	4	4	4	4	4	4	4	4	4	4	4
	4	4	4	4	4	4	3	3	3	4	4	3.7
	4	4	4	4	4	4	4	4	3	3	4	3.8
	4	4	4	4	4	4	4	4	4	3	4	3.9
Time sample average	4	4	4	4	4	4	4	4	4	4		

Table 2c: Data from the potentially active video installation session

	Minute 1 - 2	Minute 5-6	Minute 10 - 11	Minute 15 - 16	Minute 20-21	Minute 25 - 26	Minute 30 - 31	Minute 35 - 36	Minute 40 - 41	Minute 45-46	Median	Average for each participant
	4	5	5	5	5	5	5	5	5	5	5	4.9
	4	5	5	4	5	5	5	5	5	5	5	4.8
	4	4	4	4	4	4	4	5	5	5	4	4.3
	4	4	4	4	4	4	4	5	5	5	4	4.3
	5	5	5	5	4	5	5	5	5	5	5	4.9
	5	5	5	4	4	5	4	4	5	5	5	4.6
	5	4	5	4	4	4	4	4	4	4	4	4.2
	5	5	5	5	4	4	5	5	5	5	5	4.8
	4	4	5	5	5	5	5	5	4	4	5	4.6
	5	5	5	5	5	5	5	5	5	5	5	5
	4	5	5	4	5	5	5	5	5	4	5	4.7
	5	5	5	5	5	5	5	5	5	5	5	5
	4	5	4	4	4	4	4	4	4	4	4	4.1
	4	4	4	4	4	4	4	4	4	4	4	4
Time sample average	4	5	5	4	4	5	5	5	5	5		

Figure 1 shows the Mean and Median participant engagement in each of the cases and the control condition based upon the median scores of each participant from each 45-minute session observed. Table 2 presents the raw data (140 data points per case). The levels of engagement for the Control condition appear to be substantially lower than for the other cases. It would also appear that the mean level of engagement in leisure cases increases as number of sensory modalities increases. The findings from the Friedman test confirmed that there was a significant difference between the engagement scores across the different cases (x^2=74.8; df=7; p<.001).

Figure 1: Mean and Median participant engagement levels.



Key to the engagement scores:

Active non-engagement	1
Passive non-engagement	2
Undifferentiated engagement	3
Passive engagement	4
Active engagement	5

Table 3: Signed-rank differences between the control condition and the Interactive Video session.

Occupation		Control	Film show	Interactive video
Maximum number of sensory components		0	2	4
Control	0			
Filmshow	2	3.08**		
Interactive video	4	3.42***	3.00**	

*$p<.05$; **$p<.01$; ***$p<.001$

Table 3 presents subsequent Wilcoxon tests findings, showing that both cases produced significantly different levels of engagement from the Control condition. There was no significant difference between the engagement levels resulting from watching the Filmshow or participating in the "Interactive Video" installation. However, the Filmshow generated significantly different levels of engagement from the "Interactive Video" session.

As shown in table 3, the "Interactive Video" (3.00), produced significantly higher engagement levels than the filmshow ($p<0.01$). Table 3 shows the results of a Wilcoxon signed-rank test used to assess whether the means of engagement (of the repeated measurements data) across the different cases are statistically different from each other. This is an appropriate test to use whenever the distributional assumptions that underlie t-tests cannot be satisfied, as in this case where the data appeared continuous but not necessarily equidistant. Tangentially, a series of t-tests were conducted on the mean engagement scores for each case at each time-sample. This aimed to demonstrate whether the means of engagement across the different cases are statistically different from each other. T-tests were calculated (see table 4) because the data appeared continuous but not necessarily equidistant. However, the more cautious assumptions of the non-parametric tests appeared more appropriate to use and therefore have been presented in table 3. Table 4 on the other hand presents a comparison of engagement between the passive and the potentially physically active cases.

Table 4: One-Sample t-Test

	score	Deviation	t	Degrees of Freedom	Significance	Mean Difference
Control	2.0	.000				
Film	4.0	.000				
Interactive Video	4.7	.483	30.769	9	.000	4.7

Comparison of engagement between the passive and the potentially physically active cases.

Field data was collected which included whether the case being observed was a passive or a potentially active one. Although Csikszentmihalyi (2002) discounted "Flow" in this clinical group, the concept of the potentially active role may draw parallels with the idea of the "possibility of control" which is one of the six components of "Flow". Csikszentmihalyi (2002), Zaman & Vanden Abeele (2007), Jackson & Eklund (2002) and Rupayana (2008) all suggested that the possibility rather than the actuality of control is an important factor in inducing or maintaining a state of flow, even if it was not taken up. The different cases and Control condition fell into two groups: potentially physically active and passive cases. The data from the Control condition, and the Filmshow were averaged to give a mean physically passive case score (3.18) and the "Interactive Video" were averaged to give a mean potentially physically active case score (4.67). The data also produced a median passive case score (3) and the remainder were averaged to give a median potentially physically active case score (5). Comparison of the median scores of the two groups involved using a Wilcoxon signed-ranks test and the mean scores of the two groups using a t-test. There was a possibility that due to the several levels of aggregation of the data a mean score was a more appropriate estimate of the overall level of engagement for each group. However, both tests supported a difference between the two groups of cases and indicated that the potentially physically active group had significantly higher levels of engagement.

Table 5: Analysis of engagement between potentially physically active and passive cases

	Median	Z	significance
Potentially active cases	5	3.35	P < 0.001
Passive cases	3		

The ICER median engagement scores for each case are shown in figure 1. The "Interactive Video" session and the filmshow generated a median engagement score of 4, while the Control condition generated a median engagement score of 2.

When these median engagement scores are grouped into cases which were either potentially physically active or passive as shown in table 5, there was a statistical significant difference in the engagement levels between the two groups ($p < 0.001$). When the data is aggregated into these two groups, the potentially active cases were also the ones with the higher supporter to participant ratios. For the purpose of this study, supporters did not facilitate the participants in the Control condition in order to reduce the number of sensory modalities that participants experienced. This might contribute to the substantially lower engagement level of participants during the Control condition.

	Control condition	Watching a Film	Interactive Video Installation
Supporter To Resident Ratio	0:1	.3:1	.66:1
Novel/ Frequent	Frequent	Frequent	Novel
Physically Active/ Passive	Passive	Passive	Potentially Active
Minimum Senses	0	2	3
Maximum Senses	2	2	4

Table 6: Comparison of minimum and maximum sensory involvement, supporter to participant ratios and the passive or potentially active status of the control condition and the Interactive Video session.

Table 6 presents a comparison of minimum and maximum sensory involvement, and field data such as the supporter to participant ratios and the passive or potentially active nature of the case. Table 6 demonstrates that a low supporter to participant ratio, was observed in the control condition (0:1), and the film watching (.3:1) cases. Mid level supporter to participant ratio was observed during the use of the "Interactive Video" installation (.66:1). The cases could be grouped into whether the case experienced was novel or frequent; with control condition, and film watching, occurring frequently while the "Interactive Video" installation was a novel occurrence. Whether a case was physically active or passive was noted in the field notes.

Discussion

Engagement in occupations is an innate human need (Wilcock 1993). However, for individuals with such profound levels of disability, the tendency appears to be to withdraw from all but the most passive of cases (Farrow & Reid 2004, Pollock & Stewart, 1990), either because sensory overload renders them unable to withdraw further or because they prefer a passive spectator role. Occupations that are more active may be carried out for the individual (Nyman & Larsson-Lund 2007), so that the only opportunity of being a truly occupational being available, is through their leisure engagement. In the facility studied, the leisure occupations offered were mainly casual leisure ones, and therefore they have a high sensory content (Stebbins 1997). Engagement in leisure occupations matters because without it general satisfaction with life was suggested to fall markedly (Backman 1991), leading to consequences, which may be injurious to well-being, self-esteem and health. Equally, occupational deprivation matters because it might result in active or passive non-engagement in the shorter term, with altered patterns of time use. In the longer term, it might lead to negative effects such as imposed dependence, lower mood, lack of social acceptance and social status, reduced abilities, loss of self-identity and diminished sense of self-efficacy, and social isolation (Fenech & Shaw-Fisher 2012). Therefore, it is of relevance that the key findings of the observations of engagement study include mean engagement for all participants in each condition at each time-sample, which appears to demonstrate that across the entire occupation the Control condition appears to be non-engaging, whereas the filmshow demonstrated a mean engagement score of passive engagement and the "Interactive Video" demonstrated a mean

engagement score of active engagement. In addition, by simplifying the data into two categories i.e. non and undifferentiated engagement, and engagement, the control condition remains non-engaging throughout. Whereas the filmshow, and the "Interactive Video" projection both appear to be engaging occupations.

Therefore a difference in the sensory content of the casual leisure occupations observed may have contributed to the participants' engagement significantly. On the other hand, the observed increase in engagement at the higher number of sensory modalities of the "Interactive Video" installation may have resulted from other factors in the occupational environment. These could include supporters attitudes to enabling participant's leisure, and the role offered compared to the participant's role preference. Other factors may include a preference for (safe) independence as a spectator as opposed to the risk of/ need for support as a participant, or personal interest/ preference. Another factor may be that what is leisure for one individual may not be leisure for another (Taylor, 2008).

Brown & Dunn (2010) proposed that behaviour (including engagement) might be influenced by contextual factors. However, the original data was collected using the ICER, so the data about whether the occupations were passive or potentially active, and the numbers of supporters available and whether the occupations were totally novel or experienced frequently before was collected in the field notes. Because this additional contextual data was not part of the planned data collection these factors were not built into the observed occupations prior to their occurrence, so the field data did not lend itself to regression analysis and therefore to identifying whether there was a significant relationship between engagement and occupational role, between engagement and the level of support offered, or between engagement and the familiarity or novelty of the occupation.

The study was conducted with a group of participants rather than individual participants because the author was concerned that many of the casual leisure opportunities offered at the facility were offered on a menu basis, tailored towards neuropalliative conditions in general; but not taking into account the individuals sensory preferences. The conditions observed varied in terms of their supporter to participant ratio as shown in table 6. The control condition involved a passive role whereas in an "Interactive Video" session the participants had the choice to take a passive or an active role. These two conditions also varied in the number of sensory modalities provided. The results from the statistical tests confirmed that "Interactive Video" has significantly higher engagement levels than the control condition.

Clinical implications

Engagement in leisure occupations matters for individuals with neuropalliative conditions because without it, life satisfaction has been suggested to fall markedly (Fenech & Shaw-Fisher 2012), leading to consequences, which may be injurious to well-being, self-esteem and health.

Its opposite, occupational deprivation matters because it might result in active or passive non-engagement in the shorter term, with altered patterns of time use. In the longer term, it might lead to negative effects such as imposed dependence, lower mood, lack of social acceptance and social status, reduced abilities, loss of self-identity and diminished sense of self-efficacy, and social isolation

(Fenech & Shaw-Fisher 2012). So having little or no leisure engagement may negatively influence life satisfaction. Therefore, it is of relevance that the key findings were that the "Interactive Video" session led to mean and median ICER scores demonstrating participant engagement (see figure 1).

The observation data suggested that the number of sensory modalities influenced engagement in casual leisure occupations, in combination with other contextual factors in the environment (Brown & Dunn 2010) around the occupation. These contextual factors have been suggested to include supporters attitudes to enabling participant's leisure, and the role offered compared to the participant's role preference (Fenech & Shaw-Fisher 2012). Other factors may include a preference for (safe) independence as a spectator as opposed to the risk of/ need for support as a participant, or personal interest/ preference (Nelson & Gordon-Larsen, 2006).
Other co-existing factors, which might have encouraged engagement, included the ease of accessibility of the occupation (Verghese et al 2006, Verghese 2006). In addition, the importance of preventing boredom and of time passing may have been a factor, since occupations are a way of using time (Wilcock 2006). Another influencing factor may have been the participant's sense of engaging for someone else's benefit (Borell 2006). .Moreover, the sense of experiencing an occupational balance has been suggested to be important, as has the meaning of the occupation for the participant (Fenech 2009). Other factors, which contribute to the occupational context to note, may include the novelty, ability and the complexity of the occupation.

The limitations of the study

Many of these limitations are compromises that had to be made to protect these vulnerable adults. The participants represented a particular sub-group of individuals with neurological disabilities. The sample size was limited by the participants' capacity to express consent and the small population of individuals with such profound levels of disability. The sample size limitation was inevitable given the small size of the sub-group of individuals with neuropalliative conditions.

The observation data gathered made this a multiple, single-case methodology study; however, this is felt to be appropriate given that the conditions being observed were casual leisure opportunities. Ideally the observations should have been conducted by more than one observer and then compared for inter-rater objectivity; however this would have been inconsistent with the facilities POVA Policy, which limited observers to one per case, and so would have heightened the likelihood of altering their behaviour in response to being observed. The presence of the observer may have drawn the attention of the participants since the observer attempted neither to hide nor to join actively with the sessions. Videoing of all participants might have given an opportunity for more detailed observation, but was classed obtrusive and possibly intrusive by the POVA policy. The use of video would have been helpful in determining whether the engagement was with the control condition or "Interactive Video" session rather than other factors. The use of a single marginal observer offered no possibility of inter-rater reliability comparison. The implications of the small number of participants in the observation study were partly countered by the data saturation

resulting from the large amount of data collected using a time sampling methodology.

Conclusion

The unique contribution of this study is that it has studied the influence of sensory stimulation on engagement in casual leisure occupations for a group of individuals who experienced a leisure lifestyle as a result of NPC. It has therefore reported on a population with extreme and special needs. The study occurred with a group of participants rather than individual's; because the researcher had noted that many of the casual leisure opportunities offered to the participants, were offered from a menu. As such, although they were tailored towards NPC in general, they did not take into account the sensory profile of individual participants. It has used a data collection tool from the domain of learning disabilities and suggested its appropriateness for use in other domains of profound disability.

The use of an "Interactive Video" installation appears to be a satisfying, leisure opportunity for those participants who experience it, leading to mean and median ICER scores of active engagement. Not engaging in leisure occupations may be injurious to well-being, self-esteem and health to the point where active or passive non-engagement might lead on to dependence, lower mood, reduced social status, reduced abilities, loss of self-identity and diminished sense of self-efficacy. The observation data suggested that the number of sensory modalities influenced engagement in casual leisure occupations, in combination with other contextual factors in the occupational environment. These contextual factors might include attitudes to enabling leisure, the participant's role preference, ease of access, and the meaning of the occupation for the individual. Other factors may include the novelty of an occupation, the individual's abilities, and the complexity of the occupation. Therefore it would be useful to consider these contextual environmental factors, the occupation itself and the individual's preferences in combination, when planning leisure occupations for individuals with such profound disabilities.

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