

Online Social Participation among Older Malaysian Living with Dementia during the Pandemic COVID-19: the 'Take the Purple Pledge' Project
 (Penyertaan Sosial Dalam Talian dalam Kalangan Warga Tua Warga Emas yang Menghidap Demensia semasa Pandemik COVID-19: Projek 'Take the Purple Pledge')

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ABSTRACT

The 'Take the Purple Pledge' project a collaborative project between UKM and the Alzheimer's Disease Foundation Malaysia (ADFM) was conducted. The undergraduate students from the Speech Sciences, Physiotherapy, Occupational Therapy, and Audiology programs organized this event as part of the Community Based Rehabilitation course requirement. The program's main objective was to engage with individuals with dementia and their caregivers. The 'Take the Purple Pledge' project consisted of two parts: (i) an interactive session with individuals with dementia and (ii) posting posters and materials on social media to spread awareness about dementia among the public. The first part of the program was conducted via Zoom on 14th August 2021 from 8:00 am to 11:30 am, while the second part of the program was completed on the same date. For the interactive session, 99 participants comprising students, ADFM staff, individuals living with dementia, and their caregivers attended the Zoom session, filled with virtual activities such as exercises, memory games, gamebooks, checklists, and tours. Individuals with dementia, their caregivers and staff from ADFM provided positive feedback about the program. The 'Take the Purple Pledge' program not only allowed individuals with dementia and their caregivers to interact with other people, it also provided an opportunity for them to participate and be included in a social event during this challenging time.

ABSTRAK

Projek 'Take the Purple Pledge' projek kerjasama antara UKM dan Yayasan Penyakit Alzheimer Malaysia (ADFM) telah dijalankan. Pelajar sarjana muda dari program Sains Pertuturan, Fisioterapi, Terapi Pekerjaan dan Audiologi menganjurkan acara ini sebagai sebahagian daripada keperluan kursus Pemulihan Berasaskan Komuniti. Objektif utama program ini adalah untuk melibatkan diri dengan individu yang mengalami demensia dan penjaga mereka. Projek 'Take the Purple Pledge' terdiri daripada dua bahagian: (i) sesi interaktif dengan individu yang mengalami demensia dan (ii) menyiarkan poster dan bahan di media sosial untuk menyebarkan kesedaran tentang demensia di kalangan orang ramai. Bahagian pertama program telah dijalankan melalui Zoom pada 14 Ogos 2021 dari jam 8:00 pagi hingga 11:30 pagi, manakala bahagian kedua program selesai pada tarikh yang sama. Untuk sesi interaktif itu, 99 peserta terdiri daripada pelajar, kakitangan ADFM, individu yang menghidap demensia, dan penjaga mereka menghadiri sesi Zoom, yang dipenuhi dengan aktiviti maya seperti senaman, permainan memori, buku permainan, senarai semak dan lawatan. Individu yang mengalami demensia, penjaga mereka dan kakitangan dari ADFM memberikan maklum balas positif tentang program ini. Program 'Take the Purple Pledge' bukan sahaja membenarkan individu yang mengalami demensia dan penjaga mereka berinteraksi dengan orang lain, ia juga memberi peluang kepada mereka untuk mengambil bahagian dan diselitkan dalam acara sosial pada masa yang mencabar ini.

INTRODUCTION

COVID-19, an infectious illness that alarmed the nation and brought dozens of new changes to populations since its report at the end of 2019. Although the first wave of the outbreak in Malaysia started around January 2020, it was the cases that emerged at the end of February that sparked the country's attention. Despite the challenging situation, people strive to do their utmost to adapt to the new circumstances and tackle the barriers by adjusting to the instances. With the sudden shift of norm, younger generation are in denial of the older adaptation of technological utilisation, be it upon education or at work.¹

With the implementation of the Movement Control Order (MCO) by the government, citizens were restricted in terms of their whereabouts at certain stages according to the enforcement. While physical distancing and isolations are essential in avoiding the spread of this highly infectious virus, this is also associated with a variety of adverse psychological impacts, including loneliness. Older people and adults, who were not used to being alone, were abruptly cut off from their social networks. They have no one to talk to when visiting and dining outside were not allowed during that critical period. According to a study of 1,163 respondents conducted by Universiti Malaya, the incidence of depression, anxiety, and stress symptoms increased consistently across four distinct MCO in Malaysia (Wong et al. 2021). Thus, it was shown that loneliness is a significant contributor to citizens' deteriorating mental health.

Social interaction is crucial as it allows people to engage with others to relieve tension or build stronger companions. Since the pandemic has taken a toll on social life, citizens must alter their lifestyles to engage in social activities. Digital technology such as online social platforms has been seen as a feasible choice to somehow aid the process of socialising without compromising meet-ups and connections among humankind despite having to adapt to the fact that everything has to be virtual. Citizens have had to rely more on technology for communicating and socialising. Nonetheless, certain citizens, particularly the older people who are less likely to utilise technology, may find this difficult. The older people may face technical challenges such as lack of computer skills and are reluctant to adjust and learn on viewing complicated website design likewise multiple functions that are distinct across all platforms available. Aside from the obstacles that senior citizens may experience, online social engagement has its own range of benefits for the older people. Pensioners have been proven to benefit from constant brainstorming that

reflects on their cognitive ability through their online ventures, as likely as how humans improve daily life activities through the act of constant involvement and repetition.

In this project, we conducted an online activity with older Malaysians living with dementia with the aim of evaluating how older people adapt to the social media platforms as well as their responses to this online social interaction during the COVID- 19 pandemic. This viewpoint allows us to go beyond the technology adoption of old-age individuals.

METHODS

Participant recruitment

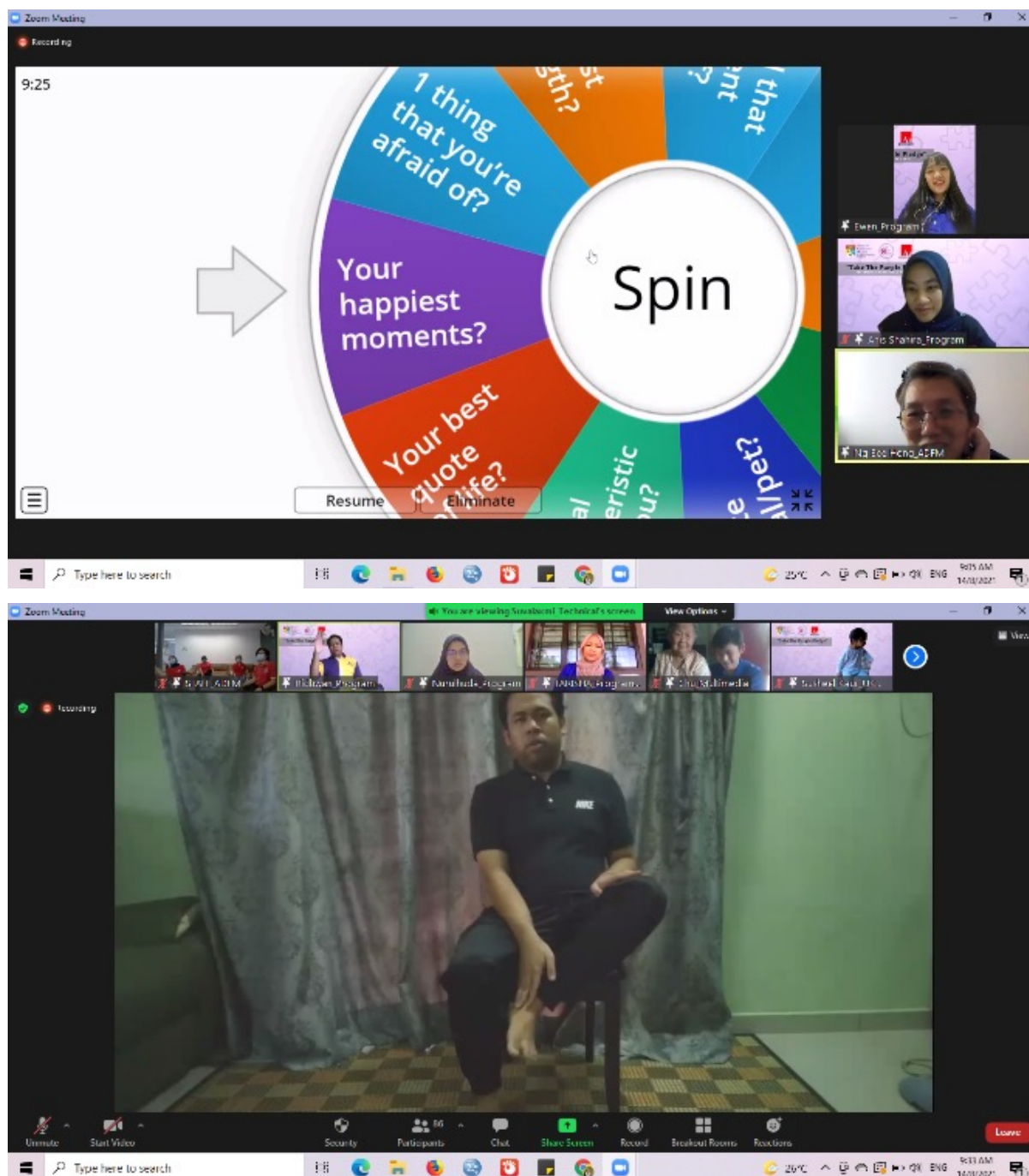
Participants were recruited by ADFM staff and through poster distribution through the students' social media. A google form was provided for registration purpose. A link of the Zoom, date and time will be emailed to the participants upon registration. Targeted participants were older people population, aged 65 years and above and have been diagnosed with Dementia.

Procedure

“Take The Purple Pledge” project was a community based rehabilitation organised by four courses of undergraduate students from The Universiti Kebangsaan Malaysia, primarily Speech Science, Physiotherapy, Occupational Therapy and Audiology with the goal of engaging dementia patients and caregivers. This project was broken down into two parts, (1) an interactive session with individuals with dementia that includes exercises, memory games, gamebooks, checklists, and tours, and (2) posting posters and materials on social media to raise awareness about dementia among the general public. To detail the agenda on that particular day, an ice-breaking session was conducted with all participants right after the official opening ceremony. It was then followed by the virtual exercises, which were conducted by the students to warm up the participants beforehand. All three games conducted throughout the entire session were intended to improve cognitive function among participants. The day was rounded up by a virtual tour of Malaysia and a photography session.

Instrument

A satisfaction assessment was used. Items includes six (6) quality and were rated in a 5-Point Likert Scale, “1”, which indicate “unsatisfactory” to “5”, which



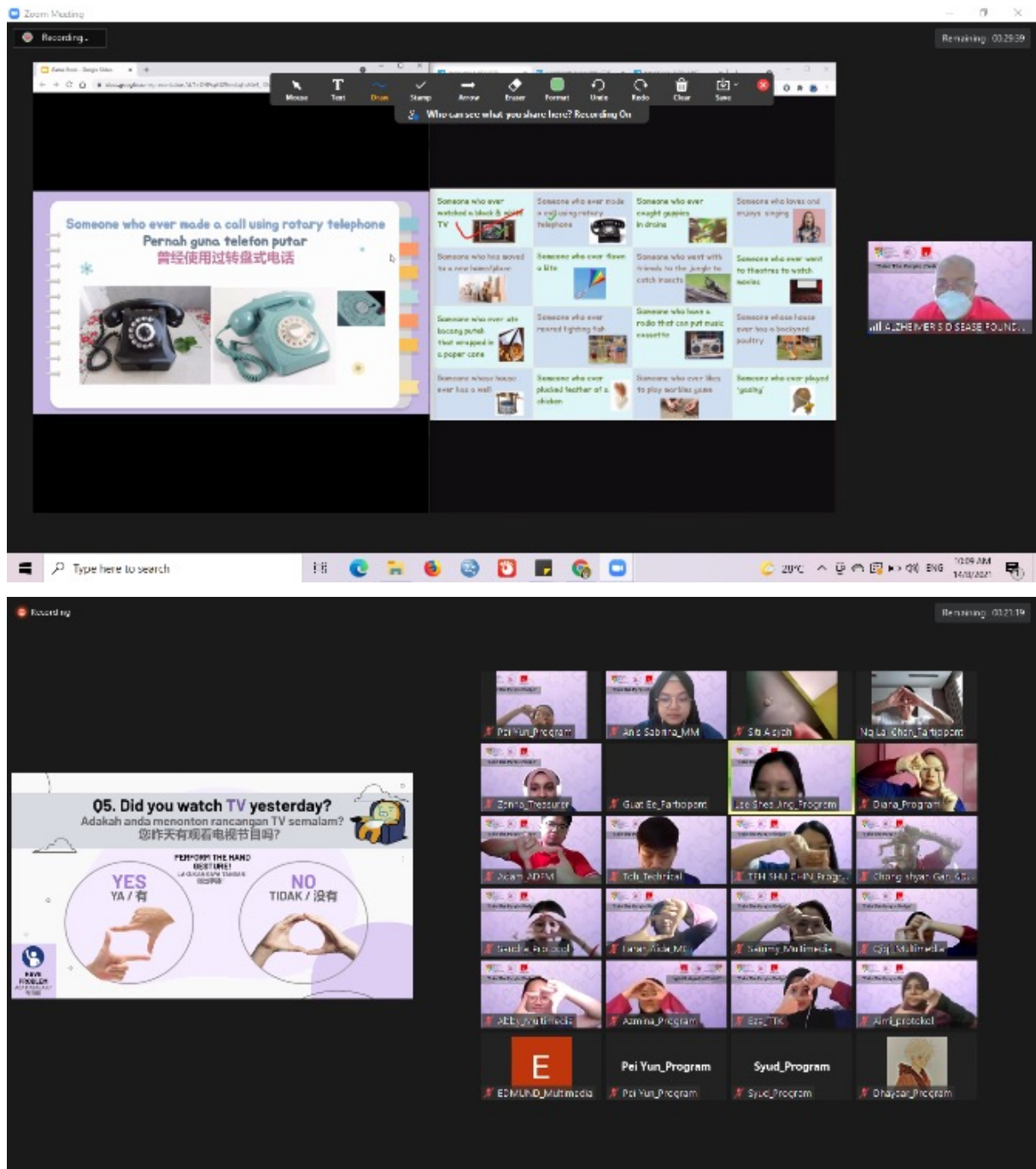
indicate “excellent”. An overall impression of the event was taken as well with the scale of 1 to 10, where “1” indicates “unsatisfactory”, to “10”, which indicates “excellent”.

RESULTS AND DISCUSSION

On the 14th of August 2021, ninety-nine participants, comprising Universiti Kebangsaan Malaysia (UKM)

students, Alzheimer’s Disease Foundation Malaysia (ADFM) staff, dementia patients, and their carers, participated in the “Take The Purple Pledge” program through Zoom platform from 8:00 am to 11:30 am. The details of responses were recorded and analysed as presented in Figure 1.

As seen in the Figure 1, five out of seven respondents gave the overall project a perfect score. The majority of responses were positive about the project’s overall impression. They were very satisfied with the



students' attitude and performance throughout the project. Furthermore, most of the respondents agreed on the project's benefits to the community. However, as compared to other aspects, the quality "The event is good for those with hearing impairment" had a lower score, with zero rates on the perfect score. The project's respondents also made several suggestions on how to enhance certain criteria, including the use of sign language throughout the session to better interact with individuals who have hearing impairments.

Results suggest the feasibility and potential

utility of using online social networks in engaging Malaysia citizens, especially those living with dementia. Caregivers of older people with dementia in Malaysia were found to have a positive attitude towards this activity. Majority of participants were highly immersed during the process and likely to appreciate the conduct. Similarly, they rated the project a relatively high rating on the post-project feedback assessment form. Hence, this article suggests that online social networking can be an engaging platform for this vulnerable group. During a pandemic in which people's movements and

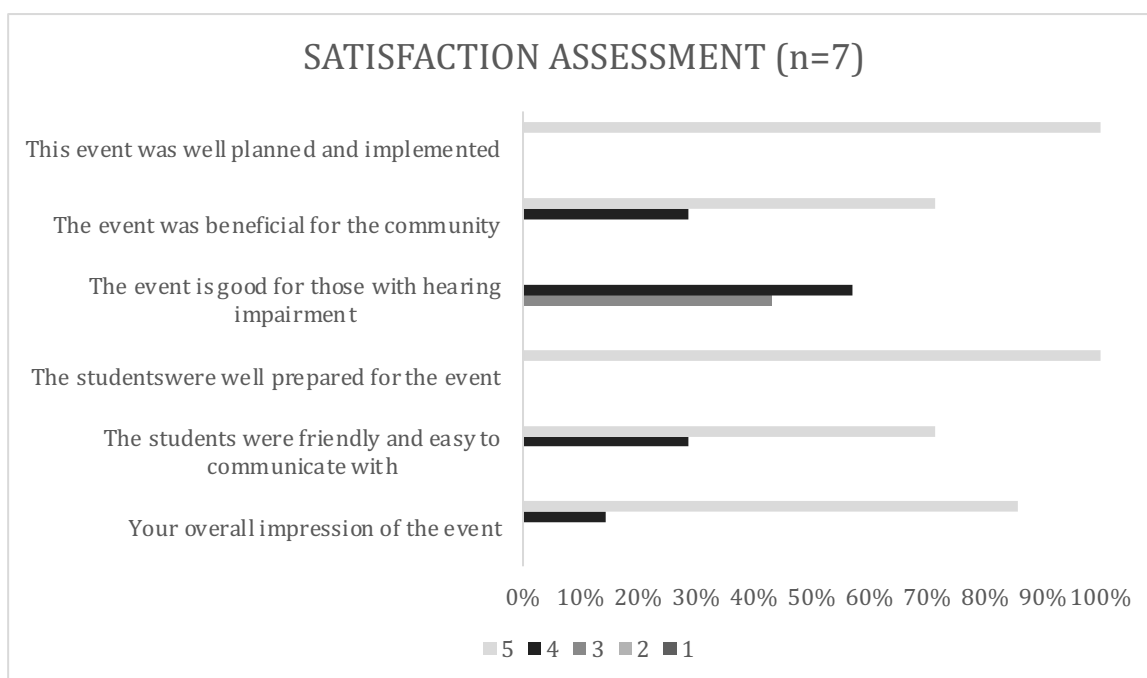


FIGURE 1. Feedbacks from the participants.

freedoms were restricted, online social networks are the only method for them to interact with the outside world. The project is practical as it aids in the socialisation of the older people and prevents boredom. Older people might use online social networks to broaden their options for keeping in touch with family and friends. Online socialising is helpful not only in terms of the sense of companionship, but also in terms of the expression of emotion, which is most likely linked to the engagement with other people (Benvenuti et al., 2020). Likewise, the project which involved online social interaction promotes senior citizens' health, particularly in those living with dementia, where online games aid to improve their memory and cognitive function. In consequence, caregivers play a vital role in assisting older people who are unfamiliar with the rolling in of upfront technologies. They will certainly take additional time to become comfortable with the new technology. Thus, online social platforms allow older people to maintain and engage existing offline social relationships more regularly but in a variety of communication methods. Seniors who have a certain level of user understanding will be able to not only connect with people socially, but also use medical services such as telehealth or telerehabilitation, which are critical to their health-related quality of life (Sen et al., 2022).

The "Take The Purple Pledge" project included a variety of choices and exciting games to attract participation. The friendly moderators and colourful

pictures on the slides had likewise taken effect into the intention of the project. All three games enabled the students and participants to communicate with one another. Furthermore, students' willingness to patiently educate participants on how to use Zoom features such as turning on/off the camera and audio, taking into consideration that the older people may be slow to pick up on advanced technologies. Despite having dementia, they felt a sense of human equality as students accepted their condition. Similar online programs might be created or organised in the future to help people cope with loneliness and unpleasant emotions during a pandemic.

The project appeared to be a success, as participants enjoyed the activities and requested that they be performed on a monthly basis. The older people benefited from the new technology, yet they needed assistance from their carer. Based on our findings, we may conclude that the project had an impact on dementia patients and benefited them. Overall, the participants' satisfaction scale is excellent, with seven of the respondents giving it a high rating, although there were some suggestions that the use of sign language may aid those with hearing problems.

Nevertheless, the most significant limitation of the article is the number of respondents on the post-project satisfaction assessment form, with just seven out of the ninety-nine participants responding to the assessment form. There was no follow-up study done, and no long-term effects were documented. As a result,

the final findings on the older people's attitude to technology were restricted. Second, since the project is internet - based, it inherently discriminates against older individuals who do not have access to technical gadgets at home. As a result, the number of participants was limited.

CONCLUSION

The findings of this article highlight that this online programme is feasible and participants find it convenient and enjoyable. Coming to the finale of this project and the overall analysis conducted, we can reach to a fruitful retrospect that the feeling of isolation especially within dementia and Alzheimer's older people during any difficult times or precisely the current pandemic, will not necessary be distinguished with the only solution of receiving care and compassionate love from others nevertheless their unaverred intention to learn and ever-trying from their end to stay connected with their love ones and the society more than that the global

happenings, and that is all what matters, for the best of their well-being.

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