An Immersive Art-Based Approach to Engaging with the Embodied, Sensory and Affective Experience of Living with Dementia

Gail Kenning, Jill Bennett, Volker Kuchelmeister, Natasha Ginnivan, and Melissa Neidorf

Abstract

This paper discusses the design and exhibition of *The Visit*, an immersive media artwork, featuring a digital character with dementia. Created from verbatim interviews with people living with dementia, the character 'Viv' shares experiences of audio and visual hallucinations, confusion and confabulation, as well as her insights and reflections. Viewers are thereby drawn into the perceptual world of dementia, but also challenged by the depth of the engagement with the character.

Keywords

Dementia · Immersive media · Empathy

1 Introduction

The Visit is an immersive experience which explores the relational dynamics between people living with dementia and others by staging an interaction between a realistic digital human character, 'Viv' and the viewer (visitor). The participatory artwork was produced as part of a research program investigating the lived experience of people living with dementia by an interdisciplinary team of artists, designers, technologists, psychologists and dementia researchers, who work closely with people living with dementia. The artwork focusses on the experiences of Viv, a woman with dementia who visitors interact with as she moves about her kitchen. The work draws the viewer into her emotional and perceptual world as she speaks both to the viewer and to a hallucinated child, as if both are seated at her table. The monologue is constructed near verbatim from interviews with, and reports of, four women living with (vascular) dementia who experienced auditory and visual hallucinations, confusion or confabulation, and shared details about their condition.

The artwork involved the creation of a realistic embodied character which presented a rich, contextual portrayal of dementia foregrounding the subjective lived experience rather than the pathology of the condition. Through Viv we gain insight into the agency and capacity of people with dementia as we see how she perceives,

G. Kenning (✉) · J. Bennett · V. Kuchelmeister · N. Ginnivan · M. Neidorf
fEEL (felt Experience and Empathy Lab), University of New South Wales, Sydney, NSW, Australia
e-mail: gail.kenning@unsw.edu.au

G. Kenning · J. Bennett
Ageing Futures Institute, University of New South Wales, Sydney, NSW, Australia

reflects upon and finds ways to manage the hallucinations that are part of her every day. This strengths-based rather than deficit focused characterisation [1] implicitly challenges preconceptions about dementia through a direct engagement in a compelling relational encounter. By focusing on the nature of interpersonal interactions and relational dynamics, *The Visit* creates conditions for empathy rather than merely sympathy [2].

This paper discusses the iterative process of development. The process began with semi and unstructured interviews of the participants' experiences. These were subject to close analysis by the research team to understand how they made meaning from them. Artists and designers then developed two immersive modes of artworks; a Virtual Reality (VR) headset and a life size screen as part of an installation which extended the onscreen space into the gallery environment through the use of props and an ambisonic sound track. The artwork was exhibited as part of an arts health festival. The two modes of viewing allowed for greater accessibility, the VR headset being more portable. In addition, it allowed for a focussed individual viewing.

2 Background

Understanding dementia from the perspective of those living with the condition is increasingly the focus of research and design [3]. However, all too often those living with the condition feel they are not understood, and their voices are not heard [4]. As one of the participants in this research program suggested "I remember when I was diagnosed [with dementia] it sticks firmly in my head how I was shocked that the so-called experts didn't know the reality. You know, the consultants couldn't tell me what to expect apart from, you know, the decline and the basics, but they didn't understand the—you know—how our senses are so affected and that was just totally alien to them and that shocked me" [PID 8]. This lack of knowledge and understanding of what it feels like to live with dementia can enhance

perceptions of deficit and impede any recognition of intelligence, agency and other indicators of personhood [5]. Such perceptions and judgements that focus on deficits, can in turn impede any experience of empathy [6]. To overcome this, it is important to slow down the perception process and the rush to judgement of what it means to live with dementia.

Those with limited experience of interacting or being with people living with dementia are often confronted by not knowing what to do. There is a tendency to 'take-over' which can work against listening, being understanding, or just being *with* [7]. By cultivating empathy and greater understanding of inter-subjective (social and shared) dynamics, we can not only breakdown stigma, but facilitate inter-group understanding and motivate pro-social helping behaviors [8–10]. Empathy is a complex and multidimensional construct that Davis [11] suggests, "connects the responses of one individual to the experience of another". Empathy studies have explored this through the use of perspective taking or affective role playing [12]. It has also been explored using immersive technologies to simulate and promote imaginative perspective shifting.

Art-based approaches allow for embodied, sensory and affective modes of communication that can engender empathy and promote empathic interactions [13, 14]. Immersive technologies, in particular, have been shown to increase empathy and pro-social behaviours [15, 16]. Such immersive experiences focus on simulating physical context and promoting, 'being in the shoes of'. This has led to immersive media and VR in particular being posited as the "ultimate empathy machine" [17]. However, while placing people into a different space may prompt imaginative transposition to a new condition, it does not necessarily register the subjective presence or *lived experience* of the 'other'. In other words, temporarily occupying—or appropriating—the position of another may be illuminating but it is not the same as engaging with that other. The ability to imagine another's experience is one part of empathy—but interactive art may also develop the capacity for *being with*

rather than simply simulating *being*. *The Visit* moves beyond the imaginative transposition, and the problematic politics of colonising the position of the other without any real person to person engagement. It facilitates the experience of "being with" another and the associated capacities of attunement, and deep listening that exemplify empathy in the classic person-centred psychotherapy advanced by Carl Rogers [6, 18] by attending to the affordances of an experience, as suggested by Gibson [19].

The Visit draws on the longer tradition of the 'talking head', screen-based monologue that breaks the fourth wall, addressing the user/viewer directly—an approach skilfully developed in the portraits created by Alan Bennett in his *Talking Heads* Television Series [20]. *The Visit* aims to cultivate, in the viewer, sensitivity towards personhood and agency by making them perceive themselves as part of a dynamic relationship in which the character of Viv, in this case, potentially knows more than the viewer.

The authenticity of the character of Viv, and her demonstrated agency and personhood, comes from the detailed testimonies and reports of four older female adults living with vascular dementia who were able to understand their conditions, and had strategies for managing their hallucinations, confusion and confabulations. The authenticity is further developed in the characterization in the use of professional actors to voice and develop the movements of the character portrayed.

2.1 The Immersive Experience

The Visit offers a content rich, immersive engagement running on two distinct platforms; a VR Oculus Quest headset and an installation consisting of a large screen on which the character is perceived as life-size, a chair—which matches the chairs seen onscreen to enhance the sense of presence,—and an ambisonic sound track accessed through personal headphones (see Fig. 1). *The Visit* is also being developed as an interactive real-time film on the apple and android App Store. In the installation version in the gallery, a viewer takes a seat, seemingly at her table, triggering the interactive sensors and causing Viv to become 'aware' of their presence. She begins offering them tea and food. A third place is set at the table which, it becomes apparent, is occupied by a hallucinated child who is included by Viv in the conversation. The encounter with Viv intentionally promotes ambiguity prompting the viewer to question if they too are part of Viv's hallucination. Through the unfolding conversation the confusion and clarity of Viv's world is revealed. She talks of her love of music, walks, and gardens, and her disagreements with various carers. She tells of her confusion at visual hallucinations, such as when her garden shed disappears, only to appear again later. The immersive spatial soundscape, heard through personalised headphones, underlines the emotional transitions and creates the impression for the viewer of being 'inside' Viv's hallucinated world. The viewer hears the sounds overhead of, Viv tells us, her father's typewriter clicking away "upstairs". Thus, the viewer experiences a little of Viv's perceptual world but then is reassured as Viv herself reveals that this is a hallucinated reality. The unfolding dialogue, revealing Viv as a complex character, aims to counter any preconceived judgement with regard to dementia. The immersive media creates a palpable and vivid sense of presence. However, the viewer is deliberately not presented with interactive choices in the manner of a video game, but the work is rather designed to operate on Viv's terms. The aesthetic elements combine to create conditions conducive to a relaxed and unhurried listening, supporting openness and attunement.

3 Methodology

3.1 The Participants

The interviews and reports of four women with vascular dementia were purposively selected based on the need for information rich cases (and no intention to aim for generalisability) [1]. Each of the women had audio and visual

Fig. 1 *The Visit* left: the visit installation, [art festival name], 2019, [gallery name]. right: the visit VR [location]

hallucinations, confusion or confabulations and had an awareness and understanding of their conditions. Each were highly proficient in their chosen careers, with responsibilities, organisational, and virtuoso skills as General Practitioner (GP), health Administrator, musician, and writer and had raised families. We were able to gain insights into how their capabilities in their personal and professional lives had equipped them with coping mechanisms which were carried over into their 'after diagnosis' lives. They revealed the strategies they employed for adapting techniques from their parenting or professional lives and were able to reflect on both their auditory and visual hallucinations and on their experience of confabulation. They were able to provide information on how they had developed ways of 'testing' whether they were hallucinating or engaging with reality. They were also able to offer up ways of coping to their communities.

A series of interviews semi-structured and unstructured interviews were conducted over period of six months. Each participant was interviewed between three to eight times for between an hour and ninety minutes. The interviews were audio recorded, researchers made follow up notes, and the interviews were transcribed verbatim. The interviews began as semi-structured interviews focusing on their experience of ageing and changes that they had noticed to their cognitive and physical functioning. As the relationships and trust developed the interviews became less structured, allowing the interviewee greater control over the content discussed.

3.2 Experiential and Interpretative Analysis

The data was subject to analysis of phenomena relating to the experience of the participants and interpretative analysis of how they made meaning from these experiences [21]. Although, it did not employ Interpretative Phenomenological Analysis per se (IPA) [22]. The aim was to 'give voice' to the participants rather than representing them, and to move beyond 'first order' analysis which focuses on concerns and identifies themes [23]. Researchers were engaged in analysis of the data at an interpretive and conceptual level working from "highly intensive and detailed

analysis of accounts produced by a comparatively small number of participants" [21]. The researchers' aims are to understand the participants' world, and 'what it is like' for them and to locate the initial 'description' in terms of wider social, cultural, and theoretical, contexts.

Researchers engaged with the interview material both individually and as a group. To 'hear' (and attune to) the voices of the participants, researchers listened to the audio recording of the interviews and in group analysis took turns reading the transcripts closely and out loud. This involved reading and re-reading and listening to the audio over again. The aim was to not only understand what was being said, but also how and why it was said. This means taking into account language used, expression and emotion and understanding how participants contextualised what they said in relation to their own background and experience of, for example being mother, GP, person with dementia, their coping strategy, and broader issues of for example, dementia as a social, cultural and medical phenomena in the twenty-first Century. The analysis revealed participants experiences of hallucinations, their life experiences which informed their coping strategies, their self-awareness of their condition, their ability to articulate their experiences, and how the re-telling of their experiences gave them agency and seemingly a sense of control over how they were understood and viewed.

3.3 Script Development

The phenomenological and interpretive analysis aimed at identifying the emotional valency of reported events and understanding the experiences of participants. In addition, a series of descriptive terms were applied to allow for an exploration of differences and similarities in storylines or experiences. They included, for example, awareness, cognitive, confabulation, coping, emotion, friends, hallucination, etc. The data was not thematized or categorized as such. A structuring element for the artwork was the inclusion of a piece of music discussed by one of the participants (and later voiced by Viv) by Australian composer Peter Sculthorpe. His string quartet no. 16 in five movements give rise to five 'chapters': I. Loneliness II. Anger III. Yearning IV. Trauma V. Freedom. A series of vignettes based on the interviews were created and allocated to chapters according to the five movements. The script was prepared for the immersive experience in a non-linear form, with storyline changing for each viewing of the *The Visit*. The script was developed with a core storyline and story options for each of the chapters (see Fig. 2). A team of experts in dementia, psychology, art, and design worked on the script in consultation with a scriptwriter. They selected topics for inclusion in the script that revealed both the agency of the participants, the impacts of dementia, and challenged the audience.

The creative process of developing script and dramaturgy from the verbatim and reported data meant that stories needed to be adapted to fit within a unified and a single character. This was done by selecting topics and stories that overlapped and allowed for continuity in the script. In addition, *The Visit* was staged in a domestic kitchen which enable Viv to be in her home, have agency over her surroundings and be in conversation with the viewer and the hallucinated child. To achieve this participants' data were combined, with additional scripting to link scenarios
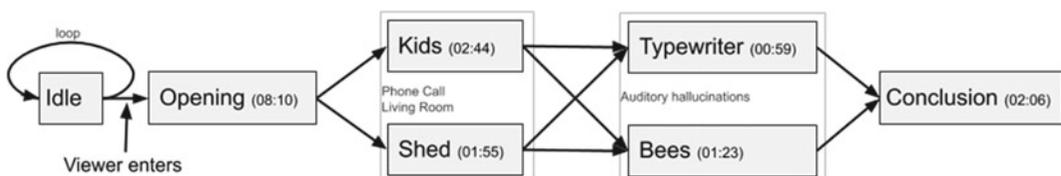

Fig. 2 The script developed into a non-linear narrative

and address the viewer. The script was developed in this way by the team in consultation with a professional playwright.

3.4 Character Construction

Viv is a composite portrait created from four women, whose accounts of living with mid-stage dementia (vascular dementia) were unified through the staged setting and the voice of an actor, who expressed the stories in the way they were related. The script was derived verbatim from semi-structured interviews, supplemented by additional reported activity. The aim was for all dialogue/events to have validity in terms of reflecting true experiences of vascular dementia. Minor modifications were made to the script detail to achieve consistency across the accounts, and names and identities of people mentioned were changed (the contributors themselves are credited with real names or pen names as per their individual preference). The script is thus intended to have scientific validity but is also driven by feeling and emotional valence, allowing for character development. The factual accuracy of Viv's monologue (her reality) is not always clear to the viewer, but she is compelling, smart, self-reliant and reflective. She experiences moments of confusion but is able to recover quickly. Viv has a strong, thoughtful, calm voice and a friendly but assertive manner. She sometimes gets 'on a roll' with her stories but in many places she pauses for reflection and reorientates herself.

A professional actor was employed to voice the character of Viv. The aim was to convey a range of controlled emotions, suggesting the inner emotional content of narrative that is sometimes broken and drifting. The voice which was developed for Viv had an authority and warmth to undercut the stereotypical notions of women with dementia. It allowed for ambiguity and depth and for the character to be alluring and commanding, and for the viewer to not be able to take a position of superior understanding but be a little intimidated by Viv. The voice needed to promote connection, encouraging visitors to sit with and listen to Viv without judgement,

irritation, pity or despair, and to find a way into her world. While her monologue is coherent and more or less flowing it also has a slightly fragmented quality as one thought or memory leads to another and she seems to float off into her own reminiscing. She has a warmth and can be funny and wry, making knowing comments or little jokes. Viv makes eye contact and connects with the viewer, especially after 'drifting off topic'.

3.5 Virtual Production

While the data was analysed and the script was being developed, work began on the virtual production (VP) of *The Visit*. VP is a broad term used for computer-aided production and visualisation film-making methods. The process leverages real-time visualisation of characters and digital sets in combination with live-action capture of the cast. Here the physical elements of film-making are brought together with the digital of computer games technologies merging traditional practices with current and ongoing advances in real-time technology to enable filmmakers to make better creative choices earlier in the production process.

3.6 The Virtual Character

The virtual character of Viv was sourced as a 3D scanned digital human and adapted accordingly. Viv's movements were animated realistically by using Motion Capture (MoCap) to digitally record an experienced MoCap actor. MoCap is a process of digitally recording patterns of movement for the purpose of animating a digital 3D character in a film or video game. Unlike a video recording, a MoCap system records spatial data of the performers joints. This data is then mapped onto a digital human's skeleton and its skin deforms according to the movements, manual modelling and animation processes of the facial expressions are then employed to increase the realism.

The MoCap sessions were directed by one of the lead script writers [second author] and

involved sessions in which the professional voice actor performed the character in situ. The MoCap actor then worked further with the director [second author] and immersive media designer [third author] to model the movement. Her voice was developed by well-known Australian TV and film actor Heather Mills who is experienced in film and television characterization. The voice was recorded separately with LipSync technology used to map the character's voice and lips. The character was depicted in a digital set which was a 3D scan of the 'real-life' functioning kitchen of a participant on the project (See Figs. 3 and 4 for of the virtual production processes and Fig. 5 of screenshots of Viv in her kitchen).

The artwork is designed to be viewed in VR on an Oculus Quest headset, which offers six degrees of untethered spatial tracking (not requiring a computer or cables). The viewer is only required to wear the headset and headphones and is not required to operate controllers. In addition, The Visit was exhibited onscreen in a gallery as an installation which was part of [exhibition name, Festival name and location]. Viv was perceived as life-sized in the interactive real-time video and was sensitive to the motions of the viewer, responding to the presence of the viewer sitting in front of the screen on the chair provided. The immersive experience is further supported by the ambisonic sounds of Viv's audio hallucinations and the kitchen environment, which is her reality are spatially perceived.

The viewer, seemingly seated on chair at Viv's kitchen table is required to adhere to the social conventions of visiting someone's home and is not free to roam around the virtual space. The call to movement and action of the viewer (the usual format of immersive experiences) is deliberately curtailed as the agency of the encounter remains with the onscreen character who 'recognizes' the presence of the viewer and moves and responds accordingly. Immersive experiences are often used to allow the viewer to 'step into' a character, in this artwork the awareness of the viewer becomes focused on their role *alongside* another. They are not positioned in this immersive experience, as 'seeing through the eyes' of Viv [15], which is often expected in a VR and immersive experience, rather they are encouraged to be *with* Viv.

4 Conclusion

The visit extends the field of experience simulation and relational VR because of its use of deep context rich data, and in positioning the viewer *beside* another, rather than offering a transpositional experience of becoming another.

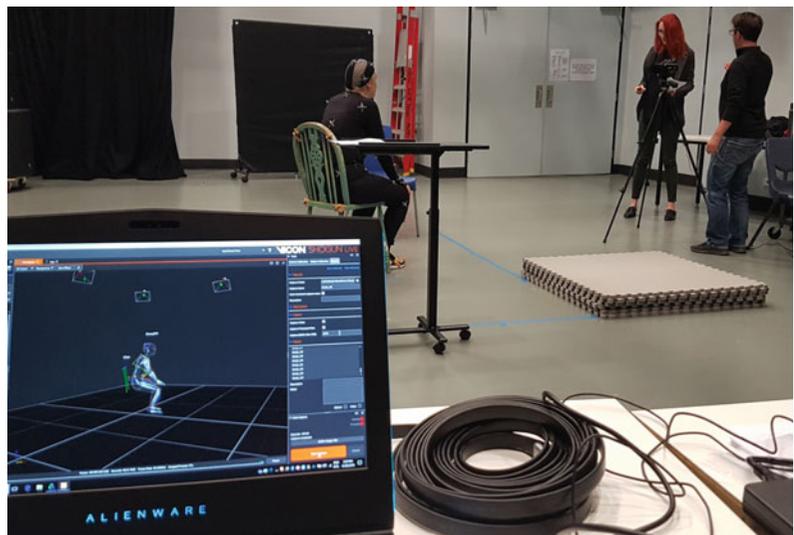Fig. 3 Visual production processes using motion capture

Fig. 4 Visual production processes using an actress to voice the character

Fig. 5 Screenshots of the visit which show the digital character Viv in a 3D-scanned kitchen

We argue that to 'experiences homelessness' by virtue of being placed in a street at night as in the Stanford project or 'seeing through the eyes of another' or perceiving from a different embodied situation does not engage psychosocial inter-subjectivity to the same extent. The artwork does not aim to provide the viewer with what it is like to *have* dementia, but to be alongside a person with dementia, to cultivate empathy for what *they*

are experiencing from being *alongside*. The script and character development employed the services of people experienced in dramaturgy and in how creative engagements can present nuanced and ambiguous experiences that avoid the didactic informational approaches of 'knowledge transfer'. In addition, the use of imagination and memory by the viewer ensures it remains a part of their knowledge base as an

experience which promotes schema building and awareness of the issue. Viv, embodying the accounts of lived experience of people with dementia, both manifests the internal perceptual world of dementia *and* the capacity for insight and self-knowledge that confounds the judgement and preconceptions of dementia. A formal evaluation of the cultivation of empathy as a result of *The Visit* has also been published [in press].

It creates the potential for an experience by attending to affordances, rather than directing the experience per se [19]. It presents opportunities for action "that neither demand nor allow a participant to easily co-opt, normalise or resolve the experience of another" [14]. The non-linear narrative produced from assembled transcripts for use both on screen and VR give the viewer insights into the contested realities experienced by the character Viv and brought a greater awareness of what it is like to be *with* and *attuned to* a person facing these challenges.

The resulting psychosocial understandings are layered and complex as the psychological and social context of the participants are overlaid with the experience of the viewer and their engagement with an immersive media artwork exhibited in a gallery context, an arts festival, and in public and community space. As part of an international mental health arts festival, with film screenings in the US, and shown as part of health and wellbeing conferences the audience for *The Visit*, and psychosocial 'knowledge translation' of the lived experience of dementia is socially, demographically and geographically diverse.

References

1. Peacock, S., et al.: The positive aspects of the caregiving journey with dementia: using a strengths-based perspective to reveal opportunities. J. Appl. Gerontol. **29**(5), 640–659 (2010)
2. Sinclair, S. et al.: Sympathy, empathy, and compassion: a grounded theory study of palliative care patients' understandings, experiences, and preferences. Palliat. Med. **31**(5), 437–447 (2017)
3. Brankaert, R., Kenning, G.: HCI and design in the context of dementia. Cham, Springer International Publishing, Imprint, Springer (2020)
4. Villar, F., Serrat, R., Bravo-Segal, S.: Giving them a voice: challenges to narrative agency in people with dementia. Geriatr. (Switzerland) **4**(1) (2019)
5. Mitchell, G.J., Dupuis, S.L., Kontos, P.C.: Dementia discourse: from imposed suffering to knowing otherwise. J. Appl. Hemeneutics **12**, 1–19 (2013)
6. Rogers, C.R.: A theory of therapy, personality and interpersonal relationships as developed in the client-centered framework. In: Koch, S. (ed.) Psychology: A Study of a Science. Study 1, Volume 3: Formulations of the Person and the Social Context, pp. 184–256. McGraw-Hill, New York (1959)
7. Phillipson, L. et al.: Dementia attitudes and help-seeking intentions: an investigation of responses to two scenarios of an experience of the early signs of dementia. Aging & Ment. Health **19**(11), 968–977 (2015)
8. Batson, C.D. et al.: Empathy and attitudes: can feeling for a member of a stigmatized group improve feelings toward the group? J. Pers. Soc. Psychol. **72**(1), 105–118 (1997)
9. Batson, C.D. et al.: Five studies testing two new Egoistic alternatives to the empathy—altruism hypothesis. J. Pers. Soc. Psychol. **55**(1), 52–77 (1988)
10. Ahn, S.J., Le, A.M.T., Bailenson, J.: The effect of embodied experiences on self-other merging, attitude, and helping behavior. Media Psychol. **16**(1), 7–38 (2013)
11. H., D.M.: Empathy. In: Stets, J.E., Turner, J.H. (eds.) Handbook of the Sociology of Emotions. Springer, Boston (2006)
12. Galinsky, A.D., Moskowitz, G.B.: Perspective-taking: decreasing stereotype expression, stereotype accessibility, and in-group favoritism. J. Pers. Soc. Psychol. **78**(4), 708–724 (2000)
13. Bennett, J.: Empathic vision: affect, trauma, and contemporary art. Stanford, CA, Stanford University Press (2005)
14. Bennett, J., Froggett, L., Muller, L.: Psychosocial aesthetics and the art of lived experience. J. Psychosoc. Stud. **12**(1) (2019)
15. Herrera, F. et al.: Building long-term empathy: a large-scale comparison of traditional and virtual reality perspective-taking. PLoS ONE. **13**(10)
16. Oh, S. et al.: Virtually old: embodied perspective taking and the reduction of ageism under threat. Comput. Hum. Behav. **60**(C), 398–410 (2016)
17. Milk, C.: How virtual reality can create the ultimate empathy machine. TED, Ideas worth spreading (2015)
18. Rogers, C.R.: The necessary and sufficient conditions of therapeutic personality change. J. Consult. Clin. Psychol. **60**(6), 827–832 (1992)

19. Gibson, J.J.: The ecological approach to visual perception. New York, NY, Psychology Press (1986)
20. Bennetts, A.W.: Talking heads. In: S.D. Burge (ed.) UK (1988)
21. Larkin, M., Watts, S., Clifton, E.: Giving voice and making sense in interpretative phenomenological analysis. Qual. Res. Psychol. **3**(2), 102–120 (2006)
22. Smith, J.A., Flowers, P., Larkin, M.: Interpretative phenomenological analysis: theory method and research. London, Sage (2009)
23. Tuffour, I.: A critical overview of interpretative phenomenological analysis: a contemporary qualitative research approach. J. Healthc. Commun. **2**(52), 1–5 (2017)