NHS Forth Valley
Playlist for Life Project Report
2015

Yvonne Cairns, National Dementia Champion/Staff Nurse
Clare Calder, Quality Improvement Facilitator
Oonagh Cameron, Quality Improvement Manager
Tracey Gow, Psychiatric Liaison Nurse

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Research on the use of personal music with individuals with dementia has tended to focus on the use of music as an aid to reduce agitation and drug therapy in patients with a diagnosis of dementia.

The aim of this project was to evaluate the potential use of personalised music upon social engagement and interaction and the wider value of this to both patient and relative during visits. Given the dearth of existing literature surrounding this particular area and the exploratory nature of this research, a qualitative case study approach was used.

Method

Following ethical approval from the East of Scotland Ethics Service, one patient-carer dyad was recruited to include one female patient and one male carer (patient's husband). An initial, pre-test interview of the patient's husband was conducted to gain an insight into his current visiting experience. Thereafter, using an evaluation framework, observation of the couple by nursing staff was conducted daily over a period of one month. A follow-up interview 6 weeks later was conducted to determine the impact if any, the Playlist had on the both of them. The data collected pre and post interview, was reviewed to gain an understanding of any recurring themes or comments.

Findings

The case study revealed the importance of personal music as a tool for increased social interaction and engagement between patient and family. In addition, staff noted a change in the husband's appearance in which he appeared happier and more relaxed. They also indicated they had more positive thoughts and would be more confident in using the Playlist for Life on other patients in the future.

Conclusion

Results from this study highlight the use of personalised music as an emotionally significant stimulus that holds the unique potential to evoke memories and reconnect patients with family again.

1. Background

Dementia is now recognised as one of the most socially and economically oppressive health conditions globally. Since 2007, the Scottish Government has made dementia a national priority and it is now estimated that the number of people in Scotland, diagnosed with dementia will double between 2011- 2031, due in part to an increasing elderly population. Aligned with the 2020 vision, the focus of Scotland's National Dementia Strategy is on improving the quality of dementia services (Scotland's National Dementia Strategy 2013-16).

At present there is no cure to prevent or halt the progression of dementia. Behavioural and psychological symptoms (such as depression, psychosis, agitation and distressed behaviour) are often treated with sedatives, anti-psychotic or anti-depressant drugs. However, these often prove ineffective, and there is great concern about their inappropriate use (Mohr, Petti & Mohr, 2003). Accordingly there is now an increasing emphasis on the use of non-pharmacological interventions to improve the wellbeing of people with dementia. (Douglas et al., 2004)

In light of this, there is increasing research (c.f Gerdner, 2010; Sung & Chang, 2005; Sung, Chang & Abbey, 2006; Sung, Chang & Lee, 2010) to suggest that music-based activities for individuals with dementia can result in:

- A significant decrease in typical symptoms such as agitation
- A marked decline in both anxiety and depression
- Increased interaction with others, reducing isolation
- Speech reconstruction amongst people who struggle to communicate verbally
- Perhaps most importantly, a reinforced sense of personal identity

What's more, it is also now recognised that the person with dementia needs to be known and understood as an individual in order to provide person-centred care, with a focus on what they can do rather than what they can't.

To this end, Scottish based charitable organisation, Playlist for Life© (Registered Charity: SC044072) and Glasgow Caledonian University research team have formed a music and dementia network entitled: Playlist for Life: The Personalised Music and Dementia Journey. This research aims to enable policy makers to assess the efficacy of this intervention for roll-out across the Board in the treatment of all forms of dementia, in keeping with Scotland's National Dementia Strategy (2013-2016). http://www.playlistforlife.org.uk/.

A further aim is to ensure that every person living with dementia can gain access to the Playlist of their lives via an mp3 player or other digital device as often as they need it. As detailed within the remainder of this report, the charity has since partnered with the Playlist for Life team from NHS Forth Valley to pilot this personalised music intervention within community hospital settings.

2. Aim

On learning about the effect personal music can have on patients with a diagnosis of dementia at a Person-Centred Health and Care event, nursing staff within NHS Forth

Valley community hospitals specialising in dementia care, were enthusiastic to explore this concept further.

Visiting their family member in a hospital environment, carers would describe a sense of loss, loneliness and guilt and at times experienced difficulty in adjusting to their new role. There was also a wish to maintain their relationship with their family member. Therefore, following consultation, the agreed aim of this project was to implement and evaluate whether the use of music personal to the patient had an effect on their social engagement or interaction such as eye contact, vocalisation or touch and the value of this to both patient and relative during visits.

3. Methodology

Yvonne Cairns, Dementia Champion, FVRH and Tracey Gow, Staff Nurse, formerly based in Bo'ness Hospital identified the patient and relative suitable to take part in the project, and ensured risk assessments and informed consent were in place. Quality Improvement contributed by providing a project protocol and timeline, developing family consent and information documents, and devising an evaluation framework to measure outcomes for the project. The outcome measures for the patient were adapted from Cohen-Mansfield et al. (2009) and included:

- Rate - toleration of headphones
- Duration - participation time
- Attention - such as eye contact, facial animation, verbalisation, motor responses
- Attitude - whether positive or negative such as happy, sad, tearful and any other activity as a result of the use of music

It was agreed that to be included in the project, the patient must have a diagnosis of dementia and that the family had consented for the use of the Playlist. Patients not thought suitable were those who had a significant hearing impairment or those who exhibited an agitated behaviour that would limit toleration of headphones. A registered nurse and nursing assistant would act as facilitators throughout the study, recording their observations on a daily basis on the data collection tool provided.

Based on previous studies, the outcome measure for family members was to assess if playing music during their visits had an impact on their level of engagement in comparison to what they had experienced previously.

Contact was also made with Andy Lowndes, Deputy Chair, Playlist for Life, Glasgow Caledonian University and Christine Proudfoot, Senior Charge Nurse, Borders General Hospital whose experience in setting up Playlist for Life projects informed NHS Forth Valley of lessons learned from other areas. Utilising 'Yammer', an online network facility, we have been able to share our project plans and documents with a wide range of professionals and members of the public to enhance the range of comment during their development. Other project teams and one researcher have since expressed interest in using the tools developed by NHS Forth Valley.

To ensure compliance with NHS Forth Valley policies and procedures, particularly around consent and the use of ICT equipment, contact was made with Information

Governance and ICT Security, who, after being provided with background information of the project, advised contacting Risk Management. This subsequently led to a Basic Principles of Risk Management module being completed in order for a risk assessment to be submitted which would allow for the release of the media players by Procurement once purchased. The project was also added to the Safeguard reporting system in the event of any adverse incidents occurring.

It was also identified that support would be required from the ICT Department and following a discussion with the Head of ICT, contact was made with the appropriate ICT analysts who concluded that as the purchased laptop had been encrypted the iTunes could, not be installed which ultimately led to a delay of several weeks. However, with their ongoing technical support they overcame the challenges involved in this process, deciding to download on to a designated base unit. With this issue resolved, a request was sent to Procurement to purchase iTunes vouchers which took several weeks to complete.

During this time, the documents produced by Quality Improvement were sent to the East of Scotland Ethics Service for consideration. Following their decision, classifying the work as an observational case study, the project was implemented.

Procedure

One family was invited to participate, being fully informed of the project, and consented to be involved. They were supported to identify a 30 minute list of music of which 11 songs were identified linked to life events or songs personal to them, such as those that they sang or danced along to, which were then downloaded to our iPod devices. This family was approached as the ward staff had observed the husband, who visits every day, having very little personal interaction with his wife due to her agitation and who frequently appeared to leave the ward despondent and were concerned about his wellbeing. Before initiating the programme, baseline relative outcomes were measured by conducting a semi-structured audio recorded interview and the use of positive and negative flash cards. In discussion with the patient's husband, he described a typical visit, revealing the mixed emotions he experienced such as feeling "low" or "relaxed" throughout the visiting process, which was ultimately determined by his wife's emotional state. He commented that while his wife did not make any eye contact with him he felt that she was aware of his presence and that there was not much he could do other than comfort her.

Staff, were also encouraged to report their personal perceptions of the patient and relative whilst using the Playlist, and to record any anecdotal details they felt relevant to the evaluation.

A follow-up interview was repeated 6 weeks after implementation to ascertain what value, if any the use of the Playlist had added to their visiting experience.

4. Findings

During visits, the music was played at different times for 15-30 minutes via headphones which could be listened to by the patient, relative or a member of staff.

Another member of staff monitored the intervention and using the evaluation framework tool, recorded their observations of the engagement.

Patient Observation

The patient was observed over a one month period in which staff witnessed a noticeable change in her social engagement whilst listening to her Playlist, becoming more animated and exhibiting different mannerisms. This included making eye contact, having gentler physical contact with her husband, reaching out to touch and hold hands and an increase in body movement such as swaying to the music. This is in distinct contrast to her previous level of activity which included, screaming, gripping tightly, ripping her own and her husband's clothing along with staff's tunic pockets or scratching and nipping those in close circumference to her. Furthermore, she responded appropriately when asked about particular songs saying words such as "that's nice", "Oh God" and an attempt to sing along which would suggest her ability to connect with the music.

Nonetheless, this engagement has had a discernible impact on her husband whereby ward staff report him appearing well and more relaxed and at the end of the day's visiting, going away with a smile on his face and having a more positive parting conversation with the staff.

As this activity of playing music appears to have had a positive effect on both the patient and her husband, and to ensure continuity this has now been implemented into her individual care plan.

Follow-up interview

In a 6 week follow-up interview with the patient's husband he stated that keeping to much the same routine as before, he had been playing the music at different times during the day but found that playing the music for approximately 30 minutes after his wife had eaten her evening meal, they were both more relaxed. He revealed that visiting was easier for at least half an hour he would have what he considered to be 'a good visit', feeling at ease and enjoying his wife "getting comfort" from the change in routine. He further commented that his wife would often elicit words relating to the song being played, so much so that he jokingly stated he was 'waiting for her to start singing! Overall, he felt that the Playlist for Life experience had "definitely been worthwhile" as it was something that they could share together. Leaving at the end of the night, he indicated feeling much better as he saw his wife much more relaxed, describing the use of Playlist for Life as something that is able to add "comfort" to him, leaving after a good visit.

Overall, it would appear that his daily visiting experience is more enjoyable with his wife engaging in verbal communication. Prior to the use of Playlist for Life, he was concerned about notable periods of no or very little communication.

Staff Reflection

Having observed the patient and her husband over a period of time, staff, were invited through discussion groups and completing a questionnaire using the Gibbs

Reflective cycle to provide their thoughts on the use of the Playlist for Life and the impact it has had on the both of them. In view of the patient's distress when encountering new interventions, some staff had initial concerns that this activity would increase her agitation when wearing the headphones however, this was not evident. Observing only the positive impact the Playlist has had on the couple in uncovering past memories and associated positive emotions and engagement, the staff frequently reported that the patient's husband experienced more relaxed and enjoyable visits than previously. In addition, staff further noted an improvement in the patient's husband's health and wellbeing, in addition to the patient herself, who appeared more settled and less vocal due to her anxiety during visiting and remained relaxed for a period of time afterwards. With regards to behavioural outcomes, staff also reported that the patient 'pulled less at their uniforms' and was also more receptive to routine care tasks, such as washing and undressing. Staff did not report any negative outcomes regarding the Playlist for Life Experience.

With regards to the sustainability of using the Playlist for Life, the overarching consensus from staff was that they felt more positive and would be more confident in trying this with other patients in the future.

Overall, these findings have demonstrated to staff that listening to personal music is an emotionally significant experience for individuals with dementia which holds the power to evoke positive memories and therefore help to reconnect patients with family members.

5. Current Work

Playlist for Life has since been implemented across several other families in the community hospitals and again, the outcomes appear positive for both patient and relative. As there are 10 iPods available at present, it is anticipated the programme could be rolled out across the organisation with further financial support to purchase more at a cost of approximately £40 per patient (estimated cost of one iPod). It is further suggested that this intervention is largely cost-effective, owing to the ease of implementation.

This would result in a positive, non-pharmacological intervention to enhance and add value to the experience of visiting a family member with dementia that is in-keeping with the principles of a person-centred approach. However, discretion should be used when considering patients for this activity as they could be unsuitable due to other underlying factors such as hearing impairment or those who exhibit an agitated behaviour that would limit toleration of headphones. Furthermore a process for the tracking and return of the iPods may be required particularly for patients who transfer to other facilities.

6. Conclusion

Whilst this project is still in its infancy findings thus far indicate a number of positive outcomes for patients, staff and families.

Exploring the husband's journey across the implementation of Playlist for Life has highlighted that the intimacy of listening to personally meaningful music with his wife

appears to have had a positive effect on both the patient and relative. With regards to the relative, it has provided the relative a sense of purpose, where the patient's husband appears more content and relaxed as a result of his wife's increased engagement during visiting periods. In support of this, in contrast to his previous despondent look and hunched stance, staff, have noted that the husband now smiles, laughs and jokes when visiting and appears to walk straighter. In view of the patient, key outcomes include decreased agitation and increased receptivity to routine care. A vast improvement in her social interaction and engagement with her husband is particularly evident whereby she is seen to be making gentler contact rather than her previous aggressive physical behaviour.

Overall, Playlist for Life can be seen as a powerful tool at visiting time for families in relation to social engagement, therefore, the significance and value of personal music from a patient and carer's perspective should not be underestimated.

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