Qualitatively exploring the suitability of tablet computers to encourage participation with activities by people with moderate stage dementia

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Abstract - Opportunities to participate with enjoyable activities is one of the most frequently reported unmet needs by the person living with dementia. Enabling and intuitive technologies may offer accessible ways to engage with such activities. **Objectives** –to explore how tablet computers might encourage participation in enjoyable activities by people with moderate levels of dementia and to consider how such technologies might be incorporated into the repertoire of activities currently provided through day care settings. **Methods** – A focused visual ethnographic approach was developed specifically to meet the research objectives. Twelve participants attending a community day care centre and nine supporters (both volunteers and paid staff) consented to take part in the research. Technology facilitated group activity sessions took place twice a week for a period of 4 weeks and all were video recorded. **Findings** – Video analysis demonstrated that the majority of people with dementia found the technology an effective means of participating in enjoyable activities. Analysis also revealed the extent to which participation relies on the existence of effective support. It showed how maintaining focus on retained strengths and abilities enabled the group overall to meet and often exceed their capacity to participate. Finally, analysis confirmed the importance of enjoyment of activities 'in the moment' and the need for those supporting people in the moderate stages of dementia to acknowledge and work with this. **Conclusion** – The use of tablet computers to enhance participation in sociable and enjoyable activities in day care settings is realistic and achievable if supported appropriately.

Keywords : dementia, tablet computers, qualitative, participation, ICT

Introduction

Opportunities to participate in activities that are meaningful to the individual are known to be frequently unmet in people living with dementia (Miranda-Castillo, Woods, & Orrell, 2013). In common with the rest of society, people with dementia can value opportunities to stay socially connected. As the disease progresses, such opportunities can be successfully provided through community groups (Genoe & Dupuis, 2012). Newer forms of accessible technology has the potential to increase the quality of life of older adults including those with a dementia diagnosis (Mulvenna, Nugent, Moelaert, Craig, Droes & Bengtsson, 2010). This is acknowledged in the Prime Ministers Challenge on dementia 2020 which states that new ideas need to be incorporated into dementia research and services, including the translation of technological solutions into everyday practice (Department of Health, 2015). Thus research is required to identify the ways in which technology might perpetuate the engagement and self-efficacy with people with dementia at all stages of the disease trajectory.

Applied Health Researchers have often used qualitative methods that rely on the coherent articulation of users' experiences and views of health; these include interviews and focus groups. The skills required for communicating through writing, reading and speaking can be compromised in certain groups, older adults with a diagnosis of dementia for example. Qualitative research methods need to be adopted that consider the spoken word but do not necessarily rely on it as the only form of communication. Non-verbal behaviours are of equal importance when researching with people with dementia thus the development of

novel, stimulating and creative research methods are required that can contribute to existing knowledge and increase our understandings of the person and the condition. As such, attending to non-verbal communicative behaviour including gestures, body language, facial expression and posture become paramount as non-verbal behaviour cannot be effectively captured using audio recorders or field notes (Rose, 2012). Despite this, attention to non-verbal behaviour remains limited in dementia research. This highlights a lack of appropriate methodology enabling dementia researchers to access and capture the experiences of the condition that are not easily articulated. This research emphasises that meaningful communication and interaction is achievable with people living with the moderate stages of dementia using novel and creative methods.

The research described in this paper explored the potential of tablet computers to promote participation in enjoyable and social activities by people living with moderate stage dementia attending day care services and living in the community. A review of the relevant literature identified significant evidence gaps (Smith & Mountain, 2012). First, the use of technology in the context of dementia care has focused primarily on issues of safety and security as well as carer reassurance; second, previous research into activity provision has focused on studies undertaken in residential care, with those living at home being under researched; third, how people with dementia can be assisted to use their residual capacities is frequently neglected in favour of a deficit model. Research is now required to explore the strengths and retained abilities and potentially the positive aspects of living with dementia. The research described in this paper aimed to address these evidence gaps with an emphasis on positive psychology, thereby focusing on the

maintained strengths of the person as oppose to existing loss-deficit approaches that have characterised dementia research in the past (Wolverson, Clarke, & Moniz-Cook, 2016).

Research question:

1. How might it be possible to successfully incorporate tablet computers into the repertoire of activities currently provided through day care settings?

Method

Qualitative methods are appropriate when the phenomenon under investigation is characterised by certain features. These include topics that are not well understood, that are highly emotive, sensitive and deeply embedded in personal experience, interaction and practice as well as the social processes of the participants. The complex and diverse nature of experiences that constitute the condition of dementia requires a strong approach that is theoretically rigorous producing meaningful explanations. A visual ethnographic method utilising video recorders for data collection has been developed specifically to meet the aims of this research project. This technique was appropriate as this approach permitted the researcher to participate in the event and facilitate engagement with the tablet computers without the interference of explicit data collection using field notes. Furthermore, Bond & Corner, (2001) argue that to focus solely on participants meanings from qualitative interviews has substantial shortcomings as they act only as representations of reality. This method also enabled an inclusive approach to be adopted including and consulting people with dementia whilst recognising the impairments associated with the condition. Comprehensive description of his method will be available in a forthcoming paper by the same authors. Video-based fieldwork has become well

established within the social sciences although the collection, analysis and dissemination of visual data in the multidisciplinary field of applied health remain underdeveloped. Nevertheless, video based methods are integral to this project and are utilised during data collection, analysis and dissemination of the research results.

Design

Research setting

The research setting was a well-established charitable community day-care organisation, staffed by a registered mental health nurse and unqualified assistants with support from volunteers and nursing and social work students. The setting provides a meeting place three days a week for people with moderate stage dementia living in the community (some alone), with the aims of improving wellbeing through activity and friendship and also providing carers with respite. Researchers have relied on convenience samples when the group of interest already exists or alternatively may be difficult to access. An opportunity was presented to visit the group with the aim of gaining an increased understanding of the setting and how the group may fit with the research. It was concluded that the research would be a good fit for the following reasons; the researcher would be supported effectively by existing staff and volunteers, the research would provide opportunities for group members to try novel activities through their interactions with the tablet computers and all group members lived at home either with informal support or alone. Having drawn these conclusions, the researcher approached the centre manager with the research idea for her consideration which was met with a high level of enthusiasm.

Sample

The selection criteria were straight forward as the only criterion for participant recruitment was that the person was a member of the community group. However, this highlighted potential challenges due to the group context and the unique ways that the usual sessions are structured. All group members are supported on a one-to-one basis by staff, students and volunteers who collectively participate in each session by congregating around a large table. There are no opportunities for small group activities as the main aim of the group is to promote friendship and maintain wellbeing in a communal way. Thus if any group member, volunteer, student or staff member declined their involvement then the research could not proceed as members would not have been withdrawn from the context during the research. Equally, had any spouse, family member or informal caregiver declined their loved one's involvement then the research could not have taken place. Based on the support and extensive experience of the group manager it was considered good ethical practice for the manager to approach group members and their informal carers at the recruitment stage. This was because the manager had built up relationships based on trust with the members and carers over long periods of time in some cases, which ultimately resulted in the effective recruitment of all group members.

Informed consent

Establishing the basis for consent was supported by the group manager. Although informal caregivers would not be participating in the research, written consent was sought prior to the research taking place to ensure that they agreed and were happy for their loved ones to be involved. Carer, participant, staff and volunteer consent forms also

detailed that the sessions would be video recorded and images would be utilised in the dissemination of the findings to an academic audience. Consent was gained for all group members, staff members and volunteers during a usual session at the community group. It was agreed between the researcher and the group manager that ongoing verbal consent be sought at the beginning of each research session to ensure all participants remained content with their participation. Informed consent was gained from everyone involved in the group and all informal carers. No one declined to participate or declined the involvement of their loved ones.

Table 1 summarises the demographics of people with dementia who participated. There was limited experience with tablet computers as only one participant reported using them post retirement. Those in a supporting role included staff, the researcher, student work placements and volunteers. The characteristics of those in a supporting role were more variable as seen in table 2. Prior experience of dementia ranged from extensive to none as did experience of tablet computers.

Insert table 1 here

Table 1: Participant characteristics

Insert Table 2 here

Table 2: Supporter characteristics

Research procedures

The researcher attended the day care group as a volunteer for one month prior to data collection commencing. This was to become familiar with the group routine and members as well as providing an opportunity for staff, volunteers and members to become familiar with the researcher. This period of familiarity enabled an increased appreciation regarding how to stimulate and maintain interest with existing activities before the tablet computers were introduced. Based on observations as a volunteer the researcher uploaded the tablet computers with familiar activities already enjoyed by members that appeared to effectively transfer from their traditional form to technology formats, including dominos, solitaire and jigsaws. New interactive applications were also uploaded including the keyboard, guitar and drum kit because evidence suggests that

music can have beneficial, therapeutic effects for people with dementia (Sixsmith & Gibson, 2006). The quantity of applications increased as the researcher became more familiar with the group and individual preferences became apparent. The flexibility of the devices and the plethora of available applications enabled the personalisation of the devices to the voiced preferences of the group. Further, the flexibility of many of the applications enabled levels of difficulty to be adjusted to the person's capabilities. The following applications were utilised during the sessions with the tablet computers.

Insert Figure 1 here

Figure 1: Applications utilised on tablet computers

Data collection method

Prior to each session commencing, the researcher demonstrated possible ways to introduce the tablet computers using a selection of the applications to those in a supporting role. The tablet computers were placed at the centre of the table along with the familiar activities that were usually enjoyed (including reference books, puzzles and life story books). It was agreed that the best method of introducing the technology would be in small groups of 3 to 4 sitting together yet seated around the communal table. This is the usual way that group members interact with activities and each other thus a familiar part of the group routine. The optimal data collection method was video-based participant

observation, a technique which was adapted and developed specifically to meet the aims of this research. Participant observations enable a deeper understanding of the social context and when video recorded, result in rich data that may act as representations providing insight to the ways participants express their own meanings and experiences of the research. Ritchie and Lewis (2003) describe observational data as the 'enactment' of social behaviour rather than the 'recounting' of experience from interviews. The duration of the research sessions was one hour and always took place before lunchtime. Two discrete video recorders stood on tripods, each positioned at opposite ends of a large table around which the group gathered for each session. Sixteen hours of video footage from two cameras was captured during two, one hour sessions per week over a period of four weeks.

Data analysis method

Data analysis for this study was influenced by the methodological framework referred to as 'multimodal interactional analysis' (Norris, 2004). 'Multimodality' characterises research data that is not primarily words or numbers. Modes may be audible, visual or contextual but in any social situation they will definitely be multiple. Multimodality as a technique is appropriate for the purposes of this study due to the significance of non-verbal communication which comes to the fore during analysis. Although not all people with a diagnosis of dementia are challenged when communicating, differences can emerge in the ways people express themselves as the condition progresses thus, an analytical technique was required that may translate these differences effectively. Although combining multimodality and visual ethnography is novel in dementia research, this combination has been successfully utilised in numerous other qualitative projects

(Dicks, Flewitt, Lancaster, & Pahl, 2011; Hurdley & Dicks, 2011). Data analysis followed a process of familiarisation, data reduction and synthesis, merging multiple modes and meaning and explanation.

Familiarisation. The first step in the process of any qualitative data analysis is a period of familiarisation. For this research it involved familiarisation with the video footage. This initial but thorough review of the data enabled the assessment of the breadth and depth of what had been captured. This assessment highlighted the obvious volume of data but also the complexity of what was going on visually and audibly. The decision was made to undertake a second viewing of the videos with the computer monitor turned off to enable a complete focus on the audible content of the videos rather than the visual content. This process was then repeated with the sound muted on the video recordings in order to attend to all that was visible. It was concluded that viewing videos with no sound heightens what is seen whilst listening to the same video without the visual heightens what is heard.

Data reduction and synthesis. The notes that were made during the familiarisation stage of analysis illustrated various themes beginning to emerge which consequently enabled the identification of 'episodes' of video data that were selected, synthesised and reduced from the large quantity of data. Analysis did not focus on the fine detail of behaviour involving every arm movement or blink of an eye. Nor did analysis focus on the whole 60 minutes of each video recorded session. Rather, an active decision was made that could illustrate the emerging themes through episodes that captured significant and meaningful occurrences which consisted of 5-10 minutes of analysed data per hour of video footage.

Episodes transcribed. Once the data had been reduced, the episodes that illustrated the emerging themes were transcribed verbatim into charts which created a record of the prominent instances that were identified from the notes made during the familiarisation stage of analysis. Highlighting these prominent instances enabled the gradual emergence of salient themes from the data.

Merging multiple modes. Once each episode had been transcribed verbatim and emergent themes identified, prominent images that could add salient features and increase meaning were then incorporated into the text in order to communicate findings. These multimodal transcriptions incorporating both the visual and the audible illustrated the gradual unfolding of a specific event. The visual image was considered to portray equal meaning to the corresponding text of that image whereas pure 'text' was limiting the meaning of this particular data.

Meaning and explanation. Building explanations of why the patterns, categories and themes have emerged in the data is the final stage of data analysis. Comprehensive details and discussion of the analytical technique will be available in a forthcoming paper by the same authors.

Insert Figure 2 here

Figure 2: Process of data analysis

Ethics

Ethical approval was gained from the University of Sheffield Research Ethics Committee.

Findings

Video analysis demonstrated that the majority of people with dementia found the technology an effective means of participating in enjoyable activities. It showed how maintaining focus on retained strengths and abilities enabled the group overall to meet and often exceed their capacity to participate. Data analysis also revealed the extent to which participation relies on the existence of effective support. The analysis of the video data emphasised the importance of appropriate scaffolding and support to enable participant's engagement with the tablet computers. Three facets of scaffolding and support emerged through the process of data analysis and these were; effective scaffolding and support, sufficient scaffolding and support and unsuccessful scaffolding and support, findings from each will be presented in turn.

Effective scaffolding and support

Effective scaffolding is considered to be the optimum level of support and was observed to facilitate feelings of achievement and mastery of skills. An example of effective scaffolding can be seen in Figure 3. The dyad is playing a game of memory match which requires the matching of pairs depicting pictures of animals. The group member has no previous experience of tablet computers yet is confident in her technology use as she progresses through the increasingly difficult levels of the game. There is a constant dialogue between the pair as they discuss the application as the participant navigates the screen with ease. The technology and the applications remain unfamiliar to the group member despite her participation in previous sessions. Those interactions that were observed to be effectively scaffolded involved thoughtful tactical and competitive strategies using turn taking activities. The main aim of these interactions was observed to be the mastery of particular skills resulting in feelings of achievement when games were won or puzzles were solved. The appropriate encouragement and support resulted in the mastery and achievement of a particular skill enabling independent interactions to be maintained and confidence to increase. Figure 4 illustrates Eva's sense of achievement when completing increasingly challenging levels of a card matching game…she exclaims '…so I'm not as thick as I thought I was?' Despite Eva's confidence with the technology and the various applications they remain unfamiliar as past experience from previous sessions has not been brought forward to subsequent sessions. This suggests that Eva's participation with the technology is 'in the moment' or in the here and now which is illustrated in figure 5.

Insert Figure 3 here

Figure 3: Effective scaffolding and support

Insert Figure 4 here

Figure 4: Achievement and mastery of skills

Insert Figure 5 here

Figure 5: Achievement and mastery of skills ‘in the moment’

Sufficient scaffolding and support

Sufficient scaffolding and support describes how the presence of support is sufficient to maintain interest and participation with the technology and activities. If input or support from the volunteer is required during any aspect of participation, then it is available instantly providing individuals with the confidence and security to maintain interest in technology use. Figure 6 shows two group members who are interacting with an application on the device that uses a voice recorder, so everything they say is repeated back to them. The pair are talking to the tablet computer as if it were a third person in the conversation. A volunteer is sitting next to the pair and is in a supporting role.

The data illustrates that the dyad are supporting each other in terms of enabling engagement with the tablet computer. The volunteer is sitting close by but is not part of their conversation or interactions with the technology. The two women engage in a constant dialogue regarding what they are seeing on the screen and enjoying the entertaining activities. The presence of the support was observed to be sufficient and communicating this was not reliant on the spoken word. Yet more importantly, it is the interactions between the two group members and their continuous conversation instigated by what they were seeing on the tablet computer that was observed to provide mutual support.

In this case, technology interaction was observed to be a social endeavor involving increased conversation and laughter for enjoyments sake rather than the mastery of skills or competitive turn taking activities. Interactions were relaxed and informal and the

support in place during these encounters was sufficiently scaffolded and technology interaction is secondary to the social interaction taking place as depicted in figure 7. The tablet computer itself or an application on the screen acted as a prompt for a certain conversations or facilitated interesting anecdotes between group members. Participants were observed chatting and humorously conversing with each other around topics that were instigated whilst interacting with the technology. Although Janet notices the video camera and questions its purpose the experience of previous sessions have not been retained nor has providing ongoing verbal consent at the beginning of the current session by either participant. This suggests that both Claire and Janet's participation with the research session is also 'in the moment', illustrated in figure 8.

Insert Figure 6 here

Figure 6: Sufficient scaffolding and support

Insert Figure 7 here

Figure 7: Increased conversation and laughter

Insert Figure 8 here

Figure 8: Conversation and laughter 'in the moment'

Unsuccessful scaffolding and support

Unsuccessful scaffolding and support reflects limited interest, engagement or conversation with or regarding the tablet computers or each other from the perspective of group members or those in a supporting role. The influence of the person in a supporting role was observed to not always positively impact the experience of technology interaction for the participants. It may be that participants would have chosen not to engage with the technology irrespective of the support available, yet sufficient or effective scaffolding may have provided them with more opportunity too.

There were examples of the person in a supporting role who was observed to have limited interest in the technology sessions. This illustrates that experience of working with people with dementia and existing knowledge of tablet computers does not necessarily guarantee effective of sufficient support. Had an alternative approach to scaffolding been in place it is also acknowledged that this may not have been sufficient for all group members to engage with the technology on any particular day. During some sessions, indifference to the technology was observed by the same two group members but this was in addition to all other social interactions demonstrating a lack of desire and apathy to connect with the support or the activities around them.

Not all participants that disengaged did so every time the technology was presented which suggests in some instances that disengagement was the product of unsuccessful scaffolding and support at that particular time. It could also be a consideration that the condition was being experienced differently between sessions, on different days and the individual felt little desire to engage with the technology when compared with previous sessions. Alternatively, those who disengaged may not have been particularly interested in the application that was being illustrated. It was observed that some participants chose not to interact with the technologies irrespective of the support in place and these particular participants displayed limited conversation or laughter during activity sessions with or without the technologies.

Discussion

The findings from this study indicate that tablet computers can encourage participation through enjoyable, meaningful activity with people with moderate stage dementia when participants are supported appropriately in a sociable setting. The findings illustrate the divergent ways people can experience technology interaction shaped by the type of scaffolding and support within the same context. Certain facets of effective scaffolding and support were also identified. First, the need to remain focused on the strengths and retained abilities of participants and second; acknowledgement that technology interaction is 'in the moment' for people with moderate stages of dementia. For some, appropriately supported interactions with the technology were observed to promote feelings of achievement as certain skills were mastered; it also provided opportunities for increased conversation and laughter. For others, although in the minority, less engagement with the tablet computers was observed as individuals preferred to sit back and watch the interactions taking place.

Scaffolding and support

The term 'scaffolding' (Vygotsky 1978) is a psychological concept that emphasises the appropriate delivery and demonstration of new information that is dependent on the individual's interest and capabilities. The term scaffolding in the context of this study, describes effective ways of encouraging participants whilst interacting with the technologies and others. Rather than the pure delivery of information, scaffolding requires the demonstration of information which is a vital factor in the success of the method. The findings of this research have highlighted the potential of consistent and

effective scaffolding and support and the possibilities this may afford people with dementia in their technology participation.

Focus on strengths and retained abilities

Effective scaffolders recognise the importance of never taking over a task that may undermine the person's intact capabilities; equally it is important that the person is not left to struggle and fail at a task which could contribute to the further deskilling of the individual. Rather, we need to determine the person's capabilities in relation to any activity being undertaken and support it effectively. The essence therefore of effective scaffolding is to participate alongside the person whilst remaining aware of their capabilities and retained skills. Opportunities that focus on maintained strengths may then promote feelings of achievement and of self-worth. In this sense, overlooking the deficits and focusing on what is retained and enjoyed, has the potential to enhance individual wellbeing as people seek the positive experiences despite cognitive, sensory and physical impairment (Clark and Wolverson, 2016).

Nevertheless, the findings highlighted inconsistent approaches from those in a supporting role which had an impact on the efficacy of the scaffolding and support received by participants. It could be that these differences are due to the invested interest that the person in a supporting role had in this particular group. Certainly, the researcher had an invested interest to encourage participation with the tablet computers thus collecting rich visual research data. However, is should be acknowledged that not all participants would have had the same experience in every session even if had they received the same quality

of scaffolding support as this will have been dependent on numerous factors. These factors include how the condition was being experienced on that particular day, individual characteristics, individual interests and the rapport between participant and supporter. Essentially, it is the joint attention and the social interaction between those in a supporting role and the person with the condition that plays a key role and promotes this effective scaffolding behaviour (Astell et al., 2010).

The findings illustrate the diverse experience those in a supporting role had with tablet computers as well as the varied experience of working with people with dementia and the diminutive impact this had to do with the effective scaffolding and support that was observed. Effective scaffolding did not require extensive knowledge of tablet computers or the condition of dementia in order to be valuable support during the research sessions. Rather, it was the approach that was taken by some of those in a supporting role that was both personable and enthusiastic that promoted effective scaffolding and support. By taking a reciprocal approach instead of an expert/novice approach, successful scaffolders were observed to promote an experience of 'let's try this together'. It should be emphasised that the researcher and others in a supporting role greatly influence how participants experience technology interaction and may ultimately find themselves as much a part of the data as the participants and the technologies, some taking a more effective role than others.

'In the moment'

It is important that those in a supporting role acknowledge that technology participation for this group was 'in the moment' which was found to be an important element of effective scaffolding and support in this research. The findings indicate that participants retained limited knowledge of their experiences of the tablet computers or applications between the research sessions although familiarity within sessions was observed. Thus, as each session commenced the tablet computers would require reintroduction to the group and ongoing verbal consent from the previous session to ensure individuals remained happy to participate. It was found that enjoyment of activities was no less meaningful for the person just because reflection of previous sessions was a challenge but 'living in the moment' does implicate the persons own decreasing awareness of their experiences of dementia as the condition progresses (Clare et al., 2003) as well as the unpredictable speed of deterioration. Thus as awareness decreases the acknowledgement of past experiences is also hindered (Steeman, Godderis, Grypdonck, De Bal, & Dierckx de Casterlé, 2007) as the struggles and stresses of the memory impairment become less relevant or are indeed forgotten.

Key messages for research going forward

Living well with dementia is a national priority and recent research outputs are beginning to reflect how we can enable people to live as well as possible with the condition. An additional article is forthcoming by the same authors exploring technology participation involving people living with a recent diagnosis of dementia. Using the same methods, individuals participated from their own homes and the tablet computers were

personalised to each individual based on the knowledge gained through in-depth interviews. The findings indicate the capabilities that people in the early stages of the condition retain despite dementia when provided with opportunity to participate with meaningful and enjoyable technology interaction. Further exciting developments in this area are on the horizon including Virtual Reality Reminiscence in dementia as well as the use of Avatars and voice recognition software.

Key messages for practice

The reality of technology use dictates that not everyone will want to engage with tablet computers either through lack of interest or possibly due to other sensory and physical impairments. However, creativity from those in a supporting role can often overcome challenges to technology participation, time permitting. Tablet computers can go some way towards addressing the stigma associated with dementia as people with the condition are able to engage with contemporary devices in line with the rest of the population, given the opportunity and support to do so. In addition, tablet computers are an excellent intergenerational tool for families to engage their loved one with dementia with meaningful music, photographs and video.

Conclusion

The findings from this research indicate that the majority of participants were receptive to technology interaction although the heterogeneity of people with dementia was evident. These differences were found to be both physical and cognitive and were observed to be

influential in the ways people with dementia experience the condition and the ways in which enjoyment was derived. The findings emphasise the importance of the scaffolding and support in place to encourage optimum enjoyable technology interaction. Two prominent elements of effective scaffolding and support were found to influence participant's experience with the tablet computers. First, focusing on maintained strengths and abilities thus providing achievable goals can promote feelings of self-worth; second, the importance of 'in the moment' participation needs to be highlighted when involving people with moderate stages of dementia in research. Ultimately effective scaffolding and support is the key to engaging people with the moderate stages of dementia with meaningful, enjoyable technology interaction. As researchers, supporters, formal and informal, and professionals we need to explore creative ways to promote and enable participation with people living with dementia.

Declaration of Conflicting Interests

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