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**O PAPEL DA NARRATIVA DIGITAL PARA COMUNICAÇÃO NO CUIDADO DE
PESSOAS COM DEMÊNCIA**

DISSERTAÇÃO DE MESTRADO

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**O PAPEL DA NARRATIVA DIGITAL PARA
COMUNICAÇÃO NO CUIDADO DE PESSOAS COM
DEMÊNCIA**

Dissertação de Mestrado apresentada ao Programa de Pós-Graduação em Gerontologia da Universidade Federal de São Carlos, como parte dos requisitos para a obtenção do título de Mestre em Gerontologia, área de concentração: Gerontologia

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Dedico esse trabalho aos meus pais, Mário e Rosa.

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“Sou uma pessoa vivendo no estágio inicial de Alzheimer. E assim sendo, estou aprendendo a arte de perder todos os dias. Perdendo meus modos, perdendo objetos, perdendo sono e acima de tudo, perdendo memórias. Toda a minha vida eu acumulei lembranças. Elas se tornaram meus bens mais preciosos”.

(Para sempre Alice - Lisa Genova)

RESUMO

Considerando a transição epidemiológica, as demências tornaram-se uma questão primordial em saúde pública devido à alta prevalência e graves consequências. Neste contexto, o uso de Tecnologias de Informação e Comunicação (TIC) poderia fornecer suporte às narrativas digitais como uma ferramenta de comunicação para unir pacientes com demência, familiares e cuidadores, e apoiar um modelo de cuidado colaborativo e personalizado. **Objetivo:** Explorar questões e requisitos de comunicação com cuidadores formais e informais no contexto de idosos com demência e por sua vez, avaliar suas reações quanto à tecnologia de narrativa digital, como uma nova intervenção tecnológica no cuidado no contexto institucional e domiciliar. **Método:** O presente estudo promove colaboração internacional com o projeto "When TiME matters: digital story telling in care home settings" entre pesquisadores da Universidade Federal de São Carlos – UFSCar e a Universidade de Surrey (UK), dividido em duas partes. A primeira parte tem como proposta um estudo de caso realizado em uma instituição de longa permanência para idosos (ILPI) localizada no interior do estado de São Paulo, Brasil, com cuidadores formais, informais (familiares/amigos) e idoso institucionalizado, convidados e incentivados a realizar narrativas digitais por um período de teste. A segunda parte do estudo contou com uma pesquisa-piloto por meio de entrevistas semi-estruturadas para envolver 10 usuários finais (cuidadores formais e informais de idosos com demência) no domicílio. **Resultados:** Os resultados encontrados apontam para a natureza social da tecnologia e a importância do papel do cuidador como facilitador neste processo. Os resultados do estudo de caso demonstraram que em geral, a tecnologia foi mais útil para facilitar conversas mais ricas com os residentes e outros participantes, como também estimular uma maior expressividade e criatividade na idosa com demência. Por sua vez, os resultados encontrados no segundo estudo, apontam para uma provável adoção de narrativas digitais como uma forma de comunicação multimídia entre pessoas com demência e seus cuidadores, assim como identificam requisitos e necessidades na comunicação e ressalta a importância de mídias sociais inclusivas como meio de comunicação no contexto da demência.

Palavras-chave: Comunicação; Cuidado; Demência; Tecnologia, Narrativas digitais.

ABSTRACT

Considering the epidemiologic transition, dementia has become a paramount issue in public health due to its high prevalence and the gravity of its consequences. In this context, the use of Information and Communication Technologies (ICT) could provide support for digital narratives as a communication tool for a patient with dementia, family members and caregivers. Objective: To explore the issues of communication with formal and informal caregivers of the persons with dementia in the context of long-term care home and home / community context. Method: The present study is an international collaboration project with the project "When TiME matters: digital narrative in home care environments" between researchers from UFSCar and the University of Surrey (UK), in two parts. The first part is a case study in a long-term care institution (ILPI) located in the countryside of the state of São Paulo, Brazil, with caregivers from the staff, older person with dementia and family members who used digital narratives for a one-month trial period. The second part was an interview qualitative study with 10 end-users (formal and informal carers) who work with home care for people with dementia. Results: The results point to the social nature of technology and the importance of the role of the caregiver as facilitator in this process. The results of the case study demonstrated that in general, the technology was more useful in facilitating richer conversations with residents and other participants, as well as stimulating greater expressiveness and creativity in the person with dementia. Furthermore, the results found in the second study showed enthusiasm for adoption of digital narratives as a form of multimedia communication between people with dementia and their caregivers, as well as identifying requirements and needs in communication and emphasizing the importance of inclusive social media in the context of dementia.

Keywords: Communication; Care; Dementia; Technology, Digital Storytelling.

LISTA DE FIGURAS

Figura 1 – Estudos realizados.....	12
Figura 2: The Com-Phone interface, showing the home screen (left), the options for an individual frame (middle) and a frame populated with image, sound and textual content (right).....	14
Figura 3: Trial procedure.....	15
Figura 4: A typical story (number 11).....	17
Figura 5: Going to the dentists (story 6).	19
Figura 6: HR birthday party (story 8).....	21
Figura 7: Health report story (story 13).	22

LISTA DE TABELAS

Table 1: Characteristics of recorded stories.....	17.
Table 2: Participants demographic characteristics.....	32.

SUMÁRIO

CAPÍTULO 1: INTRODUÇÃO.....	1
1.1. NARRATIVAS DIGITAIS COMO FERRAMENTA DE COMUNICAÇÃO.....	6
1.1.1. Objetivo Geral	9
1.1.1.2. Objetivos específicos.....	10
1.2. Estudos	10
CAPÍTULO 2: MOBILE DIGITAL STORYTELLING IN A BRAZILIAN CARE HOME.....	13
2.1. METHOD.....	13
2.2. RESULTS	15
2.2.1. Story Characteristics	16
2.2.2. Resident Perspective	18
2.2.3. Family and friend perspective	19
2.2.4. Formal carer perspective	21
2.2.5. Researcher perspective	23
2.3. DISCUSSION	26
2.3.1. Technology.....	26
2.3.2. Values.....	27
2.3.3. Future research	29
2.4. ACKNOWLEDGEMENTS	30
CAPÍTULO 3: Communication and digital narratives in the context of dementia care	31
3.1. METHOD.....	31
3.2. RESULTS	34
3.2.1. Communication Issues involving the care recipient.....	34
3.2.2. Care coordination and Daily routine activities.....	36
3.2.3. Social media and digital content	37
3.2.4. Technology Feedback	39
3.3. DISCUSSION	41
3.3.1. Communication obstacles	42
3.3.2. Role of ICTs.....	43
3.3.3. Technology recommendations	44
CAPÍTULO 4: CONSIDERAÇÕES GERAIS	46
REFERÊNCIAS	48
ANEXO 1.....	54
APÊNDICE 1	55
APÊNDICE 2.....	56

CAPÍTULO 1: INTRODUÇÃO

O Brasil caminha para se tornar um país de população majoritariamente idosa. Dados da Pesquisa Nacional de Amostras de Domicílio (PNAD – Contínua - Características dos Moradores e Domicílios) de 2018, apontam que a população brasileira manteve a tendência de envelhecimento dos últimos anos e ganhou 4,8 milhões de idosos desde 2012, superando a marca dos 30,2 milhões em 2017. Em 2012, a população com 60 anos ou mais era de 25,4 milhões. Os 4,8 milhões de novos idosos em cinco anos correspondem a um crescimento de 18% desse grupo etário, que tem se tornado cada vez mais representativo no Brasil (INSTITUTO BRASILEIRO DE GEOGRAFIA E ESTATÍSTICA – IBGE, 2018).

Esta transição demográfica, resultante da drástica queda nos níveis de mortalidade e fecundidade e do aumento da esperança de vida, guarda estreita correlação com a dinâmica epidemiológica, na qual o perfil de doenças crônicas passa ser predominante em sua maioria pelas pessoas idosas (CHAIMOWICZ; CARMARGOS, 2011), com alterações significativas no perfil de morbi-mortalidade de sua população. Dentre essas morbidades, as demências apresentam alta prevalência.

Segundo a Organização Mundial de Saúde (WHO a, 2017) em todo o mundo, cerca de 50 milhões de pessoas sofrem de demência e há quase 10 milhões de novos casos por ano. Revisões sistemáticas globais e metanálises sugerem que a prevalência de demência é menor na África Subsaariana e maior na América Latina do que no resto do mundo. A prevalência padronizada por idade para aqueles indivíduos com idade maior ou igual a 60 anos variou em uma estreita faixa, 5% -7% na maioria das regiões do mundo, com maior prevalência de demência na América Latina (8,5%) (PRINCE, 2013; HUGO; GANGULI, 2014).

Nos países de renda mais alta, a prevalência é de 5 a 10% em indivíduos com 65 ou mais anos, geralmente maior entre as mulheres do que entre os homens, em grande parte porque as mulheres vivem mais do que os homens. Níveis educacionais mais baixos também foram encontrados associados à maior prevalência. Nos EUA, maior prevalência foi relatada em afro-americanos e latinos/hispânicos do que em populações brancas não hispânicas (HUGO; GANGULI, 2014).

Estima-se que 35,6 milhões de pessoas viviam com demência em todo o mundo em 2010, com números quase duplicados a cada 20 anos, para 65,7 milhões em 2030 e 115 milhões em 2050. Em 2010, 58% de todas as pessoas com demência viviam em países com baixa ou rendimentos médios, com esta propensão prevista para aumentar para 63% em 2030 e 71% em 2050 (PRINCE et al, 2013; HUGO; GANGULI, 2014).

Em 2015, a demência tornou-se a principal causa de morte no Reino Unido, com 529.655 mortes registradas na Inglaterra e no País de Gales (ONS, 2016). Entre as demências, a doença de Alzheimer é a mais comum entre os idosos, responsável por 60 a 80% dos casos, seguida pelas demências vasculares (AMERICAN PSYCHIATRIC ASSOCIATION, 2013; WHO, 2017; ALZHEIMER'S ASSOCIATION, 2019).

No Brasil, a prevalência brasileira média é mais alta que a mundial. Projeções para a população brasileira apontaram para um pequeno crescimento na taxa de prevalência de demência na população com 65 anos e mais, de 7,6% para 7,9% entre 2010 e 2020, ou seja, 55.000 novos casos por ano (BURLÁ et al., 2013). A doença de Alzheimer é a causa de demência que lidera em número de casos e a associação entre demência e idade, assim como escolaridade (BOFF; SEKYIA; BOTINO, 2015; TEIXEIRA et al., 2015).

Considerando a crescente prevalência populacional, as demências tornaram-se uma questão primordial em saúde pública, gerando gastos diretos e indiretos, como aposentadorias e internações, o que pode repercutir em trabalhadores ativos por acometimento de familiares que requerem seus cuidados (PARMERA; NITRINI, 2015).

Os custos de serviços de saúde e os custos informais de cuidado não remunerado para indivíduos com demência são altos e crescentes (HUGO; GANGULI, 2014). Em 2015 os cuidados com demência representaram um custo social de 818 bilhões de dólares e sua prevalência deve triplicar até 2050 (WHO b, 2017).

O termo demência pode ser conceituado como um conjunto de sintomas associados a um declínio na memória ou outras habilidades de raciocínio, como linguagem, orientação, função executiva, atenção e cálculo, por exemplo, potencialmente severas para reduzir a capacidade de um indivíduo realizar atividades cotidianas (MIOSHI; HODGES; HORNBERGER, 2013; WHO, 2017a).

As causas da demência estão ligadas a danos às células cerebrais que interferem na capacidade dessas células se comunicarem entre si. Quando as células cerebrais não

conseguem se comunicar normalmente, o pensamento, o comportamento e os sentimentos são afetados (ALZHEIMER'S ASSOCIATION, 2019).

Tendo em vista a progressão da doença, há o aumento e a demanda por cuidados e supervisão constantes, sendo uma das principais causas de incapacidade e dependência entre pessoas idosas em todo o mundo (CHAVES et al, 2011; SEIMA; LENARDT; CALDAS, 2014; WHO, 2017).

A demência reflete na capacidade funcional do indivíduo em todas as áreas de desempenho ocupacional, de modo que a pessoa pode apresentar maior dificuldade em tomada de decisões, planejar e desempenhar tarefas individuais, na habilidade de compreensão e integrar as informações (FAGUNDES et al, 2017) As etapas fundamentais para a realização de atividades básicas de vida diária (ABVD), como vestir-se, tomar banho e alimentar-se, e atividades instrumentais de vida diária (AIVD) ligadas às tarefas domésticas, administração de medicamentos e pagar contas, por exemplo, serão afetadas. Estudos apontam sobre a hierarquização do declínio funcional em idosos, iniciando-se pelas AIVD, enquanto as ABVD permanecem preservadas por um período maior de tempo (SPIRDUSO, 2005; FAGUNDES; 2017).

A demência é tipicamente diagnosticada quando a deficiência cognitiva adquirida tornou-se grave o suficiente para comprometer o funcionamento social e /ou ocupacional. Com base no Manual Diagnóstico e Estatístico de Transtornos Mentais - DSM-5 (AMERICAN PSYCHIATRIC ASSOCIATION, 2013), o diagnóstico exige evidência de declínio significativo em qualquer domínio cognitivo, além de comprometimento funcional. O que representa um afastamento dos critérios do DSM-IV para demência, que exigiam comprometimento da memória e pelo menos uma outra função cortical superior (CHAGAS; PESSOA; ALMEIDA, 2018).

No que tange as responsabilidades quanto ao cuidado para com o idoso, nesse cenário, o papel do cuidador vem à tona e a tarefa do cuidar é atribuída a uma pessoa que pode ser membro ou não da família, seja profissional ou não (FUHRMANN et al., 2015).

A literatura gerontológica define e classifica os cuidadores em dois tipos (BORN, 2008): o cuidador formal, composto por cuidadores qualificados e assalariados para o desempenho da função de cuidar e o cuidador informal, que geralmente, é representado pela família residente no domicílio, sem qualificação para tal, amigo ou vizinho que realiza tarefas de apoio e cuidado voluntário (RAFACHO; OLIVER, 2010).

No Brasil o cuidado é obrigação familiar, assegurada por políticas públicas, dentre elas a lei n.º 10.741, de 1.º de outubro de 2003, que dispõe sobre o Estatuto do Idoso e determina:

Art. 3.º: É obrigação da família, da comunidade, da sociedade e do Poder Público assegurar ao idoso, com absoluta prioridade, a efetivação do direito à vida, à saúde, à alimentação, à educação, à cultura, ao esporte, ao lazer, ao trabalho, à cidadania, à liberdade, à dignidade, ao respeito e à convivência familiar e comunitária (BRASIL, 2013).

Os serviços de atendimento domiciliar formal preenchem essa lacuna, mas criam novos desafios para a comunicação com pacientes com demência e seus cuidadores informais (MACINKO; HARRIS, 2015; BRAZIL et al., 2017). Além disso, manter o idoso no seu domicílio por mais tempo à medida que envelhecem, alivia a pressão sobre instituições estatais ou privadas, como instituições de longa permanência para idosos, mas aumenta a carga de cuidados em cuidadores informais (STENSLETTEN et al, 2016).

Por outro lado, no momento em que o familiar assume o papel de cuidador do idoso, este passa a vivenciar uma cascata de mudanças em sua rotina social, financeira, emocional e familiar. Cuidadores informais dedicam maior tempo às atividades de cuidado, com abandono de várias atividades cotidianas produtivas, de lazer e de cuidados pessoais após assumirem a atividade de cuidado (BAUAB; EMMEL, 2014; SEIMA; LENARDT; CALDAS, 2014). Além disso, os sintomas neuropsiquiátricos levam à diminuição da qualidade de vida, institucionalização precoce e aumento das comorbidades clínicas dos pacientes, assim como maior sobrecarga e estresse emocional para os cuidadores (BREMENKAMP, 2014).

Dentre esses fatores, a má comunicação contribui para a tensão do cuidador e aumenta notavelmente o ônus da doença. No contexto do cuidado formal, as dificuldades nas relações interpessoais e a comunicação com a equipe de cuidados de saúde, são considerados desafios fundamentais que causam um alto nível de frustração e carga emocional (GENTRY; FISHER 2007; WOODWARD, 2013).

A pessoa com demência muitas vezes perde a capacidade de comunicar pensamentos e necessidades a medida que a doença avança, tornando cada vez mais difícil interagir socialmente e manter relações pessoais com cuidadores, familiares e amigos, planejar atividades diárias e expressar as necessidades básicas e pensamentos para aqueles que as rodeiam (WOODWARD, 2013). No estágio avançado, os problemas de comunicação tornam-se ainda mais importantes e são agravados pela perda de memória e déficits intelectuais (WEINER et al., 2008; DELFINO; CACHIONI, 2016).

Quanto às barreiras na comunicação com o idoso com demência, a dificuldade de se comunicar devido às solicitações repetitivas, diminuição acentuada de vocabulário, frases inacabadas, dificuldades de nomeação e muitas vezes a falta de diálogo com a pessoa que eles estão cuidando são as mais comumente mencionadas por cuidadores de pessoas com demência (LEITE et al., 2014; OLIVEIRA et al., 2016; DELFINO; CACHIONI, 2016; JH et al., 2016).

Nesse sentido, intervenções podem estimular as atividades de criação de significado, comunicação e contatos sociais (BUTLER, 1963; WANG, 2007; COTELLI; MANENTI; ZANETTI, 2012; GIL, 2017). Uma tecnologia que não foi considerada neste âmbito está relacionada com a 'digital storytelling' ou narrativas digitais.

As narrativas digitais são caracterizadas por filmes pessoais curtos constituídos por uma série de imagens estáticas com arquivos de voz, música e texto (LAMBERT, 2013), podem ainda ser realizadas em smartphones e tablets, usando aplicativos para montar esses elementos de mídia (FRANK, 2008).

O uso de Tecnologias de Informação e Comunicação (TIC) teria potencial de fornecer suporte às narrativas digitais como uma ferramenta de comunicação para unir pacientes com demência, familiares e cuidadores e pode não somente resolver questões de comunicação, mas apoiar um modelo de cuidados colaborativos e personalizados que transcendem as barreiras físicas e cria uma cultura transparente de “cuidado de demência”.

1.1. NARRATIVAS DIGITAIS COMO FERRAMENTA DE COMUNICAÇÃO

Um estudo de revisão de literatura elaborado por Vecchi et al. (2016) teve como objetivo mapear como a narração digital tem sido usada na saúde mental num aspecto mais amplo (pessoas com psicose, respostas complexas ao trauma, duplo diagnóstico, deficiência psicossocial, demência e ansiedade) e identificar lacunas na literatura. Como resultado, o estudo aponta que a história digital pode ter potencial como um processo participativo para a compreensão mútua e empatia para experiências vivenciadas na saúde e que há um aumento da pesquisa nesta área. Entretanto, mais pesquisas são necessárias sobre o uso da narrativa digital em saúde mental para determinar sua eficácia e formas de uso.

Quanto à aplicação em demência, um estudo realizado por STENHOUSE et al. (2013) teve por objetivo formar reflexões sobre o processo de criação de histórias digitais durante um workshop com pessoas com demência em estágio inicial e estudantes de enfermagem como facilitadores destas atividades. Sete pessoas com diferentes formas de demência e uma variedade de dificuldades cognitivas e funcionais participaram da oficina. A oficina aconteceu durante quatro dias consecutivos, mas foram adotadas medidas preventivas de exaustão ou desengajamento durante o processo. Como principal resultado encontrado pelo estudo, o workshop realizado demonstrou que pessoas em estágio inicial da demência tem a capacidade de se envolver com a narrativa digital. A capacidade destes participantes se empenharem, com apoio apropriado ligados a aspectos mais técnicos do processo, como o uso de computadores e gravação de som, abre possibilidades de envolvimento de pessoas com demência em uma grande variedade de projetos usando tecnologia desconhecida. As descobertas sugerem que as pessoas com demência em estágio inicial são capazes de contar suas histórias dentro de um relacionamento quando são oferecidos espaço, tempo e ajuda para desenvolvê-las.

Além disso, o estudo destaca a importância da relação entre participante e facilitador, e que foi possível promover mudanças positivas nas interações dos participantes. Como conclusão, tais melhorias pareciam ser o produto da facilitação centrada na pessoa e do processo criativo que apoiava a auto-expressão e um senso de identidade. Enfermeiros ativos com o auxílio das narrativas digitais poderiam dessa maneira facilitar a habilidade da pessoa com demência para participar de seus cuidados e

melhorar sua sensação de bem-estar apoiando a auto-expressão (STENHOUSE et al., 2013).

Importante ressaltar, profissionais de saúde e do cuidado em geral poderiam dessa maneira facilitar e estimular a habilidade da pessoa com demência para participar de seus próprios cuidados e melhorar sua sensação de bem-estar, apoiar a auto-expressão, ou ainda, comparilhar cuidados em saúde e melhorar habilidades de comunicação e sobrecarga.

No estudo de Park et al. (2017) participantes com demência foram incluídos em um workshop de sete sessões durante o período de seis semanas, onde criaram histórias digitais com a ajuda de pesquisadores e cuidadores. Foram discutidas nas sessões a experiência do encontro com os pesquisadores, o compartilhamento de histórias e o uso da tecnologia, incluindo mídia digital. Os dados foram coletados por meio de notas de campo observacionais e sessões de oficina gravadas em áudio e entrevistas, posteriormente transcritas e analisadas. Ao final, os participantes tiveram a oportunidade de compartilharem suas histórias digitais com seus familiares. Os resultados mostraram de maneira geral, que a experiência foi positiva para os participantes no processo de criação de histórias digitais, apesar de alguns desafios com comunicação, memória e uso de tecnologia. O estudo aponta ainda que a narrativa digital tem o potencial de favorecer o compartilhamento e a preservação de história de maneira significativa para pessoas com demência. Entretanto, nenhum participante conseguiu usar o programa para a edição de histórias de forma independente, o que corrobora para inclusão do papel do cuidador (formal e informal) e profissionais de saúde no uso de TICs que dão suporte às narrativas digitais.

O estudo piloto realizado por Davis et al. (2015), teve como objetivo mensurar a carga percebida de cinco cuidadores e a disposição de buscar apoio social durante um período de teste de duas semanas em uma instituição para idosos. Quatro dos cinco cuidadores acessaram o aplicativo, utilizaram o protótipo de um aplicativo com instruções mínimas, registraram histórias, visualizaram e classificaram as histórias de outras pessoas e completaram as pré e pós-escalas. Para todos os quatro participantes, foi relatado que a sobrecarga foi diminuída pela informação e prazer obtido a partir das histórias gravadas em vídeo. O impacto da intervenção sobre a carga percebida e a disposição para buscar apoio social foi examinado em testes pré e pós-intervenção com a Escala Zarit Burden e a Escala de Envolvimento do Grupo Kaye's Gain Through. O pós-teste identificou alta

satisfação com o aplicativo e facilidade de uso, sugerem também que os resultados relacionados à sobrecarga do cuidador em grupo maior seja considerado para estudos futuros.

No estudo de YAMAGATA et al. (2013), foram realizados testes de usabilidade com diferentes aplicações para produzir um aplicativo que atendesse pacientes, familiares, necessidades e expectativas dos cuidadores. Dentre eles estava o aplicativo intitulado Candoo que utiliza mecanismo de reconhecimento de voz e síntese do Google para navegar na Web, fornecer o tempo e fornecer alertas de lembrete de medicamentos. Outro exemplo de aplicação incluiu um que permite às famílias enviar eletronicamente fotografias, vídeos e músicas favoritas de qualquer lugar para familiares. Os participantes aprenderam a acessar fotos e páginas quando a música tocava e foram convidados para falar sobre as fotos que retratam suas experiências. Cuidadores, principalmente filhos e esposas, foram convidados a ajudar a encontrar fotografias de família para uso no aplicativo.

O aplicativo ainda permite às famílias o envio de fotografias, vídeos e músicas favoritas de qualquer lugar para os entes queridos. Os idosos foram avaliados antes e após a intervenção. Segundo o estudo, tal aplicativo ainda pôde permitir que pessoas com demência se tornem menos agitadas e que pudessem permanecer em suas casas por mais tempo, quando ainda não se encontravam institucionalizadas e ao mesmo tempo pode proporcionar consciência e mudança para uma atitude positiva por parte de outras pessoas para com os idosos (YAMAGATA et al, 2013). Estes resultados demonstram a importância do design centrado no usuário para o desenvolvimento e adoção de produtos “dementia friendly”.

É perceptível o recente o processo de investigação acadêmico-científico, em nível nacional e internacional, relacionado à temática narrativa digital ou *digital storytelling* como terapêutica utilizada nos diferentes contextos da demência, tanto para instituições de cuidados quanto cuidadores informais. Todavia ainda há lacunas no que tange ao desenvolvimento de trabalhos que considerem o potencial da narrativa digital como instrumento de promoção de saúde e comunicação neste contexto e exigem investigação profunda sobre como profissionais de saúde e cuidadores compreendem esses desafios e possibilidades (MEDEIROS; FOSTER, 2014).

Além disso, há uma carência de diretrizes e evidências no estado da arte da narrativa digital nas questões técnicas e éticas no uso das narrativas digitais como uma

ferramenta para melhorar a comunicação entre os pacientes com demência, cuidadores e familiares (SLATER et al. 2015). Seu uso ainda continua voltado para a criação de histórias de vida e um novo estudo para investigar necessidades e a comunicação com idosos com demência por meio de cuidadores formais e informais poderia responder a essas questões e preencher lacunas da literatura disponível.

Dessa maneira, a possível customização de tecnologias de informação e comunicação (TIC) pode ajudar em atividades de recordação e entrelaçar a narrativa digital com um número maior de usuários finais, de modo que o uso de recursos de artes de inovações de expressão criativa como essas narrativas podem ajudar na relembração, comunicação, e influenciar nos aspectos sensoriais, participação e qualidade de vida (JAANISTE et al, 2015).

Apesar deste estudo não objetivar a análise da eficácia de intervenção, a experiência dos cuidadores pode favorecer uma provável adoção desses atores do cuidado no uso de histórias digitais como uma forma de comunicação multimídia entre pessoas com demência e seus cuidadores, o que poderia fornecer um canal de interação co-presente e remota entre eles, sendo estas histórias voltadas à autobiografia ou *life-logging* e diário de linha do tempo.

Diante de tais alterações e aspectos associados, justificamos a relevância em analisar os cenários e considerar, neste âmbito, as estratégias que contribuam para a promoção da melhoria da comunicação por meio de dois estudos apresentados na presente dissertação que buscam compreender as diferentes interações e o compartilhamento de informações e histórias relacionadas ao cuidado do idoso com demência e seus cuidadores.

1.1.1. Objetivo Geral

Explorar questões e requisitos de comunicação com cuidadores formais e informais no contexto de idosos com demência e por sua vez, avaliar suas reações quanto à tecnologia de narrativa digital, como uma nova intervenção tecnológica no cuidado.

1.1.1.2. Objetivos específicos

i) Compreender os principais obstáculos na comunicação com pessoas idosas com demência, tais como aquelas experimentadas por cuidadores formais e informais em uma instituição de longa permanência para idosos;

ii) Apresentar opiniões e atitudes de cuidadores sobre as tecnologias de informação e comunicação (TICs) e as estratégias para minimizar a sobrecarga e melhorar a comunicação e a coordenação entre os cuidadores, os idosos e a família no contexto domiciliar.

1.2. Estudos

Os presentes estudos promovem colaboração internacional com os projetos “When TiME matters: digital story telling in care home settings” e “Time 4 design” entre pesquisadores da Universidade Federal de São Carlos – UFSCar e a Universidade de Surrey (UK), dividido em estudo 1 e estudo 2, conforme figura 1. O primeiro estudo tem como proposta um estudo de caso realizado em uma Instituição de longa permanência para idosos (ILPI) localizada no Brasil com a tríade de cuidadores formais, cuidadores informais (familiares/amigos) e idoso institucionalizado, no qual estes participantes foram convidados e incentivados a realizar narrativas digitais por um período de teste descrito no capítulo 2, a fim de atender o primeiro objetivo específico desta dissertação.

Neste cenário, histórias digitais com imagem e música foram usadas como uma ferramenta de comunicação. As descobertas nos ajudaram a explorar a viabilidade e a aceitabilidade de uma solução baseada na história digital que poderia auxiliar a comunicação de cuidadores formais e informais (familiares e amigos) com pacientes com demência em uma ILPI.

Para esta primeira etapa, quatro pesquisadoras da Universidade Federal de São Carlos - UFSCar participaram do trabalho de campo. A instituição era visitada pelas pesquisadoras em pares, devido à demanda de atividades e manuseio dos instrumentos. Seus papéis variaram e evoluíram ao longo do tempo, dependendo do tema da história, dos participantes e dos requisitos do projeto.

A análise de dados desta primeira parte do estudo contou com a colaboração de dois pesquisadores do Reino Unido (Theopisti Chrysanthaki e David Frohlich). Além disso, esses resultados também foram aceitos para serem apresentados e publicados no HCI INTERNATIONAL 2018 – 20th International Conference on Human-Computer Interaction no formato de artigo (ABRAHÃO et al., 2018).

Os resultados do primeiro estudo foram considerados na atual dissertação de mestrado devido à relevância dos resultados encontrados e sua importância como subsídio para a segunda etapa do projeto.

O segundo estudo, por sua vez, descrito no capítulo 3, compreende ao segundo objetivo específico e contou com uma pesquisa-piloto por meio de entrevistas semi-estruturadas para envolver usuários finais no domicílio. Cuidadores formais e informais foram os informantes quanto à requisitos e necessidades sobre a comunicação com o idoso com demência a fim de minimizar a sobrecarga e melhorar a comunicação e a coordenação de cuidado entre eles, os idosos e a família. Participaram desta segunda etapa uma amostra total de 10 cuidadores, divididos em dois grupos: formais e informais (familiares / amigos).

A entrevista foi dividida em parte 1 e parte 2. A primeira parte foi composta por sete questões que buscaram entender os obstáculos na comunicação com o idoso com demência e apresentar opiniões e atitudes para minimizar estes problemas. Na segunda parte da entrevista, os participantes puderam assistir algumas histórias criadas no primeiro estudo (capítulo 2) por meio de um álbum multimídia ou ainda, pelo canal criado no Youtube para compartilhamento das histórias. Após as demonstrações, os participantes responderam seis questões relacionadas às suas reações quanto o uso da tecnologia do aplicativo Com-Phone, como suas impressões gerais, usabilidade e até mesmo sugestões de expansão e aprimoramento desta tecnologia.

Além disso, a análise de conteúdo qualitativo dos resultados encontrados pôde ainda, nos fornecer recomendações para o desenvolvimento de uma aplicação relacionada ao design do próximo produto de narrativas digitais.

As pesquisadoras Paula Fernanda Carlos da Silva, professora Paula Costa Castro e a aluna de graduação Larissa Ferraz, foram responsáveis pela coleta de dados da

segunda parte do estudo. A candidata Paula Fernanda Carlos da Silva se tornou a principal pesquisadora nesta etapa.

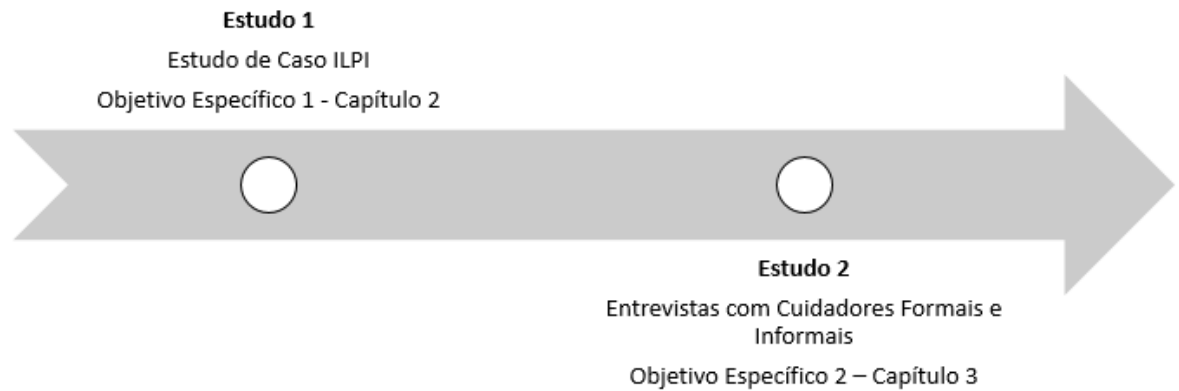


Figura 1 – Estudos realizados

Os estudos realizados são descritos nos próximos capítulos, assim como seus resultados.

CAPÍTULO 2: MOBILE DIGITAL STORYTELLING IN A BRAZILIAN CARE HOME

2.1. METHOD

A simple field trial was conducted using the *Com-Phone Story Maker* app as a ‘technology probe’ (HUTCHINSON et al., 2003) to uncover the benefits and requirements for future systems, customised for this context. *Com-Phone* is part of the Community Media (*Com-Me*) toolkit designed to support multimedia communication in communities with low levels of literacy (<http://digitaleconomytoolkit.org>). It is an open source Android app available free on the Google Play store. It allows users to assemble photo narratives on a smartphone or tablet and annotate each photograph with voiceover and/or text in a multimedia slide show (FROHLICH et al., 2012). Three screen shots of the interface are shown in Figure 2. The narratives can be saved as movies and uploaded to social media sharing systems such as YouTube. Full details of its capabilities are given in the user manual for Com-Phone from the website above. For our study, we created a Portuguese language version of the app and made it available within a single care home, acting as a case study.

The case study was conducted in a private care home, having about 24 residents and 26 care staff, in São Carlos, in the countryside of São Paulo state in Brazil, in 2017. All the residents of this care home have neurocognitive impairment and present dependency for daily living activities of levels 2 or 3 (in a 0-3 Katz scale, being 3 totally dependent) (LINO et al., 2008).

One female resident aged 60 with dementia was invited to participate following the inclusion criteria of presenting important neurocognitive impairment but still having communication skills remaining, with score of ten on the Mini Mental State Exam (MMSE) (LOURENÇO; VERAS, 2010). After that, we invited the resident relatives and carers to participate. Final participants were: two family members, one sister and the brother-in-law; and two caregivers, one manager and the nutritionist. Four Brazilian researchers (Abrahão, da Silva, Castro and Gratão) also participated in the fieldwork. The study protocol (875.356/2014 and 2.069.671/2017) received ethics approval from the Federal University of Sao Carlos Ethics Committee and all volunteers signed a consent form.

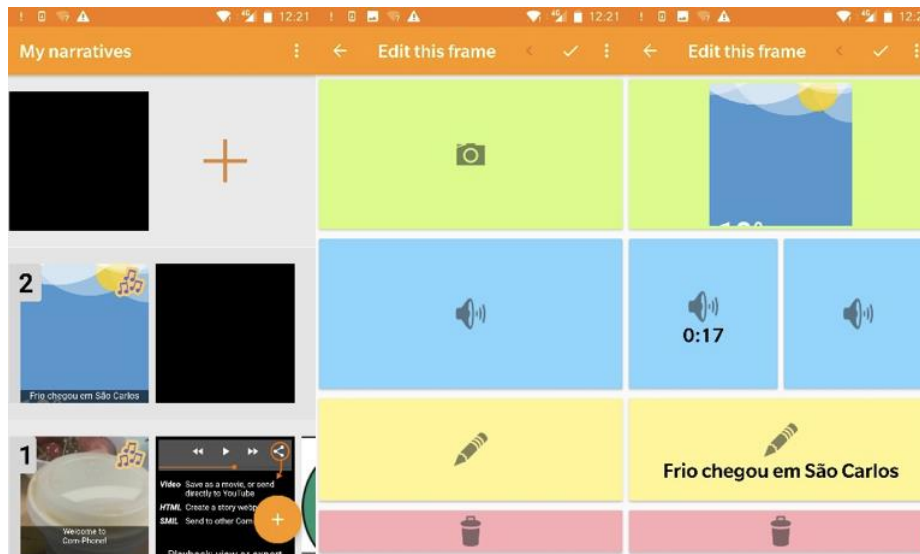


Figure 1: The Com-Phone interface, showing the home screen (left), the options for an individual frame (middle) and a frame populated with image, sound and textual content (right).

The procedure used in the trial is illustrated at Figure 3. After a baseline interview, the participants attended a half-hour workshop about digital storytelling and the *Com-Phone* app, and then used tablets and smartphones to create their stories over the next four weeks. A Portuguese version of the app was installed on an Android tablet kept in the care home for the duration of the trial, and also on the Android smartphones of the researchers and the resident's sister. A principle researcher and author (Abrahão) led the fieldwork in the trial and attended all care home visits. She was occasionally accompanied by another field researcher on a subset of visits (da Silva, Castro or Gratao). In fact, these researchers became important participants in the study itself because the technology proved difficult to hand over to other participants for unassisted use. During the trial period, the researchers met the resident for twelve one-hour sessions (usually scheduled every 2 days). They also met family members and care home staff four times to support story creation and upload onto YouTube. Every week the researcher uploaded the narratives at YouTube for sharing them.

After the four-week trial period, participants answered questions in two post-trial interviews (soon after and follow-up) about their experiences with the software, as well as about the values of the system in supporting communication. Because of the significance of the field researchers in the trial and their involvement in both therapy and

story creation sessions, they were also interviewed as additional ‘participants’ by UK author four (Chrysanthaki) who did not attend any of the sessions in Brazil.

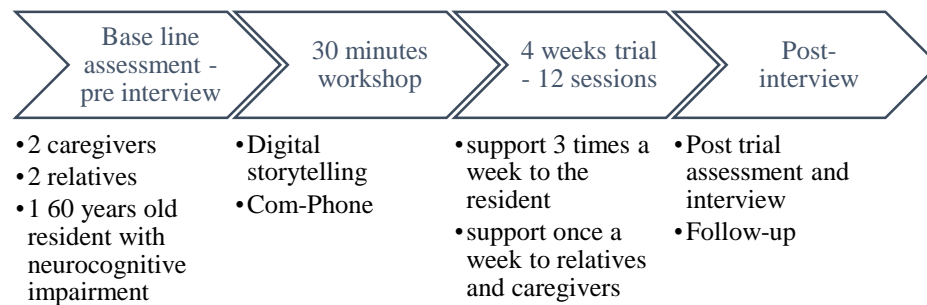


Figure 2: Trial procedure.

2.2. RESULTS

The data were analysed with frequency and thematic analysis in the following way. First, we collected 15 digital stories made by participants in the study, over one month from 24th May to 26th June 2017. These stories comprise multimedia narratives in sound, image and text. Stories were assembled into a ‘story-book’ transcript with English translation in the form of a PowerPoint slide show with associated sound. This was eventually printed (without translation) as a photobook which was given back to the care home resident as a memento of the study. The storybook was also used to code the technical characteristics of stories as described in Section 4.1 below. Unfortunately, the content of the 15th story was lost due to a failure of the authors’ phone, which had to be reset. We include it in the analysis so far as we can, without knowing the exact characteristics or including it in the storybook transcript.

Second, we recorded all pre and post-trial interviews with participants and field researchers, and created both Portuguese and English transcripts. These were subject to separate content analyses for each type of participant; generating four different perspectives on the technology intervention from the care home resident, care home staff, family and friends, and researchers themselves. The results of these analyses are given in Sections 4.2-4.5 below, summarising answers to similar questions asked and themes which emerged in each type of interview as salient to participants themselves.

2.2.1. Story Characteristics

The best way of introducing the characteristics of stories made in the trial is to describe a typical story, such as that shown in Figure 4. This comprises five frames containing one image each, in which some of the frames have additional text, voiceover or music. The total duration of the story was one minute, 45 seconds (1:45) and was authored by one of the field researchers with help from the resident and her sister. Creation was done on the sister's phone. The features of this story approximate to an average story of 6.53 frames and images, with 2.2 voiceovers and text messages and 0.4 music clips, all with an average duration of 1:25. Most stories were authored by the researchers in collaboration with other participants on either a phone or tablet. The distribution of these characteristics across the story corpus is shown in Table 3, together with a description and classification of their content and authorship.

This particular story is not very story-like, which is also typical of the corpus. It was recorded during a visit to the resident of her sister and brother-in-law, by a researcher who was also present. The researcher begins the story by recording a short conversation with the resident about what she is wearing for the visit, perhaps prompted by the fact she is wearing a warm woollen hat, scarf and cardigan indoors with her legs covered by a blanket. The first three frames show this in pictures and sound before showing the exchange of a prescription between the resident and her sister, and a group shot of all visitors around the resident's chair (researchers in white). In effect, the 'story' is a **visit conversation** illustrated with photographs, text and music in no particular order, and serves as a reminder for all parties of the time they had together. Four other story types could be observed in the corpus. These were **social events** beyond a regular visit, **therapy sessions** documenting progress in some ongoing cognitive or sensori-motor training programme, **health reports** by formal carers, and **media albums** containing collections of artwork or media of various kinds. These appeared to have different functions and appeal depending on who they were made by and made for. Therefore, we illustrate them below in relation to the perspectives of different trial participants.



Figure 3: A typical story (number 11).

Table 1: Characteristics of recorded stories (key to authors: RS=Researcher, HR=Home resident, FF=Family or Friend, FC=Formal Carer).

Story number	Primary author	Co-authors	Platform	Story type	Story content	No. Frames	No. Images	No. Voice overs	No. Music clips	No. Texts	Duration (Min:Sec)
1	FF	HR	Phone	Media album	Family makes a photo album for resident						
2	RS	HR, FF	Tablet	Visit conversation	Resident made her first story and had 3 visitors	6	6	2	0	5	00:31
3	RS	FC	Tablet	Health report	Resident was not feeling well	2	2	2	0	2	01:13
4	RS	HR, FF	Phone	Visit conversation	Discussing forthcoming birthday party	7	7	7	0	0	02:17
5	RS	HR	Tablet	Media album	Resident exhibits her art work	20	20	0	1	7	02:57
6	FF	RS	Phone	Social event	Resident goes to a dentist appointment	2	2	2	0	2	00:29
7	FF	RS	Phone	Social event	Sister-in-law's birthday party	5	5	1	0	5	00:39
8	FF	RS	Phone	Social event	Resident's birthday party	8	8	1	1	2	01:02
9	RS	HR, FF	Phone	Therapy session	Cognitive training session	7	7	6	0	0	03:52
10	RS	FF	Tablet	Health report	How the resident felt the past week	1	1	1	0	0	00:30
11	RS	HR, FF	Phone	Visit conversation	Talking on a family visit	5	5	2	2	2	01:45
12	RS	HR	Phone	Therapy session	Cognitive stimulation through craft	9	9	2	1	0	01:17
13	RS	FC, FC	Phone	Health report	Resident care history and diet	2	2	2	0	1	01:19
14	RS	HR	Tablet	Therapy session	Learning to use whatsapp voice calling	5	5	2	0	2	00:39
15	RS	HR, FF	Phone	Visit conversation	Saying goodbye with photos	10	10	3	0	0	01:29
					Mean	6.53	6.53	2.2	0.4	2.2	01:25

2.2.2. Resident Perspective

The formal post-trial interview with the resident was difficult because the resident found it tiring and wasn't able to answer many of the questions. However, she was much more talkative in the story creation sessions. So findings in this section are brief and taken mainly from these sessions and the content of stories themselves.

The resident's favourite stories were the social events, specifically her dentist appointment (story 6) with her brother-in-law and sister. The two frames of story 6 are in Figure 5. She may have felt a sense of freedom because of the trip outside the care home to the dentist office, excitement due to being with her family and she got a gift (toothbrush) from the dentist. She told us that she would like to share this story with her extended family, in the post interview.

Story 5 was also noteworthy for the resident. In this one, a story was created as a kind of media album to showcase the resident's artwork with music clips. It is worth mentioning that she has hypergraphia and repeatedly draws simple nature pictures such as apples and flowers, making them almost without interruption every day. She also colours different pictures made by others as a gift, for example, the painting of a cake drawing, because her birthday was due soon.

In this sense, simple everyday actions are special to her, and most of the stories are about these routine activities. She likes to win little gifts and mementos, shoes or even school supplies, such as paper clips described on story 4.

In addition, the resident therapy sessions were also theme for many stories, as for example the cognitive stimulation activities with smells and colours on story 9 and tactile therapy in story 12.



Figure 4: Going to the dentists (story 6).

The resident was unable to perform the activities alone using the Com-Phone application and required help for commands and direct aid for using the features of the app, as described in the second story. She had co-participation in carrying out the stories and tried to interact with another app (*WhatsApp*) (story no. 14). However, she had positive interaction with researchers, was responsive and communicative during the meetings, as portrayed in the story 4. In effect, the main benefit of the technology to the resident was in the process of story creation which was done collaboratively with either the researchers, her family or both.

She greatly enjoyed the family and researcher visits in their own right, and welcomed the opportunity to create multimedia artefacts about her life with their help. In fact some of the stories are about the resident's relationship with the researchers, such as the last Story 15 in which she says goodbye and says to them: "*Don't forget me*".

2.2.3. Family and friend perspective

The family participants showed great interest in trying new ways of communication with the resident. They made about half of the 15 stories and were very engaged with the process and possibilities of the trial. The extended family visited the resident on festive dates, while the close family members such as the sister responsible for the resident, visited on average three times a week for four weeks.

The resident's sister and brother-in-law needed aid to interact with the application in the beginning of the project, but gradually became more independent in making stories

themselves. At the end of the study, they needed help only to upload the stories to the study YouTube channel.

The sister did not choose just one favourite story, but pointed out all the stories with family reunions. She said that every story has its own meaning. These were stories of social events, such as story 8 describing the resident's birthday when the largest number of family members and friends were gathered. The sister is the primary author of this story, which contains eight frames, seen in Figure 6, with photos taken by her own family. Family, friends and caregivers reunion was what made the story so important and meaningful for her, according to her post interview comments: "*The most beautiful is when we are all gathered... was her (resident) birthday here at the care home, with all the carers, the care home owner, a party that symbolizes happiness, friendship, joy, because every year of life is a new opportunity.*"

On the first voice recording, the resident and her sister are naming and saying the relation of each of the people in the photos, which the resident does not meet often, the other siblings and mother. She is happy because all these people had gone to visit her. The song on the following frames is Roberto Carlos' musical track "Happy birthday to you", whom is one of the resident's favourite singers since childhood.

The family appreciated the possibility of sharing day-to-day activities with the resident and her artwork, by means of digital narratives, according to a statement from the post-trial interview: "*We took more pictures of her, didn't we? We took more of her daily routine in the clinic, like the little flowers that she likes to draw... Bringing her the pictures, the colours, because she cannot walk and she does not go out of the clinic. So we are bringing some of the beauty, a little joy, the positive energy also that I think this is to live: it's sharing.*" The sister reports that regular conversation on her visits is repetitive, covering topics such as food, paintings the resident has done, people she has seen. But there was a sense with the storytelling technology that a wider range of topics are introduced through photographs and the things different people say about them.

When asked what she would like to do with the stories after they are made, the sister mentions their historical value for her and the rest of the family, and sharing with younger generations such as her daughter (the resident's niece). The family have an awareness that the stories will be even more precious in the future when the personality or the person of their loved one is lost: "*It is history. It means that it was what we lived;*

moments, souvenirs and memories. So we have to keep it in the heart...” These memories are not just those of the resident herself in happier times before the care home, but of the times spent with her in the care home, good and bad, and the care given to her by the family itself. *“I have as recorded, I have as photos, very important to remember also that I was here with my sister for the best steps (crying)”*”.

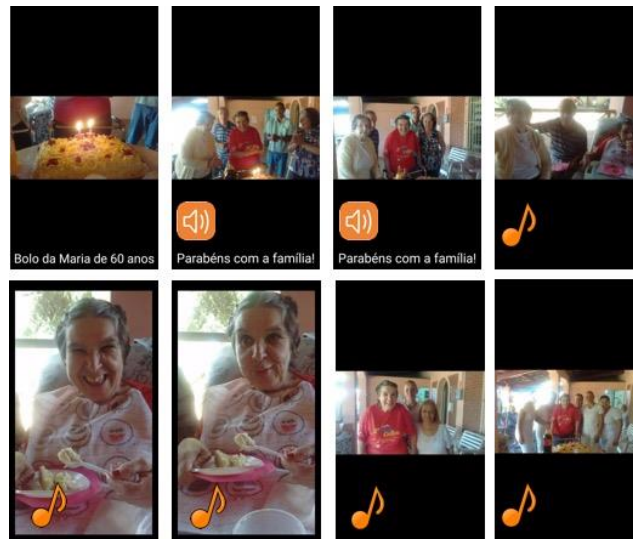


Figure 5: HR birthday party (story 8).

In this connection, it is also worth mentioning that the family liked to watch the stories related to formal caregivers, to see the care that is being provided to the resident and thus establishing a better communication with the formal caregivers.

2.2.4. Formal carer perspective

The formal caregivers who work in the institution failed to participate in most story-making sessions and didn't create stories pro-actively. Probably the task of making the stories brought more demands, increasing the burden of care. Another issue observed by the researchers was the lack of support and guidance of the care home management. For these reasons the care home staff did not keep track of all the stories being made in the trial and did not have a favorite as such.

However, they did make three stories collaboratively with the lead field researcher (Abrahão). The researcher interviewed them about the resident and recorded their talk on *Com-Phone*. She later added image files to the frames. In these conversations, the formal caregivers made comments about the resident, how she arrived at the institution to live, her health condition, her diet (story no. 13) and about what happened in her day-to-day care (stories 3 and 10).

For example, story 13 depicts the story of the resident with the institution when she arrived at the care home, including the rehabilitation after a surgery due to a hip fracture (see Figure 7). At first, she could not walk and had limited locomotion, but after a while with physiotherapy and adequate diet, the patient was able to walk with the aid of a walker. In the first frame of story 13 the care home manager discusses the state of the resident when she joined the home. *“The resident arrived in a very difficult condition in order to have a quick recovery. She had surgery to put on a prosthesis after a trochanter fracture, but she suffered rejection... the prosthesis was removed, and later the movements rehabilitation was very difficult because without articulation it is almost impossible to walk. But today she still presents difficulty to walk, even on account of coping with her weight. But she walks normally today, like any other person with the disability that she has, without the trochanter.”* In the second frame of the story, the nutritionist discusses her diet. This is important due to the resident’s tendency to gain weight caused by knee joint problem, reduced mobility and low physical activity level. *“Her diet is normal, except that she is using skim milk, non-fat yogurt, we are not giving dessert candy, she is eating more fruit and we have reduced the calories of all her meals a little, that's all.”* Together the resulting story summarises the early care of the resident in a way which may be useful to other staff or to the resident’s family and friends.

When asked about the value of the system in the post-trial interviews, the manager was sceptical that the resident would be able to use it, and didn’t see the need to record health reports herself since she speaks to the family almost every day. The nutritionist felt that the system might be evolved into a game which could help the resident communicate better, but did not see a professional value in it for herself or her colleagues.



Figure 6: Health report story (story 13).

2.2.5. Researcher perspective

There were four Brazilian researchers in total involved in the study recruitment and data collection (Abrahão, da Silva, Castro and Gratão). They usually visited the care home in pairs. Their roles varied and evolved over time depending on story theme, participant and project requirements. During the first session, after meeting and consenting all participants involved (resident, family/relatives/staff), researchers acted as facilitators in the digital technology training workshop. Using content from their story of arrival to the care home and weather example, the purpose of this workshop was to teach both the resident and the family members what digital story telling was and how they could use the app using the tablet and/or the smartphone to make their own stories. It was soon realised by the researchers that the tablet was the most appropriate technology platform for the resident whilst family members decided to use their personal mobile devices for the duration of the study. After the training session, using pictures from her phone and in collaboration with the resident, the resident's sister decided to make their own first story. *“They were doing it together. The main practice person was the sister who was putting everything in but she was showing the resident, the brother in law. They seemed to be doing it together. The resident actually chose one of the pictures”.* (Researcher)

The researchers' role in this instance was just to observe the resident with the family interacting with the new technology and assist them when in need. For example, the resident's sister requested some help for uploading the media from her phone and for posting the finished story on YouTube channel. Uploading did not seem to work directly from the sister's phone. Furthermore, since the resident did not use the internet, she couldn't view any stories on YouTube. These technology issues acted as a barrier to the development of a culture of digital story sharing on the project. Stories tended to be made locally in the care home or at the sister's house, and then shared face-to-face on a tablet or phone during a family or researcher visit. Further technology use and access problems prevented the resident from privately reviewing stories on the tablet.

During the second visit, and whilst family members were also present, the resident started using the tablet for the first time. With a step by step guidance by the researcher, the resident took photos of the researcher, selfies with herself holding the tablet, created an audio and created a whole story by herself. Researchers felt that the resident was really efficient and intuitive in using the touchscreen whilst family members felt really pleased

that the resident could create the content on her own and learn how to use the tablet. Family members would even take the opportunity to change the task (story making) and use the *Com-Phone* technology for other cognitive task performance (colour identification task, reminiscence). The main difficulty identified by researchers for a resident with dementia in the use of *Com-Phone* technology was the ‘click and hold’ function: *“If you click it, just touch one click you open the frame to watch the video, if you click and hold you are going to add the story. On the day this was the main difficulty and the access to the whole story. She did not overcome this difficulty. She was not able to click when she wanted to watch it and click and hold when she wanted to add it.”* After the end of each session, the tablet was returned to the researcher as the care home did not want to leave the technology with the resident or care home staff. Lack of access to the tablet in between visits was an indication of the lack of care home staff engagement with the study in the absence of research staff. It also compromised the ability of care home staff and resident to develop a sense of ownership and familiarity with technology and the growing repository of stories.

Researchers spent most of their time with the resident and helped her with the story making process as a joint act. During this time, they developed a close relationship with the resident and learned via this task who she was and what made her happy and motivated: *“When she usually draws it is flowers and apples. When it is something different, someone else has drawn for her to colour inside. She considers them as presents. She does not like books for colouring. She likes people to draw for her... We talked about what she draws, what she likes and she asked us to put some music with the drawings and then she watched all the photos. She watched the presentation and she enjoyed it very much. She laughed throughout. She asked us if she could have it and we said yes, she could have it all in an album at the end”.*

Stories became a means of communicating the resident’s likes and dislikes (e.g. photo frame layout) and her daily routines and activities within the care home. For example, towards the end of the 9th session the resident talked to the researchers about how she liked to eat in the kitchen as eating on the porch or dining room was too isolating. Walking to kitchen though was challenging so she asked them to take a picture of her favourite object ‘the walker’. This eventually appeared within story 8.

The use of the storytelling technology helped researchers to facilitate rich conversations with the resident and their relatives, and stimulated greater expressivity and

creativity in the resident herself. On the last day of the visits, the sister brought in a picture of the resident as a child. Although the resident liked seeing herself as a child what she loved mostly was a frame that she asked the researcher to create which captured both herself now and her picture as a child.

Creating digital stories not only gave the residence a sense of purpose but also for family members it was a mean of connecting their loved one with the world and her relatives/friends outside the care home environment. During the 7th session the researcher was asked to help the family put a story together about a birthday party they attended so they could share it with the resident. They brought photos, texts to put on the smartphone and asked the researcher to post it directly on the You Tube channel:

“resident was watching as the story was being made. The sister also provided some narratives and was explaining to resident ‘who is who’ and how the people were after some time that she has not seen them, what they are doing and how the party went”.

In other instances (on visit days of cognitive training) and usually in the absence of relatives, the researchers’ role in the digital story making process was different. Researchers became the core authors of stories usually to document in real time or narrate an incident that involved resident’s engagement (bonfire, 2nd birthday party with interns) or non-engagement with a task (Visit 3, resident’s refusal to do the cognitive training). Similarly, the researchers created stories about their interviews with care home staff.

For the researchers using digital story telling technology in this context was a new and exciting learning experience. When asked about what they liked the most in the study they argued that they enjoyed the interaction with the resident, the family and the opportunity they both had via the study to access and learn how to use the technology:

“What I liked the most was the interaction. I feel that I was able to enter the life of the resident. The family’s life as well but mainly the resident’s life because I went inside the care home. I also liked the technology part because it was new and the resident did not know it and she learned how to use it. Sometimes she would not even look and she would continue to draw but she was listening and then she was asking us to put it again, and again and again. She enjoyed more listening than watching. She started to talk with the stories as if someone was asking a question. She answered again as if the person was there but she realised it was a story, She still talked to it anyway.”

One researcher focused more on the benefits of the technology in bridging the gap between the relatives and the resident in the care home: *“Talking to the sister was my favourite one as she was the only one who verbalised the communication problem because the resident feels it and if she had access to the phone she would talk a lot to her family.”* The researcher felt the technology provided another way for the sisters to talk.

2.3. DISCUSSION

At the outset of the study we noted the distressing nature of admitting a family member with dementia into a care home, and the need for **remote** involvement of family and friends in their care. We also cited research showing problems in communication with dementia sufferers and the need for meaningful and enjoyable **co-present** activities with them, particularly as the disease progresses. In the context of a relative lack of technology support for these problems, we cited multimedia systems for the support of co-present **reminiscing** conversations. We wondered if digital storytelling could extend this approach as a more general form of multimedia communication between care home residents with dementia and their formal and informal carers.

The short answer to this question is that we have found a strong value in the co-present creation and sharing of digital stories for a resident and her close family who visit regularly to spend time with her in the care home. Surprisingly, and in contrast with computer-supported reminiscing therapy, the most common and valuable stories were those relating to the resident’s current rather than past life. These served to elicit richer conversations with the resident in the process of creating the stories, and acted as mementos for the family themselves to look back on in the future. Other values were evident in the findings, together with additional discoveries about the design, integration and management of storytelling technology in this context. These will now be discussed under the headings of Technology and Values, before outlining their implications for Future Research.

2.3.1. Technology

Surprisingly few usability problems were discovered with the *Com-Phone* app, even when used by the resident herself. It quickly became evident with her that a tablet was more suitable for interaction than a smartphone, because of the larger size of the fonts and display. But only a click-and-hold action was singled out for criticism, since this could be invoked accidentally with different consequences for story creation than a single

click. With help from the researchers, the resident learned to contribute to the media design of stories, and enjoyed sharing them with others as they played full-screen.

Of far greater significance were problems of integration of the storytelling app with other software on the tablet and social media services on the web. Being able to select a photo or sound clip from the tablet relied upon knowledge of the repository structure for media on the device, and a means of navigating it. Even more difficult was uploading a completed story to the YouTube channel created for the trial. This had to be configured on the device to point to the right account, and simply never worked from the sister's smartphone. Unfortunately, this was where the sister made all her independent story content relating to her own activities that she wanted to share with the resident. Even if this had worked, the resident has no independent access to the YouTube channel anyway and wouldn't have been able to see such stories without assistance. This compromised the remote sharing of stories in the trial and meant that we didn't really test this value.

A final lack of integration of the technology was with the care home management. For busy staff, new technology is a burden to master and maintain. This is even more true in a small-scale field trial where the technology will be removed at the end of the trial. Consequently, in this case, the staff chose not to engage with it and even refused to keep the tablet in the care home between researcher visits. This meant that the staff did not really test its value for themselves or allow the resident access to stories independently. If the first author (Abrahão) had not taken over the role of maintaining and using the tablet with the resident, the trial would have collapsed. In effect, she took over some aspect of care for the resident in this decision, and even became facilitator for the care home staff to record stories about the health of the resident. We will return to this point in Section 5.3 below because it has consequences for how care homes might accommodate such technology in their day-to-day care of residents. For now, it is sufficient to note that the cooperation of care home staff is as important as the technology itself to its long-term success.

2.3.2. Values

The range of values experienced by participants in the trial can be illustrated in connection with the five different types of stories they created. By far the greatest values were associated with the **visit conversation** and **social event** stories which made up

nearly half the stories. Together these began to form a multimedia journal or diary of the resident's life in and out of the home, with special trips to the dentist and birthday celebrations making up the highlights. While these were fun for the resident to make and share, they had deeper meaning for the family. The resident's sister was aware that they were documenting her own care of her sister in the home, and the happy moments that she planned to look back on in the future. Given the progression of dementia over time and the gradual loss of memory and personality of the sufferer, this is not a surprising observation. However, it does reinforce the value of these stories for future reminiscing by family and friends.

The documentation of **therapy sessions** and **health reports** by the researchers, sometimes on behalf of care home staff, formed another set of stories. These were valued by the resident's family as a record of professional care given, and also as a testimony of character through adversity. The latter was illustrated most dramatically in health story 13 featured in Figure 6, which contained two bland photographs but a powerful narrative about how the resident had overcome mobility problems on admittance to become mobile with the use of a walker (now her favourite object).

The final category of **media album** stories was also valued by the resident as a record of her many drawing and art works, and by family and friends who saw these as reflecting her personality. The use of digital media technology to essentially digitise and collate art works for archiving and broader review is a latent value which might be developed further in the future. It begins to connect with other forms of occupational therapy performed in care homes involving arts and crafts, and might be seen either as a method of capturing the outputs of those, or as a form of digital media art in its own right.

Moving away from a focus on the story **outcomes** in the study, there is much that can be said about the **process** of story creation and sharing that took place. Perhaps the strongest value of the technology discovered in the whole trial was its ability to draw the resident and her visitors into richer and more creative conversations about her life than usual. This was true for the researchers as much as for family members, who expressed delight in getting to know the resident on a deeper level through the kinds of conversations involved in story making. One reason for this may be that stories were essentially photo narratives with an average of 6 photos per story. This meant that participants were always looking to illustrate activities and ideas visually, as scaffolding for voice or text annotation. Another reason is that the images and stories themselves became points of

conversation, and could be recycled with other visitors in different ways. The fact that they were always created and shared collaboratively, points to the highly social nature of the technology and some new possibilities for enhancing this in the future, as described below.

2.3.3. Future research

A number of implications for the design of digital storytelling technology follow from these observations, and we begin with these here. An **end-to-end solution** is needed for care homes, which allows stories to be remotely shared as easily as they can be made. This should either attend to integration with existing ICT systems in the care home, or alternatively provide a self-contained solution that operates without dependence on existing infrastructure. The former route is likely to be less expensive, but more challenging across the diversity of systems currently in place. Once achieved however, this solution should begin to address the requirement of remote communication between the care home and the family and friends of residents. This may unlock new values such as the sharing of social events outside the home that residents are not able to attend, and the reception of health reports by family and friends reassuring them of resident care in their absence.

Given that story creation was collaborative and involved interesting conversations with the resident, much more could be done to support this. **Larger displays** might be used in tabletop orientation or via projection on a wall, to facilitate better media browsing and larger group review. Indeed, a latent possibility exists to share or even make stories locally with other residents. This was not tested in our trial but would reinforce the capture and sharing of *current* care home life by the whole population of residents.

The assembly of individual stories into a larger ‘book’ was used as a mechanism for analysis in the trial. This was surprisingly effective in educating the remote UK researchers about the life of the resident, and something that the family appreciated as a memento in both digital and printed form. Future developments might pay greater attention to the packaging of story collections as **digital or physical mementos**, and explore augmented paper technologies that allow media assets to be linked and played back from printed photos and photobooks (24).

Other implications for care home management and research follow from our findings. We recommend the establishment of a **new staff role** in care homes focussed

on the mental health and wellbeing of residents, rather than their physical health. A large part of this role should involve liaison with family and friends, addressing *their* need to feel involved in the life of the resident as well as the resident's need for an active social network. This was essentially the role played by Abrahão in our study. We think digital storytelling technology has a role to play in this process, but only if it can be embraced and managed by 'wellbeing staff' who see it as an integral part of their professional work.

Finally, our findings imply that research on reminiscing in dementia care should take a new direction. This should focus on documenting the current life of dementia sufferers, and support for future reminiscing by family and friends. More attention should be paid to the kinds of conversations involved in creating multimedia stories of the everyday lives and activities of people with dementia. These appear to have the potential to increase social engagement and creativity in dementia sufferers, and to deepen the topics of conversation that can be had with them by family, friends, care staff and strangers. The current case study did not record such conversations but reports their benefit anecdotally from the comments of participants. Future studies should examine this systematically with a larger population.

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CAPÍTULO 3: COMMUNICATION AND DIGITAL NARRATIVES IN THE CONTEXT OF DEMENTIA CARE

In this paper, we explore the communication issues and requirements of people with dementia living in their own homes or the homes of their relatives. We also assess their reactions to the same digital storytelling technology we employed in our care home trial (ABRAHÃO et al., 2018). We interview both formal and informal caregivers as informants on these issues, with a view to working with people with dementia themselves in follow-up work involving a new technology intervention.

Hence, the main contributions of our study are:

- i) An understanding of the main obstacles in communication with elderly people with dementia, such as those experienced by formal and informal caregivers at home;
- ii) We present caregivers' opinions and attitudes about information and communication technologies (ICTs) and strategies to minimize burden and improve communication and coordination among caregivers, the elderly, and family;
- iii) We identify some recommendations for meeting the communication needs of people with dementia and their formal and informal caregivers.

3.1. METHOD

This exploratory qualitative study had a total sample of 10 caregivers (professionals who provide home care services and informal caregivers (family / friends) of older persons with a diagnosis of dementia in the interior of the state of São Paulo, Brazil.

Caregivers were invited by phone to participate in an interview and later divided into Formal Caregivers and Informal Caregivers according to the following inclusion criteria: being caregivers of dependent persons with dementia (formal or informal), being older than 18 years old, and having preserved cognitive and communication skills. Table 1 shows demographic characteristics of the sample. A total of 4 informal and 6 formal carers took part in the study.

This study was approved by the Research Ethics Committee of the Federal University of São Carlos (3,105,608). All participants signed the Consent Form and Copyright Declaration. Participation was voluntary and the participants' full anonymity was assured.

Table 2: Participants demographic characteristics

		Formal carers	Informal Carers	Total
Age (years)	Mean	34.6	43.2	38.9
	Min	22	22	22
	Max	46	74	74
Gender	Female	6	3	9
	Male	0	1	1
School	Highschool	3	1	4
	Bachelor	2	3	5
	Post-grad	1	0	1
How long have you been caring for elderly (years)	Mean	7.5	3.7	5.6

Fonte: Autor, 2019.

Data collection took place through interviews previously scheduled at the home or place suggested by the participants with a semi-structured questionnaire and performed by the field researchers (Paula da Silva and Larissa Ferraz). All interviews were recorded, transcribed and translated into English.

First, the researchers presented the project aims as well as its methodology. Doubts that eventually occurred were clarified immediately. This reduced the risks of induction through the researcher's own posture and the expression of statements.

The interview was divided into two parts. The first part contained issues related to care and challenges in communicating with persons with dementia:

- 1) What are your roles and responsibilities in the care of the person with dementia?
- 2) How do you work together with other people / professionals to provide this care?
- 3) Can you describe a typical day in your life with the cared person?

- 4) What are the main challenges and problems in communication between caregivers?
- 5) What types of communication problems do you have with the cared person?
- 6) How do you record and share life experiences and memories with the person?
- 7) When you think of technology, how do you think it could help with these communication problems?

In a second part of the interview, participants watched a video story on a Youtube channel created in the earlier study for sharing these stories. They were then shown a printed ‘talking photo album’ that reproduces through the picture and audio originals from the multimedia narratives created in the Brazilian case study.

The Com-Phone application provided support for digital narratives created in a long-term institution (ILPI) with the triad: person with dementia, caregiver and family (ABRAHÃO et al., 2018), is part of the Community Media (Com-Me) toolkit designed to support multimedia communication in low literacy communities (<http://digitaleconomytoolkit.org>). It's an open source Android app available for free on the Google Play Store. A simple interface that allows the creation of multimedia narratives, combining photos, audio and text for the purpose of digital storytelling, documenting data and information (FROHLICH et al, 2012). The choice of this application was due to the fact that it was developed by the research partner of the study and was translated into Portuguese.

After the demonstration, another round of questions was asked to get initial reactions and critical feedback:

- 1 - What were your overall impressions of the Com-Phone application to make stories?
- 2- Would you use that? Would that be useful? Why?
- 3- What devices do you think would be best for using this technology?
- 4-What should be the social network for sharing these stories? Who should be part of it?
- 5-What communication problems did you report in the first part of the interview? And which ones were not addressed?
- 6- For problems that have not been addressed, can you think of other technologies that could solve them or how our technology can be expanded and improved?

5.3 DATA ANALYSIS

The data were analyzed through the thematic analysis of content by impartial judges, which consists of a set of communication analysis techniques. These use systematic procedures and objectives to describe the content of messages (BARDIN, 1977).

All interviews were recorded and transcribed. Subsequently, spreadsheets with categorization of the data were generated. Categories were created for communication, technology and feedback and its subcategories consisted in:

Communication: ADL; feelings; sensations; aggressiveness; consent; autonomy; Social participation and legacy.

Technology: Coordination of care; sharing coordination; past memories; current memories; networks and social media - Whatsapp / Facebook / Instagram; photography - participation / attention and connectivity.

Feedback: Communication potential; potential of connectivity; positive aspects; negative aspects and why ?; adoption - would not use; utility - yes or no and why? devices - tablet, cellular, album and suggestions; social network - family, friends, caregivers and others. The data analysis was also supported by the Atlas.ti software for word counting (reference number cleverbridge: 161154502). The program facilitates more systematic analysis of data from open interviews that have followed the roadmap of topics and other types of data, including those in audio format, figures and videos, available at <https://atlasti.com/>. The data were analyzed by two independent researchers (Carlos da Silva & Ferraz) and the results are described below.

3.2. RESULTS

3.2.1. Communication Issues involving the care recipient

Our participants face communication challenges every day when caring for persons with dementia. When delivering care, both types of caregivers mentioned difficulties for coordinating personal hygiene (bathing), resistance to ingest the medicine and difficulty understanding what the person is feeling or needs. The biggest fear is not realizing if the person cared for is in pain:

"Ah ... it's a difficult thing, not knowing... sometimes she gets very restless, so we do not know what she wants, at the same time she says that it is one thing, she changes to another, I have doubts about what she really wants, then we ... the bigger difficulty is this ... if it's pain. " Formal Caregiver.

"It's when you think they're feeling something and they do not know how to communicate, they cannot anymore, right? So there you have to see what it is they're feeling, the pain where it is, what place, then you have to find out as if they were a child." Informal Caregiver.

In our study, both formal and informal caregivers mention the difficulty of understanding what the cared person is feeling, difficulties with speech, as well as lack of communication and symptoms of aggression were commonly mentioned. Boundaries to communication in later stages of dementia when the person does not understand and cannot express themselves may be relevant in this case. Further communication distresses them and knowing when to persist and when to stop may be an important strategy. Management of conflict with the person with dementia when they get angry and sometimes resist suggestions or instructions was considered an important challenge to overcome.

"...Speech, the speech is coiled, complicated, sometimes we do not understand and have to ask to repeat, it is the main ... the main communication problem." Formal Caregiver.

"With the elderly; mainly understanding problems, there are persons (with dementia) who do not express themselves verbally, so I have problem in that context." Formal Caregiver.

"This problem of communication is because they arrive at the stage that they no longer communicate with us, we try to explain to them but they do not understand and then they just ... If you start to talk a lot they end up getting even aggressive. " Informal Caregiver.

"He sometimes does not understand what we're talking about, he's dispersed and he ends up being too stubborn and he does not take the things that we say seriously." Informal Caregiver.

3.2.2. Care coordination and Daily routine activities

All staff desires for technology were about the daily routine, including shift work and staff handovers for staff-staff communication. That feeling was reflected by the answers about delivering care and responsibilities.

Even considering the involvement of care professional friends of the family, the focus seems to be on health care and there is a gap in wellbeing outcomes. Considering the roles and responsibilities in caring; in the majority, the group of formal caregivers indicated that the main care is focused on personal hygiene, food and medicine administration. Similar to the other group, informal caregivers also mentioned the same care and responsibilities:

"Most care is for the daily routine with the difficulties that they have ... for example, having breakfast and the typical care that they have difficulty due to age"
Informal caregiver.

In addition to the aforementioned care, the responsibility for contact with family members receiving the care was mentioned: *"So in some cases, I review the routine and the events between care team and senior."* Formal caregiver.

Considering a typical day with the person with dementia, the participants in both groups, formal and informal carers describe mainly the difficulties in the Activities of daily living (ADL), which are basic tasks of self-care, such as: eating, bathing, dressing, toileting (being able to get on and off the toilet and perform personal hygiene functions and transferring).

*" In a typical day they get up early, take a shower, then we serve breakfast. Those who cannot feed themselves, those who in advanced phase of dementia, we help feed them. Many people do not want to have coffee, we change the menu, for porridge or other things that they can swallow because they have a hard time swallowing. "*Formal Caregiver.

Both groups of caregivers agreed that there were no communication problems regarding the coordination of care within the family. Informal carers verbalized the need for them to liaise with formal carers for some aspects of care such as nutrition needs, for example. Formal caregivers highlighted the importance of teamwork between different professionals:

"We work as a team, do we not?" Everyone helps to take care, when one can be doing another task, the other goes and does it too, so it's a team, it does not have a specific function, everyone helps a little. " Formal Caregiver.

This fact was also clear in the group of informal caregivers and the word GROUP was mentioned in the different interviews:

"Listen ... The work of the group makes a whole, I and my husband as well are responsible for her, my role is to give, let's say every possible tool to the formal caregivers." Informal Caregiver.

3.2.3. Social media and digital content

When questioned about how they recorded and shared life experiences and memories with the care recipient, both formal and informal caregivers stressed the use of digital social networks to share and make the communication simpler and faster. The use of WhatsApp was mentioned by several people, (mentioned six times) as well as Instagram (mentioned three times) and Facebook (mentioned two times):

"Surely to be clear about the information, to leave the communication less formal, you know?" Although family members who seek the information are very receptive to the pass-through. " Formal caregiver.

"There are always photos that are posted on social networks as Face and Insta (in reference to Facebook and Instagram)." Formal Caregiver.

Usually the person with dementia is outside this process of sharing using social media. The sharing of social media is usually a form of communication and memory for professionals and family/friends:

"We make videos using the phone, also audios, photos, we use Facebook, Whats and Instagram for posting these videos, only my grandfather does not use any, who really uses it is my cousin who post, who plays with him but he does not pay much attention, pay attention for a few minutes. " Informal Caregiver.

"Perhaps if the activity that uses technology was gradually inserted into his routine, he would get used to the idea and follow the activity" Informal Caregiver.

However, attempts were made by informal caregivers to share photos with the person being cared for, as a way of sharing memories and promoting well-being with positive responses to visual stimuli such as smiles, for example:

"Ah you start talking about family, you talk about the kids, you show photos that they like, aaahn ... things that you think they are going to like, my father lived a long time on the farm, so he likes to see horses, cows ... you know? Then we show him these things and he's very happy. " Informal Caregiver.

"We work with her with photos from the past, our marriage, the birth of the children, the grandchildren, we show her, she looks, she does not have an answer, but you realize she is watching, so she's seeing, it's got ... I can not explain to you what it would be, but I realize that there is an interest ...and so we communicate with her this way. " Informal Caregiver.

Photos were also mentioned as evidence of quality of care, for positive or negative experiences.

"... for example, he is not eating, then yesterday he did not eat well, look today he ate, today he is fine, today he is doing the nails, we take the picture and send it to the familiar and other people via WhatsApp and then a relative ends up monitoring by that instrument. " Formal Caregiver.

When talking about new technology for addressing this communication issues, the caregivers demonstrated openness towards innovation solutions:

"I think it (technology product) could aid them understand things more easily, as well as preserve some of the memories. Communication would be easier, at least for purposes of their day-to-day routine." Formal Caregiver.

The main conclusions of the first part of the questions (1-7) were that most caregivers are active in ADL care, but mention how the main challenges relate to the difficulty of understanding what the elderly are feeling. Formal caregivers reported not having difficulties in the contact with the family in relation to the care provided and emphasized the importance of teamwork and the different professionals, as well as the issue of working together.

Both formal and informal caregivers mention the difficulty of understanding what the cared person is feeling, difficulties with speech, as well as lack of communication and symptoms of aggression.

3.2.4. Technology Feedback

After the demonstration of the digital album with stories from a previous study (ABRAHÃO et al. 2018) formal and informal caregivers believed the application Com-Phone had the potential to bring family, formal caregivers, and persons with dementia together:

“And I think ... it is a very cool initiative and mainly makes a bridge... ... I think it ends up comforting the family members...” Formal Caregiver.

“I think it's very interesting in the part of interacting with the family with the caregivers, it's a story that it is going to be kept.” Formal Caregiver.

“I think it is very useful, it serves as the basis even to prepare people for tomorrow, families, caregivers and all this comes to help, so I think we have to work and always think about tomorrow trying to bring news and things which can be absorbed by the family, by the caregivers and bring much more comfort to the patients and the people in the states that the mind really is deteriorating in the day to day.” Informal Caregiver.

The different caregivers also pointed out that they would use the application and that it would be useful for reminiscing, social participation and collecting mementos for the future. They believe that technology could help in communication problems, to share life experiences and memory, as well as to coordinate health care. For example, one informal caregiver suggested using family photos to see how much is remembered by the person with dementia:

“Oh I would use it because ... it would be useful because you take the family picture and show it to them so they can see if they are remembering these things and for them to see that they are ... seeing something different, like things they will save in the mind, try to save, right?” Informal Caregiver.

Another felt that digital storytelling could be a way for them to remember and communicate an experience of their own:

“It would use because even for us, it would be a different way of remembering a moment and an experience that we lived with some people.” Informal Caregiver.

Similarly, a formal caregiver saw digital storytelling as a tool for them to use in their work with the person with dementia and their relatives:

"I would use it, of course. Most of the elderly I deal with have remote memories about their children and relatives. With the possibility of showing a photo with sound or writing, somehow they would recover their memory, at least at that moment." Formal Caregiver.

As for the best device to use this technology, Tablets, cell phones and even notebooks were mentioned:

"The easiest would be to use the smartphone which is what we have and the most used, but I think that notebook would also be a good one." Informal Caregiver.

"Tablets ... as they have difficulties always have to have help in using, in cases that the routine is a little busy maybe that would be a con, but has the pro that is an intermediary (an interaction)." Formal Caregiver.

"I believe it would be the computer or notebook because of the size of the image... Formal Caregiver.

Both kinds of caregivers suggested features that would be useful, such as photo media and once again social networks as a support for this technology:

"Look, it would be ... I always spoke in a device ... you have the audio, right? You have the audio, everything visual has to be because in the state of the patient today, it has to be visual or audio, but the audio in the case there, depending on the stage has no more reaction, but the visual is the last stage that the person loses right? she loses everything ... her look is great, she sees, she knows ... then it would be ideal ... she reads, draws a little and such, and you see her state is in the third stage which is the last, is still having some reaction." Informal Caregiver.

"I think ... just thinking about involving family directly I think the WhatsApp and videos and share it with a relative." Formal Caregiver.

There were a diverse set of responses to the question about who should be included in a story sharing network. However, some participants suggested that the network be kept small and limited to the family and friends of the person with dementia:

"The family, the friends, right? That sometimes friends they do not have chance of being together and in the album they would be, he would be watching, remembering, it is very interesting." Formal Caregiver.

Others felt that the formal care team should be incorporated in the network, to keep them informed of family stories:

“The family, the caregivers ... and the elderly, I think they would be ideal scenario.” Formal Caregiver.

Some participants felt that the digital stories could be of benefit to other families or carers of people with dementia, creating a kind of care community across which to share information in story form:

“I think mainly relatives of institutionalized older persons, I think it would be cool to have other realities of non-institutionalized older persons but that family share experiences, routines ... I think more family members and institutions responsible for care and legal rights of older persons.” Formal Caregiver.

“Starting with who should be part, I think the community in general, but having a focus on the families who that live with them, has this coexistence precisely to share experiences and exchanges tips on how it works with them, how it did not work, and so on. But I think in general would also be very important because sometimes the person does not have in the family, when we tell the person not ... speech is exaggeration on your part because do not have socializing, so it is good to show. I think it would be a broad, open sharing easily accessible as is the case of YouTube, YouTube videos only you type, maybe the creation of a website or a page just about it, I think it would be functional.” Informal Caregiver

Ethical issues were also pointed out, such as authorization of the persons with dementia over sharing these stories:

“So I think it's kind of complicated, I think I should have the person's permission, but she does not ... sometimes she cannot have that insight, now it could be otherwise shared by the family, by the person in charge. Formal Caregiver.”

3.3. DISCUSSION

In general, poor communication contributes to the caregiver's tension and markedly increases the burden of care. Difficulties in interpersonal relationships and communication with the health care team are considered fundamental challenges that

cause a high level of frustration and emotional load (GENTRY, FISHER 2007; WOODWARD, 2013).

Poor communication can also have a particularly profound effect on the lives of people with dementia, as it affects their ability to interact socially, maintain relationships, plan daily activities and express basic needs and thoughts to those around them. The person with dementia loses the ability to communicate thoughts and needs as the disease progresses, making it increasingly difficult to interact socially and maintain personal relationships with caregivers, family, and friends (WOODWARD, 2013; DELFINO; CACHIONI, 2016).

In this sense, information and communication technologies have the potential to improve the quality of the provided care, often perceived as pressures on caregivers (PITTS et al., 2015). However, considering the results found in our present study, we emphasize the scientific and social importance of identifying, in an interdisciplinary way, the main obstacles in communication with persons with dementia by different caregiver's perspective (formal and informal).

3.3.1. Communication obstacles

Dementia produces a noticeable decline in cognitive function and usually interferes with independence in performing basic daily activities (ADL) such as dressing, eating, personal hygiene, and physiological activities (Classificação de Transtornos Mentais e Comportamento CID-10, pp. 45-46, 2011; FERNANDES, 2018).

Although the formal caregivers participating in the research report that most care is for the activities of daily living, the coordination of this care is always linked to a team with many caregivers providing this care to the same person. As far as communication is concerned, the main difficulties are related to the understanding of the feelings and sensations due to the absence or poor expression of people with dementia that they care for. Communication problems with the family were not reported, but important issues related to the autonomy of the individual are present on part of these caregivers reports and interview results, considering psychosocial factors such as family, education, health care, initiative and motivation of the elderly as well as cited by ARGIMON; STEIN (2005).

In turn, all informal caregivers reported their involvement in ADL care. Similar to formal caregivers, the main obstacles in communication are also concerned with

demonstrations of feelings and expressions such as pain. Symptoms of aggression were also mentioned by caregivers.

The communication barriers most commonly mentioned by caregivers of persons with dementia in the literature are difficulty in communicating due to repetitive requests, marked diminution of vocabulary, unfinished phrases, anomie aphasia and often lack of dialogue (LEITE et al., 2014; OLIVEIRA et al., 2016; DELFINO; CACHIONI, 2016; JH et al., 2016). Similar to our findings; it is difficult to have data about the relevance of other non-verbal levels of communication available and our carers are curious about the effect of environmental factors such as grooming (cited by our Informal Carer 5), music, soundscapes, or outdoor experiences.

In this context, caregivers care about the health and well-being of the person with dementia cared for. The quality of life is actually negatively affected in people with dementia (BÁRRIOS, et al., 2013). The various definitions of quality of life aspects in dementia lies in common points, among them humor and its effect, considering them central points for a good quality of life (FERNANDES, 2018), which can be influenced by improving the communication and social interactions during the process of sharing digital stories.

These findings are aligned with the literature considering that providing ADL care is considered central to high quality residential and home-based care, but further research is needed on the association between person centred care and wellbeing (BALLARD et al, 2001; CHUNG 2004; EDVARDSSON et al, 2014).

3.3.2. Role of ICTs

During the study, both caregiver groups made mention of using social media to coordinate care and share memories, especially the Whatsapp, Instagram and Facebook applications. It is important to emphasize that these social media were not used by the persons with dementia who they care for; in our study. In this sense, persons with dementia need activities to motivate them and that are able to involve them in something different from what they are accustomed to. The surprise factor along with tools that they are not used to can make a difference.

Issues related to the accessibility of such technologies should be increasingly investigated and discussed in the context of dementia, in view of the principle of inclusive design, especially the disabled and the elderly, can use websites in a variety of contexts

of use, including assistive devices and Assistive Technology features; so websites need to be designed and developed to support usability in these contexts (KORT, 2011; PETRIE; SAVVA; POWER, 2015).

In addition, both caregivers mention the potential of technology for communication. However, they cite "routine problems" for adoption, but on the other hand "would help to remember" and mention the role of an "intermediary" between technology and the older persons as positive. As for usability, eight of the ten caregivers interviewed would use the technology of digital storytelling when they saw examples from the study carried out with the Com-Phone application (ABRAHÃO et al., 2018). They also said that would be useful to "Show what did / did not do"; "To accompany, to approach and to interact"; "Recording of memories"; "Focused on the information of the family and caregivers, also with the comfort of the patient".

On the other hand, there is a concern for privacy regarding sharing due to the variety of networks mentioned. The family as a participant in this sharing network was mentioned by all caregivers, as well as close friends, caregivers and even government institutions or associations of families of people with dementia. However, there is a diversity of social media systems that can subsidize these sharing process and are already used by these caregivers. Some promote closed and private networks such as the Whatsapp application, with greater control of who can be a part of it; some, such as Facebook and Instagram can reach a larger number of people, or promote different ways of sharing their content.

3.3.3. Technology recommendations

PROVIDE A SHORT PARAGRAPH HERE SAYING WHERE THESE CAME FROM – ANALYSIS OF FINDING IN RELATION TO THE STORYTELLING TECHNOLOGY

1. Consider the user of assistive communication technologies in this dementia care area
2. Make social media systems accessible to people with dementia, for playback at least
3. Consider the use of digital storytelling within existing social media platforms, such as Instagram stories.
4. Re-purpose social media content in digital story form

5. Use digital stories to capture memories, demonstrate activities, provide reminders and share experiences between carers and people with dementia.
6. Decide on the 'width' of the social network over which media or stories should be shared.
7. Consider the three kinds of users of any digital storytelling system: informal carers, formal carers and people with dementia.

CAPÍTULO 4: CONSIDERAÇÕES GERAIS

A realização deste estudo visa não apenas inserir um aparelho digital na vida do idoso, e sim, discutir potenciais usos da narrativa digital, explorar questões e requisitos de comunicação com cuidadores formais e informais e avaliar suas reações quanto à tecnologia de narrativa digital como uma nova intervenção tecnológica no cuidado nos diferentes contextos- institucional e domiciliar.

Os resultados encontrados de maneira geral apontam para a natureza social da tecnologia e a importância do papel do cuidador como facilitador para esse processo. O estudo de caso realizado em uma instituição com cuidadores formais, informais e idoso com demência, demonstrou que em geral, a tecnologia foi mais útil para facilitar conversas mais ricas com os residentes e outros participantes, estimular uma maior expressividade e criatividade na própria moradora.

Por sua vez, o estudo final, no qual entrevistamos cuidadores formais e informais, a experiência de cuidadores formais aponta para a provável adoção de narrativas digitais como uma forma de comunicação multimídia entre pessoas com demência e seus cuidadores. Esta abordagem poderia fornecer um canal de interação co-presente e remota entre eles, sendo essas histórias sobre auto-biografia ou eventos da vida diária dos atores envolvidos.

Consideramos que os principais obstáculos na comunicação com pessoas com demência por seus cuidadores relatados foram quanto a dificuldade de entendimento dos sentimentos e sensações da pessoa que eles estão cuidando, como também a falta de expressão e perda gradual da fala e entendimento. Também encontramos cuidadores dispostos a experimentar novas tecnologias e outras soluções possíveis para minimizar estes problemas de comunicação.

Quanto às opiniões e atitudes desses cuidadores sobre as TICs, consideramos que pode melhorar as estratégias de coordenação e comunicação do cuidado, tanto para registro de memórias passadas como atuais junto ao uso de mídias sociais e o uso de fotografias para participação e para evidências e conectividade, aos cuidadores formais e informais, bem como pessoas com demência.

Identificamos recomendações para atender às necessidades de comunicação das pessoas com demência e seus cuidadores formais e informais, usando a narrativa digital de forma a considerar o usuário de tecnologias de comunicação assistiva nesta área de

cuidado de demência; tornar os sistemas de mídia social acessíveis a pessoas com demência, para reprodução pelo menos; considerar o uso de narrativa digital dentro de plataformas de mídia social existentes, como histórias do Instagram; reutilizar conteúdo de mídia social na forma de história digital; usar histórias digitais para capturar memórias, demonstrar atividades, fornecer lembretes e compartilhar experiências entre cuidadores e pessoas com demência; decidir sobre a "amplitude" da rede social sobre a qual mídia ou histórias devem ser compartilhadas e considerar os três tipos de usuários de qualquer sistema de narrativa digital: cuidadores informais, cuidadores formais e pessoas com demência.

Entretanto, estudos futuros podem identificar esses e outros resultados sistematicamente por meio de novas aplicações com uso da tecnologia e o “augmented paper”, ligada à uma moderna inovação na escrita que integra a escrita tradicional no fluxo de trabalho digital. Anotações escritas e desenhos podem ser transferidos do papel para um dispositivo móvel com o simples toque de um botão, ligado ao cuidado da demência como o uso de histórias digitais para a comunicação, num grande ensaio clínico randomizado, com a parceria de pesquisadores com a Universidade de Surrey.

De maneira geral, acredita-se que este estudo pode contribuir para o avanço da prática de intervenções gerontológicas, preenchendo lacunas científicas, de mercado e sociais.

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ANEXO 1



PARECER CONSUBSTANCIADO DO CEP

DADOS DO PROJETO DE PESQUISA

Título da Pesquisa: Time Matters: narrativas digitais no contexto de cuidados em demência.

Pesquisador: Paula Costa Castro

Área Temática:

Versão: 3

CAAE: 89788818.6.0000.5504

Instituição Proponente: Centro de Ciências Biológicas e da Saúde

Patrocinador Principal: Financiamento Próprio

DADOS DO PARECER

Número do Parecer: 3.105.608

Apresentação do Projeto:

Nesta versão de esclarecimentos de pendências, a pesquisadora explicita sobre o projeto de pesquisa: "Propomos o uso de tecnologias de informação e comunicação (TIC) para apoiar a criação e o compartilhamento de histórias digitais como um novo método de comunicação entre pessoas com demência, familiares e cuidadores. Essas histórias apoiarão a reminiscência e a comunicação contínua com os residentes com demência após a transição para uma instituição de longa permanência, ou para cuidados domiciliares no Brasil e no Reino Unido. Esta abordagem tem o potencial de aliviar problemas de comunicação e também suporta um modelo de assistência colaborativo e personalizado que transcende as barreiras e cria uma cultura transparente de "cuidados em demência". O objetivo deste estudo é identificar os requisitos para um sistema narrativo digital simples, mas eficaz, para lares de idosos no Reino Unido e no Brasil e co-projetar tal sistema com cuidadores formais e cuidadores informais (familiares e amigos). Métodos: (1) Grupos Focais Qualitativos. Grupos focais serão realizados no Reino Unido e no Brasil para entender os problemas de comunicação e requisitos em contextos de atendimento domiciliar. (2) Comparação transcultural de questões de comunicação. Os resultados dos grupos focais de cada país serão comparados às diferenças culturais e explorarão suas implicações para o design. (3) Concepção conceitual e visão. Um sistema que atenda aos requisitos emergentes será projetado e imaginado em um protótipo semi-funcional. (4) workshops de co-design. Os usuários finais serão desafiados a comentar e re-projetar o sistema protótipo no Reino Unido e no Brasil".

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APÊNDICE 1

Aplicativos encontrados nas plataformas

APLICATIVO	SISTEMA OPERACIONAL	CONTEÚDOS E CARACTERÍSTICAS
Editor de HQs Pixton	<i>IOS/ ANDROID</i>	Hqs
Com-Phone Story Maker	<i>ANDROID</i>	Fotos, audio e texto
Story City	<i>ANDROID</i>	Fotos, audio, texto e localização
ConneCTales: The Collaborative Story Writing App	<i>ANDROID</i>	Textos; rede de histórias colaborativas
Storyboard	<i>ANDROID</i>	Videos, hq, transforma vídeos em hq, sem a possibilidade de inserir balões
Snapchat	<i>IOS/ ANDROID</i>	Vídeos, audio, fotos, localização, filtros
Instagram	<i>IOS/ ANDROID</i>	Vídeos, audio, fotos, localização, filtros
Steller	<i>IOS/ ANDROID</i>	Textos, fotos e videos montados em um "livro" pode ser publicado no steller ou nas redes sociais.
SpeakingPhoto	<i>IOS</i>	Fotos e áudios falado sobre a/as fotos Fotos, áudios, Video clips que podem ser compartilhados
Shadow Puppet	<i>IOS</i>	Fotos e videos
Glimpse – Video storytelling	<i>IOS</i>	

APÊNDICE 2

TERMO DE CONSENTIMENTO LIVRE E ESCLARECIDO

Pesquisadora Coordenadora: Profa. Dra. Paula Costa Castro

Departamento de Gerontologia / Universidade Federal de São Carlos

Telefone para contato: 16 3306 6678 ou **email:** castro@ufscar.br

O Sr(a) está sendo convidado(a) como participante da pesquisa: Tempo para o design: Integrando insights interculturais sobre o papel da narrativa digital no cuidado de pessoas com demência - **TiMe Matters. Este projeto pretende desenvolver**, ou seja, desenhar a construção de uma tecnologia de comunicação baseada em contar histórias com uso de fotos, texto e áudios. Isto irá apoiar a coordenação dos cuidados e a comunicação entre a equipe de cuidados de saúde, familiares e pessoas com demência.

Neste estudo o Sr. (a.) poderá ser convidado a participar de uma e/ou duas fases que são: 1) Pré-entrevista e grupo 1: Um pesquisador irá fazer perguntas referentes a problemas e dificuldades de comunicação e ideias que você possa ter sobre como a tecnologia poderia te auxiliar com suas dificuldades no dia a dia do cuidado. Primeiramente você irá responder perguntas individualmente e depois será convidado a participar de uma discussão de uma hora e meia sobre estas questões. Para que você possa entender como fazer uma história (narrativa) digital, a equipe levará fotos, áudios e histórias/estórias para uma oficina de montar uma história digital. Você não precisará trazer nenhum material ou compartilhar histórias pessoais sobre o ser cuidado. **Grupo 2:** No segundo grupo, que chamamos de grupo focal+, o sr(a) será convidado(a) a participar de uma sessão em grupo, respondendo questões sobre preferências e interesses no uso de aplicativos para a contação de estórias como forma de comunicação. Também usará um aplicativo para montar estórias e será convidado a sugerir mudanças e redesenhar o aplicativo. Posteriormente, entretanto, o(a) sr(a) terá acesso aos aplicativos e a todo suporte da equipe de pesquisa. Os dados anonimizados serão compartilhados com pesquisadores da Universidade de Surrey, na Inglaterra, para desenvolvimento do aplicativo. O(a) sr(a) não será submetido(a) a nenhum tipo de tratamento sem estar ciente ou sem seu consentimento, a qualquer momento você pode desistir de participar e retirar sua participação. Todas as fases serão gravadas em áudio e vídeo para que depois possamos escrever as respostas e discussões e analisar os dados. Só as pesquisadoras irão ter acesso a estas gravações.

Desconforto e risco: Devido à natureza observacional do estudo, os procedimentos não são invasivos e considerados seguros. Mesmo assim eles podem apresentar riscos, tais como: preocupações em relação à coordenação e comunicação do cuidado no contexto da demência em um ambiente doméstico, uso de novas tecnologias. A fim de minimizar os riscos na medida do possível tomamos medidas para a sua proteção. Quanto aos riscos sobre informações e imagens digitais, para evitar tais problemas somente os equipamentos do laboratório serão utilizados e todas as histórias ficarão no usuário do projeto timematters@gmail.com, que terá seu acesso privado impedindo o acesso público do canal.

Nesta folha de informação do estudo constam informações de contato caso sinta a necessidade de receber apoio adicional durante o estudo. Se você desejar sair deste estudo, é livre para o fazer sem que isso tenha qualquer prejuízo. Todos os participantes receberão treinamento e aconselhamento da equipe de pesquisa durante o estudo. A equipe de pesquisa organizará os grupos focais em um horário mais conveniente para todos os participantes e fora de seu horário de trabalho. Os pesquisadores também enviarão lembretes mais perto da data marcada, fornecerão informações suficientes e ajudarão durante os workshops, assegurando que as informações

pessoais sejam protegidas, os dados serão digitados de forma anônima no banco de dados, de forma que os códigos se mantenham anônimos para manter o sigilo dos participantes e serão arquivados no Departamento de Gerontologia sob responsabilidade da pesquisadora.

Possíveis benefícios: Participando deste estudo, o(a) sr(a) contribuirá com descobertas desta pesquisa piloto na exploração das barreiras de comunicação com pessoas com demência e projeto de uma nova rede social baseada em histórias que promove um modelo de cuidado centrado no cuidado e apoia a comunicação contínua entre a família, os cuidadores e a pessoa com demência. O TiME é um sistema desenvolvido por usuários finais para apoiar suas necessidades e deve suportar reminiscências, continuidade autobiográfica, inclusão social e conectividade, não apenas para pessoas com demência, mas também para aqueles que cuidam delas. A participação no workshop de Narrativas digitais também pode capacitar os cuidadores a usar esse método para apoiar reminiscências, continuidade autobiográfica, inclusão social e conectividade com seus entes queridos ou clientes em suas atividades diárias.

Acompanhamento e assistência: Todas as avaliações serão realizadas pelos responsáveis por este projeto. A qualquer momento os pesquisadores estarão disponíveis para orientar e esclarecer dúvidas que possam ocorrer, no decorrer desta pesquisa. Os resultados da pesquisa estarão à sua disposição quando finalizada. Seu nome ou o material que indique sua participação não será liberado sem a sua permissão.

Liberdade de participação: A sua participação nesse estudo é voluntária. É seu direito interromper a participação a qualquer momento sem que isso incorra em penalidade ou prejuízo à sua pessoa.

Sigilo de identidade: Sua identidade será mantida em **sigilo absoluto**. As informações obtidas nesta pesquisa não serão de maneira alguma associada à sua identidade e não poderão ser consultadas por pessoas leigas. Estas informações serão utilizadas para fins estatísticos ou científicos, desde que fiquem resguardados a sua total privacidade e anonimato. A utilização de fotos poderá ser feita apenas com autorização prévia. Pedimos sua colaboração em não reproduzir as informações discutidas para a proteção da privacidade das informações. Também pedimos que não se identifique por nada além do primeiro nome. A afiliação e instituição a qual os cuidadores formais estão vinculados não foram conhecidas nem dos pesquisadores. Vocês foram selecionados de um banco de dados de outro projeto de pesquisa da pesquisadora associada Aline Gratão, por ela, e a mesma não estará presente no grupo focal. Desta forma, não haverá ligação entre o cuidador e sua instituição, que não será identificada nem na pré-entrevista, nem no grupo focal.

Ressarcimento de despesas e indenização: Todos os procedimentos, equipamentos e avaliações deste estudo são gratuitos. Além disso, o(a) sr(a) tem direito ao ressarcimento e cobertura de eventuais despesas tidas com a pesquisa; e não perderá seus direitos de buscar indenização diante de eventuais danos decorrentes da pesquisa. Esta pesquisa não oferece qualquer despesa ou compensação financeira pela participação.

Este termo de consentimento encontra-se impresso em duas vias, sendo que uma via assinada e rubricada será arquivada pelo pesquisador responsável, no Departamento de Gerontologia da UFSCar e a outra será fornecida a você.

Eu, _____, declaro que entendi os objetivos, riscos e benefícios de minha participação na pesquisa e concordo em participar. Recebi uma via assinada e rubricada deste termo de consentimento livre e esclarecido e me foi dada à oportunidade de ler e esclarecer as minhas dúvidas.

A pesquisadora me informou que o projeto foi aprovado pelo Comitê de Ética em Pesquisa em Seres Humanos da UFSCar que funciona na Pró-Reitoria de Pesquisa da Universidade Federal de São Carlos, localizada na Rodovia Washington Luiz, Km. 235 - Caixa Postal 676 - CEP 13.565-905 - São Carlos - SP - Brasil. Fone (16) 3351-8028. Endereço eletrônico: cephumanos@ufscar.br

São Carlos, _____ de _____ de 20__.

Dra. Paula Castro
Universidade Federal de São Carlos

Assinatura do(a) participante da pesquisa

APÊNDICE 3

ROTEIRO DAS ENTREVISTAS CUIDADORES FORMAIS E INFORMAIS

1. DN ____/____/19____ Id Atual ____ Sexo (1)masc (2)fem

2. Escolaridade: ____ anos

3. Tempo de trabalho: _____

4. Quais seriam os principais objetivos, para você, das redes sociais:

() Comunicação; () Entretenimento; () Conhecimento; () Interação com o mundo; ()
Outros: _____

- Explicar o projeto Time for Design (15 min) Boas vindas + termo de consentimento livre esclarecido aos participantes.
- Orientações gerais sobre sigilo de identidade, informações e reprodução do que for dito
- Pedir que não exponham detalhes e informações sobre a Instituição ou os idosos cuidados.
- O papel do Cuidador Comunicação com Idosos com Demência

QUESTÕES PARTE 1

1. Quais são os seus papéis e responsabilidades no cuidado do idoso?

2. Como você trabalha em conjunto com outras pessoas/ profissionais para fornecer esse cuidado?

3. Você pode descrever um dia típico em sua vida com o idoso?

4. Quais são os principais desafios e problemas na comunicação em relação ao cuidado? (família; idoso)

5. Que tipos de problemas de comunicação você tem com o idoso?

6. Como você grava e compartilha experiências de vida e memórias com o idoso?

7 - Quando você pensa em tecnologia, de que maneira você acha que ela poderia ajudar com esses problemas de comunicação?

3. DEMONSTRAÇÃO – EXEMPLO DE NARRATIVAS DIGITAIS COM DIFERENTES TEMATICAS TABLET + LISTA DE HISTÓRIAS + ESCOLHA DO VIDEO A SER ASSISTIDO + APRESENTAÇÃO DE UM ALBUM MULTIMIDIA

(Todos os materiais e mídias, bem como, estórias serão disponibilizados pelas pesquisadoras)

QUESTÕES PARTE 2

1 - Quais foram suas impressões gerais do aplicativo Com-Phone para fazer histórias?

2 -Você usaria isso? Isso seria útil? Por quê?

3 -Quais dispositivos você acredita que seriam melhores para utilização dessa tecnologia?

4 - Como deveria ser a rede social para o compartilhamento dessas histórias? Quem deveria fazer parte?

5) Qual (is) problema (s) de comunicação que você relatou na primeira parte da entrevista pôde ser identificado em nosso estudo? E quais não foram abordados?

6) Para os problemas que não foram abordados, você pode pensar em outras tecnologias que poderiam resolvê-los ou em como nossa tecnologia pode ser expandida e aprimorada?